Executive Summary

Adira Impact Evaluation Metrics Summary Report

Adira Foundation (Adira) is a 501(c)3 public foundation that envisions a world where people with neurodegenerative diseases and their caregivers are living fully. Founded in 2019, we bring together, among others, people impacted by Alzheimer's disease and related dementias, ALS, Huntington's disease, multiple sclerosis, and Parkinson's disease to work toward one outcome: better lives for people impacted by neurodegenerative diseases (ND). We believe that people in these communities have far more in common than not. We aim to galvanize support for co-created and co-financed solutions to those common problems to provide improved quality-of-life (QOL) on a broad scale to people most impacted by ND.

Purpose

There are currently no cures for Alzheimer's disease and related dementias, ALS, Huntington's disease, multiple sclerosis, or Parkinson's disease. For people most impacted by ND like these, programs focused on improving QOL become of particular importance.

We believe the co-creation of one simple, standard tool might help common communities of people here and around the world assess how responsive different interventions are to the diverse, urgent needs common to all people living with neurodegenerative disease or providing care for someone who is.

This report examines the metrics defined in assessment tools used to evaluate QOL. Currently, there are hundreds of instruments used around the world to measure quality of life. They vary in perspective, simplicity, utility, and adoption. Through this analysis we sought to better understand the existing landscape of QOL assessment tools, including how established metrics collectively define QOL today.

The report also aligns the current metrics identified with a suggested set of 5 common metrics to evaluate QOL, **time, money, energy, confidence, and connection (Appendix 1).** Based on this alignment, the report provides recommendations for establishing a standard, shared approach to evaluate total system impact on QOL in ND groups.

In our analysis we describe numerous examples of specific metrics developed to assess the impact of health and social care programs on QOL and explore how these metrics relate to the universal concepts Adira is recommending as a shared standard.

For any person, balancing **time, money, energy, confidence,** and **connection** can be difficult. The busy and demanding pace of our lives today almost ensure that at least one of these areas is being steadily drained at any given time. For people most impacted by ND, navigating the multiple unknown and complicated circumstances of a serious, incurable diagnosis and its complications is a near constant assault on their **time, money, energy, confidence**, and **connection**.

The Parkinson's Disease Questionnaire-39 (PDQ-39) measures...	These align with the Adira recommended QOL metric of ...
Difficulty walking, carrying bags	Energy
Feeling depressed, anxious	Energy
Feeling isolated, loneliness	Connection

Figure 1. An example of the alignment categorization between existing tool metrics and recommended QOL measures

We also describe other features of the tools, like comprehension accessibility and responder burden, that have traditionally been identified as best practices in evaluation processes.

Ultimately, we seek to open a discussion with you to ask, "What's missing from our current analysis?" and "How can we, as a collaborative, go on to create a tool that is more responsive to the needs of people most impacted by ND, simpler to understand, and more universal in its application, adoption, and examination?"

Report Overview

When reading the **Full Report,** the **Background** and **Introduction** sections begin to lay out our argument that existing evaluation tools measure QOL outcomes, specific manifestations of factors affecting QOL which vary from person to person, not QOL measures themselves.

We propose that an approach to evaluating QOL in ND which focuses on universally understood needs and a shared human identity will support the de-stigmatization of the unique needs of people most impacted by ND and provide the tools and practices to accurately assess program impacts on QOL not only at the individual level but at the system level as well.

In the **Tool Analysis** section, we describe the library of assessment tools **(Appendix 2)** we have created and provide a detailed analysis of select tools. This analysis provides the information and examples which form the basis for the concepts described in our recommendations.

We'll cover **Key Findings** and **Recommendations** in this Executive Summary, but you'll find those sections again following the Tool Analysis in the Full Report. We hope you find yourself considering the questions posed and recommendations made from a new perspective after digesting the material.

> **Key Findings** is where we communicate highlights from the full tool analysis. We spotlight analysis trends and describe the immediate applications of our research.

> **Recommendations** are just that - How we see a way forward on this effort through a common set of QOL metrics and resources to effectively translate specific program impacts to total system impact on QOL in ND.

Next Steps

Because we commit to listening and learning before we act, we invite people most impacted by ND and professionals to comment critically on the purpose, content, and recommendations of this report.

Specifically, we seek comments and contributions to the design, development, and implementation of the tool and resources we describe in our Recommendations to be used as a common standard for evaluating impact on QOL in ND. Feedback can be sent to programs@adirafoundation.org

We also seek feedback on the assessment tool library we have developed alongside this report.

- Comments on the specific subscale and QOL metric alignments *(i.e., reducing pain aligns with energy)*
- Comments on the features selected for analysis (*i.e., plain vs. simple language, populations previously tested in, # of items, etc.)*
  - Are there additional features that we should add to the library to better match organizations with evaluation tools for their specific program goals?
- Comments on the library's utility to support evaluation planning and implementation
- Comments on the library's accessibility and ease of use/ comprehension

If your organization is interested in partnering with Adira Foundation to act on the Recommendations in this report, please contact Greg Smiley and Lauren Ruiz at programs@adirafoundation.org.

Finally, we invite you to participate in the coming conversations we will host as we continue to explore QOL in ND. With the contributions of people most impacted by ND and ND professionals we look to publish a revised version of this report in the future and present additional findings at our upcoming inaugural ND Congress in early 2022.

Key Findings

Metrics Analysis

- Strong alignment was found between the specific metrics, which describe factors affecting QOL, of the 50 tools analyzed and the distinct QOL metrics Adira recommends as a common standard of QOL evaluation (**time, money, energy, confidence, connection**).

- Energy and connection are the QOL areas most often evaluated by existing assessment tools. Every tool we analyzed asked questions which aligned with these areas of QOL.

- Our analysis suggests that the QOL areas of time, money, and confidence are under-evaluated by existing assessment tools.
  - Further information is needed to determine if we are simply not capturing evidence of QOL impact in these areas or if we, as a system, are failing to adequately address these needs for people most impacted by ND.

Critical Features

Two tools stood out in our analysis as those that most closely met all the critical features we considered for this report – metrics which aligned with the 5 QOL areas of time, money, energy, confidence, and connection, the use of plain and simple language, and minimal responder burden.

- For people living with ND the World Health Organization's Disability Assessment Survey 2.0 (WHODAS 2.0)

- For ND caregivers the Kingston Caregiver Stress Scale (KCSS)

Assessment Tools Library

The database we created to organize our analysis can act as a library for organizations to easily identify assessment tools which best meet their evaluation needs and program goals. A searchable library of tools aligned with QOL measures can provide an actionable evaluation process for organizations who have historically struggled to define the QOL impact their programs have through related interventions.

Organizations can interact with the library to find tools with the features most important to their communities and project goals. Tools can be identified by

- Alignment of evaluation metrics with the QOL areas of **time, money, energy, confidence,** and **connection**

- Populations the tool has been tested in

- Length of assessment

- Simplicity of language

Recommendations

We recommend a coordinated, strategic effort among ND stakeholders to:

1. Create a common standard of metrics to evaluate QOL in ND
2. Build a stronger, living library of assessment tools to facilitate QOL evaluation
3. Implement a shared evaluation process across ND programs to measure total system impact on QOL for people living with ND and ND caregivers

Create a common standard

- Adira is proposing to start with the 5 metrics identified in this report – **time, money, energy, confidence, and connection.**

As shown through our analysis these metrics align well with the specific measures used to evaluate impact on factors affecting QOL found in assessment tools today

- We recommend creating a framework which describes the relationship between factors affecting QOL (*ex. reduction in pain, improvement of sleep*) and universal, QOL measures *(time, money, energy, confidence, connection)*

The framework will help define the conceptual nature of QOL. It will also show the inherent need and value of assessing both the unique factors affecting QOL and QOL impact on a broad scale

- We recommend creating further opportunities for conversation among ND stakeholders to further test the validity of the 5 measures of time, money, energy, confidence, and connection as a common standard for QOL evaluation for people impacted by ND.

These conversations must include people living with ND and ND caregivers.

Build a living library of assessment tools

The assessment tools library (Appendix 2) can act as a valuable resource for organizations interested in measuring QOL.

- We recommend the creation of iterative and enhanced versions of the assessment tools library, based on the feedback and input of ND stakeholders

- We recommend the utility of the library be assessed for use in the shared evaluation process

We describe the immediate applications of the assessment tools library in our Key Findings. Those, and other applications of the library, can be made stronger through your contributions and feedback as you use the library in your own QOL work.

Implement a shared evaluation process

- Adira recommends the creation of a tool that will accurately translate the metrics evaluated by existing assessment tools to the metrics in the common standard for evaluating QOL we have proposed *(time, money, energy, confidence, connection)*

This tool will need to be carefully designed to ensure metrics in existing assessment tools are properly aligned with the common QOL metrics. It will also need to consider the various scales used across assessment tools to accurately translate outcomes in a standardized way.

- Using this tool, we recommend the creation of a shared evaluation process across ND programs to measure total system impact on QOL for people living with ND and ND caregivers

  We envision the shared evaluation process may include steps like these:

a) Organization serving ND group(s) engages people most impacted by ND to identify QOL goals and specific factors affecting QOL
b) Organization designs a program to meet these needs
c) Organization uses Adira's assessment tool library (Appendix 2) to identify tools which best relate to the QOL goals and factors affecting QOL expressed by their community
d) Program is evaluated using identified tool, showing individual outcomes on factors affecting QOL
e) Organization uses translational tool to quantify individual outcomes as QOL impact

- We then recommend aggregating this data across individual programs to show total system impact on QOL in ND.

With a common set of metrics and a standard process for translating program outcomes to QOL impact we can begin to understand on a broad scale how particular interventions impact QOL. We can also ensure health care and social support systems are effectively providing support for all areas of QOL.

Adira Impact Evaluation Metrics Summary Report

Assessing the Validity of Establishing a Common Set of Measures to Evaluate Quality of Life in Neurodegenerative Disease Within the Context of Existing Quality of Life Assessment Tools and Best Practices

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Background

Adira Foundation (Adira) is a 501(c)3 public foundation that envisions a world where people with neurodegenerative diseases and their caregivers are living fully. Founded in 2019, we bring together, among others, people impacted by Alzheimer's disease and related dementias, ALS, Huntington's disease, multiple sclerosis, and Parkinson's disease to work toward one outcome: better lives for people impacted by neurodegenerative diseases (ND). Currently 8 million people in the U.S. live with these diseases and experts project diagnoses will increase to 11 million by 2030.

Guided by a model of 'Listen. Learn. Act.' we create spaces for open conversation to gather the perspectives and expertise of everyone invested in ND care solutions, prioritizing the point-of-view of people living with ND and ND caregivers (Throughout this paper we will refer to people living with ND and ND caregivers collectively as "people most impacted (PMI) by ND"). We supplement these insights with learnings from trusted sources in the fields of caregiving, navigation, health equity, technology, clinical research, health policy, and more. Then we fund solutions for the priorities that rise to the top.

Adira's approach is based on the understanding that as people we have more in common than we have differences. People impacted by complex, chronic diseases commonly express a similar list of priority needs. These may include issues with healthcare access like finding a specialist or a clinical trial, issues with mental health like depression or loneliness, issues coordinating and managing care, and many more.

Each person communicates these needs in unique ways: the specific language they use, their association of these desires with positive or negative feelings of expression, the priority of these desires. As psychologist Kenneth Gergen says in Saturated Self "We appear to stand alone, but we are manifestations of relatedness. Our identities are not created by ourselves alone. They are socially constructed. We learn what we value and validate who we are by the relationships and communities we are part of." [1] Ultimately, these unique expressions of need align with one basic, related human identity. **People want more time, more money, more energy, more confidence, and more connection.** (Appendix 1)

Thousands of interventions exist to address those priority needs cited by PMI by ND and almost as many assessment tools to evaluate their impact. This fragmented and individually siloed approach to evaluation prevents researchers, policy makers, service providers, and funders from being able to accurately answer the question "Is the current system of ND health and social support programs effectively delivering QOL impact to people most impacted by ND on a broad scale?"

Adira envisions a system that provides and measures what matters most: more time, more money, more energy, more confidence, and more connection.

Introduction

In recent memory the world has come together to reverse course on huge problems. One example is the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund). This multilateral approach collaborates with, and is financed by, multiple parties to set priorities, fund, and agree on solutions.

The success of the Global Fund (similar to other multilateral programs such as UNAIDS and the Ryan White HIV/AIDS Program) in reducing the spread and impact of its focus diseases inspired Adira to replicate successful features of these approaches in its model. [2]

Some of these features have been tried and seen success among ND populations separately:

- Biomarkers Across Neurodegenerative Disease, a 2014 global funding initiative launched by the Alzheimer's Association, Alzheimer's Research UK, The Michael J. Fox Foundation and the Weston Brain Institute "to build on existing momentum to leverage similar activities and increase impact across the neurodegenerative disease spectrum." [3]

- The Collective Impact Model [4] has been used in Alzheimer's disease [5] to seek larger-scale, multisectoral change

- The BOLD Act [6], passed in 2018, emphasizes education and caregiving

A shared measurement system is one of the critical elements in a multilateral concept. A common standard to evaluate impact can be an effective guide for priority setting collaboratives across stakeholders. This is a concept recognized not only by experts in global health but by domestic health agencies such as the National Institutes of Neurological Disorders and Stroke (NINDS). Through a collaborative, multi-site research initiative, NINDS sponsored the development of Neuro-QOL, a measurement system that "evaluates and monitors the physical, mental, and social effects experienced by adults and children living with neurological conditions." [7]

Measurement systems developed through this effort (PROMIS, Neuro-QOL, ASCQ-Me) capture information on health domains relevant to neurological care, offering neuro condition-specific assessment metrics through a common evaluation model.

We are not seeking to duplicate or dismiss work done through Neuro-QOL or similar efforts like Assessment of Quality of Life (AQOL), or the World Health Organization's quality-of-life tool (WHOQOL). These instruments are important tools in the advancement of care for PMI by ND, and many other complex diseases. We seek to complement these efforts by analyzing QOL tools and impact from a different perspective.

When we created this project, we were reminded of the evolution on perspectives relating to health equity - how previously we struggled to separate the concepts and define health disparities from health inequities. Now we can articulate those concepts and the links between them much more clearly. Current QOL measures focus on and evaluate the specific manifestations of disruptions to QOL (*ex. measuring pain*). We argue that while the respondent may express a perceived QOL improvement as a result of the specific reduction of pain symptoms, that really, they perceive a QOL improvement because *they feel better,* because they have *more energy to live their life*.

In their long-going initiative, 'Measuring What Matters', with The SCAN Foundation and the John A. Hartford Foundation, the National Committee for Quality Assurance (NCQA) noted "When treating complex conditions, the health care system typically measures progress by counting processes and clinical outcomes. These kinds of measures alone don't provide an understanding of how care is contributing to a person's quality of life. For example, measuring medication compliance could be problematic for an older

adult who can't get to the pharmacy. Similarly, adhering to a written care plan could be hard for a person who needs a translator to understand the doctor's instructions." [8]

Through this research, Adira hopes to advance the conversation around developing a standard measurement for this 'elusive concept' of QOL. [9] Utilizing elements of the Healthy People 2030 framework for action [10] as a model for success we seek to test and validate our theory to advance QOL impact for PMI by ND:

- Identify needs and priority populations
  - *PMI by ND*
- Set targets
  - *Time, money, energy, confidence, connection*
- Find practical tools
  - *Analysis of QOL Assessment Tools*
- Monitor national progress against these benchmarks
  - *Test the measures in priority populations with trusted partners*

We invite your comments, contributions, and partnership.

Goals

Goals of Analysis

We conducted this analysis to 1.) identify and describe assessment tools currently available to evaluate QOL and to 2.) validate the five QOL areas Adira is proposing to focus collective impact in (time, money, energy, confidence, and connection) through alignment with the specific metrics each tool measures.

We created a database of 50 quality of life tools including

- Non-specific assessment tools that measure general quality of life
- Disease-specific tools that measure quality of life of people living with Alzheimer's or related dementias, ALS, Huntington's disease, multiple sclerosis, or Parkinson's disease
- Tools that measure the quality of life of general caregivers
- Tools that measure quality of life of caregivers for people living with Alzheimer's or related dementias, ALS, Huntington's disease, multiple sclerosis, or Parkinson's disease

We analyzed the impact measures covered by these existing tools to better understand the landscape of current QOL measures and how QOL is defined today.

Immediate Application of Key Findings

We seek to immediately apply insights from our analysis to show QOL impact across the five ND populations engaged by Adira programs and grantmaking activities. Through a mixed methods approach Adira and grantee partners will evaluate impact in the areas of time, money, energy, confidence, and connection and begin to gather data which shows the value and effectiveness of serving and evaluating ND populations as a collective community.

Adira will publish a comprehensive library of available QOL assessment tools with information such as which areas of QOL their measures align with and what populations they have previously been tested in. Grantee organizations will select assessment tools based on their program and evaluation needs and Adira will gather data which can be readily translated to show QOL impact across aggregated ND populations.

Long-term Application of Key Findings

Ultimately, we seek to create a shared system of measures to advance progress in these five areas of impact on a broad scale. We hope to bring quality of life to the forefront of health program evaluations, fostering robust conversations around the importance of defining and measuring quality of life specifically.

Analysis Design

Assessment tools were analyzed for three key features. Tools highlighted in this report include all three key features. Many tools meeting one or more of these features were also analyzed. Further information can be found in the full library of 50 QOL tools analyzed (Appendix 2).

Metrics Alignment

Adira looks to fund programs that create impact in 5 specific areas of QOL (time, money, energy, confidence, connection). We propose these measures to define those concepts at the root of QOL, not only for people living with ND and ND caregivers, but to all people in our human relatedness.

Assessment tools highlighted in this report cover most, if not all, of these 5 metrics:

Time

- *How does the project give people most impacted by ND more time to spend doing the things they enjoy?*

Money

- *How does the project put more money in the pockets of people most impacted by ND?*

Energy

- *How does the project provide people most impacted by ND with more energy to live their lives?*

Confidence

- *How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?*

Connection

- *How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?*

Plain Language

Assessment tools that use self-reported answers from questionnaires administered to PMI should be written in plain language that is easy to understand by almost any grade level. The American Medical Association (AMA) and the National Institutes of Health (NIH) recommend a sixth-grade level or below. [11]

Questionnaires that use complex, technical language can lead to confusion and result in poor or incomplete data collection. Complex language can also put further burden on PMI by increasing stress, frustration, or feelings of loneliness.

Plain language

- *I have trouble doing all of the activities with friends that I want to do* [PROMIS-29 Profile]

Complex language

- *How satisfied are you with feeling a part of your social environment?* [HDQoL-CSF]

Minimal Responder Burden

Tools that are shorter in length decrease the burden placed on PMI filling out the form. Longer tools can become unnecessarily cumbersome to complete. Tools can range from a handful of items that take less than 5 minutes to complete to 100+ questions that take up to or upwards of an hour. In selecting tools for recommendation, priority was given to validated tools with fewer items that take less time to complete while still meeting other critical features described above.

Short questionnaire

- *The* EuroQOL Assessment (EQ5D) *contains 5 items measuring 5 subscales and takes only a few minutes to complete.*

Long questionnaire

- *The* Multiple Sclerosis Quality of Life Index (MSQLI) *contains 138 items divided into 10 subscales and takes roughly 45 minutes to complete.*

Tool Analysis

Metrics Alignment in Tools to Measure QOL in People Living with ND

Several assessment tools exist that measure different facets of QOL, such as physical function, mental well-being, and social satisfaction. Not many of these tools, however, measure the financial impact that a person's condition has on their QOL or how much time their condition takes away from participating in other activities they enjoy. This may suggest there are not many programs to address these areas of QOL for people living with ND or that those programs are not effectively being measured for impact. We seek to explore these questions further in the next phase of this project.

A few assessment tools cover the majority of the 5 quality of life areas that Adira would like to measure, including the World Health Organization's Quality of Life Instrument (WHOQOL-100), World Health Organization's Quality of Life Instrument – Abbreviated Version (WHOQOL-BREF), and the World Health Organization's Disability Assessment Survey 2.0 (WHODAS 2.0).

World Health Organization's Quality of Life Instrument (WHOQOL-100)

The WHOQOL-100 was created by the WHO after extensive testing in field centers across 19 countries around the world, including 192 participants from the U.S. to measure "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". It is composed of 100 items divided into 6 subscales: physical, psychological, level of independence, social relationships, environmental, and spirituality/ religion/ personal beliefs.

Items from these subscales align with all 5 of the QOL metrics Adira recommends.

- **Time** - How does the project give people most impacted by ND more time to spend doing the things they enjoy?

  Aligning subscale: environmental

  > The environmental subscale covers a range of items, some of which examine how much opportunity the individual has for hobbies and leisure activities, as well as how they spend their free time. Questions under this subscale include:

  > *"To what extent do you have the opportunity for leisure activities?"*
  > *"How satisfied are you with the way you spend your spare time?"*

- **Money** - How does the project put more money in the pockets of people most impacted by ND?

  Aligning subscale: environmental

  > The environmental subscale also includes items that gauge how individuals are doing financially and how much financial troubles have an impact on their lives. The financial implications of ND diseases can lead to increased stress and worry, especially amongst individuals who struggle to continue working in the same capacity they did before their diagnosis. Questions under this subscale include:

  > *"Do you have financial difficulties?"*
  > *"How much do you worry about money?"*

"How satisfied are you with your financial situation?"

- **Energy** - How does the project provide people most impacted by ND with more physical and mental energy to live their lives?

Aligning subscales: physical, psychological, level of independence, spirituality/ religion/ personal beliefs

The physical subscale includes items relating to pain, discomfort, energy for everyday life, feelings of fatigue, and sleep quality. The amount of pain a patient experiences on a daily basis and how easily they are able to relieve the discomfort ties directly to the amount of energy they have left to live their lives and participate in activities they enjoy. The same goes for symptoms that cause fatigue or impact sleep quality, as these can create barriers to participating in daily activities and lead to lower QOL. Questions under this subscale include:

"Do you have enough energy for everyday life?"
"How easily do you get tired?"

The psychological subscale includes items relating to positive and negative feelings such as happiness, anxiety, and depression, memory and concentration, self-esteem, and bodily satisfaction. A patient's mental health and cognitive functioning can have a significant impact on their motivation to participate in activities they once enjoyed and affect their energy levels. Questions under this subscale include:

"How often do you have negative feelings, such as blue mood, despair, anxiety, depression?"
"How well are you able to concentrate?"

The level of independence subscale examines the patient's mobility, ability to carry out daily activities themselves, reliance on medications, and capacity to complete work. These factors affect the patient's ability to live their lives free from dependence on others and is often a pain point for ND individuals as ND diseases often leave patients reliant on a caregiver for their everyday needs. Questions under this subscale include:

"To what extent do any difficulties in movement affect your way of life?"
"How satisfied are you with your capacity for work?"

The spirituality/religion/personal beliefs subscale examines the role religion and spirituality play on the patient's ability to cope with and make sense of their illness. These factors, if important to the patient, give the patient hope for the future. Questions under this subscale include:

"Do your personal beliefs give meaning to your life?"
"To what extent do your personal beliefs give you the strength to face difficulties?"

- **Confidence** - How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?

Aligning subscale: environmental

The environmental subscale includes items that gauge the availability of and access to health care services and the availability of information related to the patient's disease. The complexities of the healthcare system can create additional barriers for ND individuals that impacts their quality of care and, ultimately, their overall quality of life. Questions under this subscale include:

- **Connection** - How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?

  Aligning subscale: social relationships

  The social relationships subscale examines an individual's personal relationships and the support they receive from friends and family. Feeling connected to others is a vital part of any individual's life and contributes significantly to life satisfaction. With fewer opportunities for social interaction, ND diseases can often lead to social isolation and feelings of loneliness, decreasing the patient's quality of life. Questions under this subscale include:

  "Do you get the kind of support from others that you need?"
  "How satisfied are you with your personal relationships?"

World Health Organization's Quality of Life Instrument – Abbreviated Version (WHOQOL-BREF)

The WHOQOL-BREF was created by the World Health Organization as a shorter, but still reliable, version of the WHOQOL-100. After field testing the WHOQOL-100, researchers found that the initial six-domain structure could be condensed into a shorter, four-domain structure. This four-domain structure is composed of a total of 26 items. One item was taken from each of the 24 facets of the WHOQOL-100, along with 2 general health assessment items. The items are divided into four subscales: physical, psychological, social, and environmental. Items from these subscales align with 4 out of the 5 QOL metrics Adira recommends.

- **Time** - How does the project give people most impacted by ND more time to spend doing the things they enjoy?

  Aligning subscales: none

- **Money** - How does the project put more money in the pockets of people most impacted by ND?

  Aligning subscales: environmental

  The environmental subscale includes items that ask how individuals are doing financially and how their condition has had a financial impact on them or their family. Chronic conditions can have devastating financial consequences that directly impact the QOL individuals are able to lead when much of their income is redirected to manage their condition. Questions under this subscale include:

  "Have you enough money to meet your needs?"

- **Energy** - How does the project provide people most impacted by ND with more physical and mental energy to live their lives?

  Aligning subscales: physical, psychological

  Like the WHOQOL-100, the physical subscale of the WHOQOL-BREF includes items relating to pain, energy for everyday life, sleep quality, and ability to move around and participate in daily activities. These factors can have an impact on a person's energy and

motivation to live life to its fullest. A great deal of physical pain or poor sleep quality that gets in the way of daily activities can negatively impact QOL, making it difficult to function as a person once did. Questions under this subscale include:

"To what extent do you feel that physical pain prevents you from doing what you need to do?"
"Do you have enough energy for everyday life?"

The psychological subscale of the WHOQOL-BREF includes items relating to how much the individual enjoys their life, experiencing negative feelings such as anxiety and depression, and ability to concentrate on tasks. Negative feelings can impact how much a person enjoys their life, which can directly affect their desire to live life and participate in activities they once enjoyed. Questions under this subscale include:

"How much do you enjoy life?"
"How well are you able to concentrate?"
"How often do you have negative feelings such as blue mood, despair, anxiety, depression?"

- **Confidence** - How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?

Aligning subscale: environmental

  The environmental subscale also includes items that gauge the availability and accessibility of health services and information relating to their condition. The healthcare system is complicated to navigate for most individuals - an issue that is exacerbated by chronic conditions that limit cognition and physical function. Increasing accessibility to healthcare services and information and making this information digestible for the average person can directly increase QOL by making it easier to manage ND conditions. Questions under this subscale include:

  "How available to you is the information that you need in your day-to-day life?"
  "How satisfied are you with your access to health services?"

- **Connection** - How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?

Aligning subscale: social

  The social subscale includes items that gauge a person's satisfaction with their social relationships, sex life, and the support they get from friends and family. The connection a person feels with the people around them and the level of support they receive from their loved ones can have a significant impac]t on a person's QOL. Chronic conditions that limit social contact with others can cause isolation and loneliness, decreasing a patient's QOL. Questions under this subscale include:

  "How satisfied are you with your personal relationships?"
  "How satisfied are you with your sex life?"
  "How satisfied are you with the support you get from your friends?"

World Health Organization's Disability Assessment Survey 2.0 (WHODAS 2.0)

The WHODAS 2.0 was created by the World Health Organization as a self-administered general assessment of health and disability and has been validated in multiple disease populations around the

world, in both clinical and general population settings. The WHODAS 2.0 consists of 36 items divided into 6 subscales: cognition, mobility, self-care, getting along, life activities, and participation. Items from these subscales align with 4 out of the 5 QOL metrics Adira recommends.

- **Time** - How does the project give people most impacted by ND more time to spend doing the things they enjoy?

  Aligning subscale: participation

    The participation subscale also measures the amount of time that a person's condition takes away from their lives, since this can have a direct impact on the time they have to participate in daily activities or social events. Questions under this subscale include:

    "How much time did you spend on your health condition, or its consequences?"

- **Money** - How does the project put more money in the pockets of people most impacted by ND?

  Aligning subscale: participation

    The participation subscale also includes an item that measures the financial impact of a person's condition on their life and that of their family. With the financial cost of most ND conditions so high, PMI by ND can be financially limited in what they can participate in, health permitting. Questions under this subscale include:

    "How much has your health been a drain on the financial resources of you or your family?"

- **Energy** - How does the project provide people most impacted by ND with more energy to live their lives?

  Aligning subscales: cognition, mobility, self-care, life activities, participation

    The cognition subscale measures an individual's ability to concentrate, learn new things, understand others, and remember tasks that need to be done. Many ND conditions affect a person's cognition and make it difficult for them to live their lives independently and make decisions for themselves. Difficulties with cognition can decrease a person's energy and motivation to complete daily tasks. Difficulties with completing everyday tasks due to issues with concentration or memory can significantly decrease a person's QOL. Questions under this subscale include:

    "In the past 30 days, how much difficulty did you have in concentrating on doing something for ten minutes?"
    "In the past 30 days, how much difficulty did you have in remembering to do important things?"
    "In the past 30 days, how much difficulty did you have in learning a new task, for example, learning how to get to a new place?"

    The mobility subscale measures an individual's ability to move around and is similar to the physical subscale in other assessment tools. Due to the physical side effects of many ND conditions, these conditions can affect a person's ability to get around independently. A lack of mobility can lead to helplessness and prevent an individual from doing the activities they once enjoyed, decreasing their energy and QOL. Questions under this subscale include:

    "In the past 30 days, how much difficulty did you have in standing for long periods such as 30 minutes?"

"In the past 30 days, how much difficulty did you have in moving around inside your home?"
"In the past 30 days, how much difficulty did you have in getting out of your home?"

The self-care subscale measures an individual's ability to do everyday tasks like eating, showering, and getting ready. Being able to carry out self-care activities yourself can increase an individual's energy levels by allowing the body to relax and replenish energy stores. Circumstances that prevent you from doing so can make it difficult to unwind or at least do so independently and lead to decreased QOL. Questions under this subscale include:

"In the past 30 days, how much difficulty did you have in washing your whole body?"
"In the past 30 days, how much difficulty did you have in getting dressed?"
"In the past 30 days, how much difficulty did you have in eating?"

The life activities subscale measures the ability to carry out normal day-to-day activities related to work, school, and household responsibilities. This is an important measure of how well a person can independently complete regular tasks and lead a life full of purpose. Not being able to complete tasks that were once an important part of someone's life can lead to decreased energy and motivation to complete those tasks in the future. Questions under this subscale include:

"In the past 30 days, how much difficulty did you have in taking care of your household responsibilities?"
"In the past 30 days, how much difficulty did you have in your day-to-day work/school?

The participation subscale measures a person's ability to participate in daily activities, including independently doing things to relax. Many ND conditions can lead to a decrease in independence, preventing individuals from being able to participate in activities they do to relax without the help of a caregiver. This can decrease energy levels and ultimately decrease QOL. Questions under this subscale include:

"In the past 30 days, how much of a problem did you have in doing things by yourself for relaxation or pleasure?

- **Confidence** - How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?

  Aligning subscales: none

- **Connection** - How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?

  Aligning subscales: getting along, participation

  The getting along subscale contains items that gauge how difficult it is for the individual to make and maintain friends and get along with others. ND conditions can often make it difficult to connect with others, especially those who have had similar experiences, causing a sense of loneliness and seclusion. Some conditions can also cause irritability or mood swings, making it increasingly difficult to remain close with friends and family. Questions under this subscale include:

  "In the past 30 days, how much difficulty did you have in dealing with people you do not know?"
  "In the past 30 days, how much difficulty did you have in maintaining a friendship?"
  "In the past 30 days, how much difficulty did you have in making new friends?"

The participation subscale includes items to determine how connected a person is with their community and if they can connect with others in social settings. The negative attitudes and behaviors of those around you can make living with ND conditions isolating, leading to self-isolation and a low QOL. Questions under this subscale include:

"In the past 30 days, how much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?"
"In the past 30 days, how much of a problem did you have living with dignity because of the attitudes and actions of others?"

Metrics Alignment in Tools to Measure QOL in ND Caregivers

Assessment tools for caregivers that cover the majority of the 5 QOL areas Adira recommends include the Caregiver Quality of Life for dementia (CGQOL-80), the Caregiver health-related quality of life in multiple sclerosis (CAREQOL-MS), and the Kingston Caregiver Stress Scale (KCSS).

Caregiver Quality of Life for dementia (CGQOL-80)

The CGQOL-80 was created by researchers at the University of California Los Angeles as the first assessment tool meant to measure the QOL of informal caregivers of patients with dementia from a variety of ethnic backgrounds. It was tested amongst English-speaking and Spanish-speaking caregivers in the United States and was found to have good internal consistency reliability and test-retest reliability. The CGQOL consists of 80 items divided into 10 subscales: assistance with instrumental activities of daily living (IADLS), assistance with activities of daily living (ADLS), role limitations due to caregiving, personal time, family involvement, demands of caregiving, worry, spirituality and faith, benefits of caregiving, and caregiver feelings. Items from these subscales align with all 5 of the QOL metrics Adira recommends.

- **Time** - How does the project give people most impacted by ND more time to spend doing the things they enjoy?

Aligning subscales: role limitations due to caregiving, personal time, demands of caregiving

The role limitations due to caregiving subscale also includes an item that asks the caregiver whether the time they have for other activities in their life has been limited due to their role as a caregiver. The time commitment needed as an informal caregiver can get in the way of the caregiver leading their life, decreasing the overall quality of their life. Questions under this subscale include:

"During the last 4 weeks, did you have any of the following problems with your work or other regular daily activities as a result of being a caregiver?
Cut down on the amount of time you spent on work or other activities."

The personal time subscale measures how much personal time the caregiver had away from their family member with dementia and the quality of their time away. Being an informal caregiver can sometimes mean letting your caregiving role take up the majority of your time, leading to a low quality of life in other areas. Questions under this subscale include:

"How satisfied were you with the amount of personal time you had away from your relative with dementia? (that is, visiting friends or relatives, tending to personal affairs, enjoying hobbies, going to work, etc.)"
"How often were you able to spend enough time away from your relative with dementia?"
"During the last 4 weeks, I had as much time for myself as I wanted."

The demands of caregiving subscale includes an item that asks whether the time commitment of caregiving is too much for the caregiver. Similar to other subscales that measure the time dimension, this subscale also aims to gauge how much of the caregiver's time is spent on carrying out their responsibilities as an informal caregiver and how much this interferes with their personal life. Questions under this subscale include:

"Too much of my time is spent caring for my relative with dementia."

- **Money** - How does the project put more money in the pockets of people most impacted by ND?

Aligning subscales: worry

The worry subscale contains an item that gauges how much of the caregiver's worry stems from financial issues. Complex conditions like neurodegenerative disorders can be costly, even with insurance coverage. Much of the financial strain often falls on the caregiver and this stress can decrease the caregiver's and family's QOL. Questions under this subscale include:

"During the last 4 weeks, I worried about the financial cost of caring for my relative in the future."

- **Energy** - How does the project provide people most impacted by ND with more physical and mental energy to live their lives?

Aligning subscales: assistance with IADLS, assistance with ADLS, role limitations due to caregiving, demands of caregiving, worry, spirituality and faith, benefits of caregiving, caregiver feelings

The assistance with IADLS subscale measures how much the caregiver must assist the patient with daily activities like running errands and doing things around the house. The amount of care a patient needs in their day-to-day activities can affect the energy the caregiver has to complete their own daily tasks and live their own lives. Questions under this subscale include:

"The following items are about activities with which you might assist your relative with dementia during a typical day. For each activity, please indicate how much you assisted that person during the last 4 weeks.

Running errands

Paying bills

Remembering names and dates

Using household appliances"

Like the assistance with IADLS subscale, the assistance with ADLS subscale measures how much the caregiver needs to assist the patient with regular, day-to-day self-care tasks such as getting ready, bathing, and eating. These activities can also take much of the

energy of the caregiver and leave them with little energy for other tasks. Questions under this subscale include:

"The following items are about activities with which you might assist your relative with dementia during a typical day. For each activity, please indicate how much you assisted that person during the last 4 weeks.

Feeding him or her meals

Dressing

Bathing"

The role limitations due to caregiving subscale gauges how much of impact the caregiver's responsibilities have on their lives. Informal caregivers often need to put the needs of the patient above their own, which can decrease the energy they have to live their own lives. It can also limit the types of activities they can participate in and make it difficult to lead the life they once did. Questions under this subscale include:

"How much of the time during the last 4 weeks did you put your own needs aside to take care of your relative with dementia?"
"Were limited in the kind of or other activities?"
"Had difficulty performing the work or other activities (for example, it took extra effort)?"

The demands of caregiving subscale ask the respondent whether they ever felt trapped by their caregiving role and if they wanted to get away from their responsibilities as a caregiver. When taking care of a family member, caregivers can sometimes feel like they have no choice other than supporting their family member. Caregiving for an extended period can be physically and mentally taxing, even more so when it starts interfering with other responsibilities. Questions under this subscale include:

"How often did you feel "trapped" caring for the person with dementia?"
"How often did you wish you could escape from your caregiving duties?"
"Caregiving interferes too much with my life."

The worry subscale measures how stressed the caregiver is about the future of their family member with dementia and the future outlook of their caregiving role. Worry about the future can keep the caregiver from living in the present and decrease the energy they have to enjoy life. Questions under this subscale include:

"How often did you worry that you might be unable to take care of your relative with dementia in the future?"
"How often did you worry about your relative's dementia getting worse?"
"During the last 4 weeks, I worried that someone else would harm or take advantage of my relative with dementia."
"Have you felt overwhelmed?"

The spirituality and faith subscale gauges how much of an impact the caregiver's faith has on their life and the effect it has on their outlook toward caregiving. Faith can be a strong motivator for a person, especially when faced with health issues. It can provide strength and comfort in difficult times, increasing the caregiver's energy to carry out their responsibilities. Questions under this subscale include:

"My faith in a higher power gives me strength and comfort when caregiving becomes difficult."

"My spiritual beliefs help me to cope with the challenges of caregiving."
"My faith has grown stronger because of what has happened to my relative with dementia."

The benefits of caregiving subscale measures the positive affect of the caregiver toward their caregiving role. Seeing caregiving as something that brings their life meaning can increase their energy and lead to better patient outcomes. Questions under this subscale include:

"I am grateful for the time that I am able to spend with my relative with dementia."
"Being a caregiver has made my life more meaningful."
"My relative with dementia is a blessing to me."

The caregiver feelings subscale measures the negative affect of the caregiver toward their caregiving role. It directly asks the patient whether they feel anxious, stressed, or overwhelmed by their caregiving responsibilities and how much this role bothers them. Negative feelings toward the role can decrease the energy the caregiver has to not only adequately carry out their duties, but also live their lives. Questions under this subscale include:

"Some people are bothered as a result of caring for a person with dementia, while others are not. How much are you bothered by the following areas?
Depression?
Fatigue?
Anxiety?"

- **Confidence** - How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?

Aligning subscale: assistance with IADLS

The assistance with IADLS subscale contains an item that asks how often the caregiver needs to help their family member who they are caring for with important medical decisions. With neurodegenerative disorders, many medical decisions eventually fall on the shoulders of the caregiver. Without the proper information and support network, caregivers can feel overwhelmed by these responsibilities, which can decrease their quality of life. Questions under this subscale include:
"The following items are about activities with which you might assist your relative with dementia during a typical day. For each activity, please indicate how much you assisted that person during the last 4 weeks:
Making medical decisions"

- **Connection** - How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?

Aligning subscale: family involvement, caregiver feelings

The family involvement subscale measures how much support the caregiver receives from other family members in caring for the patient and the quality of support they receive. Without proper support, caregivers can feel trapped by their role and start feeling like have no choice but to be the sole caregiver. Sharing the responsibility with other family members can help create feelings of shared community and connection, lightening the burden and increasing the caregiver's quality of life. Questions under this subscale include:

"How satisfied are you with the amount of help you receive from family in caring for your relative with dementia?"
"How satisfied are you with the quality of help you receive from family in caring for your relative with dementia?"
"I feel like I have no choice about being a caregiver."

The caregiver feelings subscale has an item that asks the caregiver how often they experience loneliness in their role. Without being able to share their experiences with others who understand the challenges of caregiving, caregivers can begin to feel isolated. These feelings of isolation and loneliness can decrease the caregiver's quality of life. Questions under this subscale include:

"Some people are bothered as a result of caring for a person with dementia, while others are not. How much are you bothered by the following areas:
Loneliness?"

Caregiver health-related quality of life in multiple sclerosis (CAREQOL-MS)

The CAREQOL-MS was created in Spain as the first instrument to specifically measure QOL in family caregivers of patients with multiple sclerosis (MS). The Spanish version of the questionnaire was tested in caregivers of MS patients from 19 outpatient clinics located throughout 13 cities in Spain. It was found to have adequate content validity, high internal consistency, and satisfactory test-retest reliability. Although the instrument has been used in studies conducted with U.S. caregivers of MS patients, it has not been fully validated in a U.S. population for consistency, validity, or reliability. The CAREQOL-MS consists of 24 items divided into 5 subscales: physical burden and global health, social impact, emotional impact, need of support, and emotional reactions. Items from these subscales align with 4 out of the 5 QOL metrics Adira recommends.

- **Time** - How does the project give people most impacted by ND more time to spend doing the things they enjoy?

  Aligning subscales: physical burden and global health

    The physical burden and global health scale also includes an item to gauge how much time the caregiver has left for other aspects of their life, such as their family, after accounting for their responsibilities with respect to the patient. Questions under this subscale include:

    "Caring for a person with multiple sclerosis leaves me with no time for caring for the rest of my family."

- **Money** - How does the project put more money in the pockets of people most impacted by ND?

  Aligning subscales: social impact

    The social impact scale also includes an item that measures how much of a financial impact the patient's condition has on the caregiver and their family. This assumes that the patient's caregiver is a family member for whom they are financially responsible. Questions under this subscale include:

    "The multiple sclerosis of the person whom I care for has impacted my family's financial situation."

- **Energy** - How does the project provide people most impacted by ND with more physical and mental energy to live their lives?

Aligning subscales: physical burden and global health, social impact, emotional impact

The physical burden and global health scale measures the impact the patient's physical disability has on the caregiver's life. Needing to physically support a patient with an ND condition can be physically taxing on the caregiver and this can take a toll on the energy they have to do things for themselves in their own life. Questions under this subscale include:

"Moving and traveling with the person with multiple sclerosis whom I care for is complicated for me."
"The fatigue of the person with multiple sclerosis whom I care for poses a greater physical burden to me."
"The personal hygiene of the person with multiple sclerosis whom I care for proves complicated."

The social impact scale measures the impact the patient's condition has on the caregiver's social life. Needing to take care of another's needs and prioritizing the patient's needs over their own can lead to limited time for social functions for the caregiver and a decrease in energy to live their lives. Questions under this subscale include:

"Multiple sclerosis has affected my social life."
"Taking care of a person with multiple sclerosis has meant a change in my lifestyle."
"Multiple sclerosis has affected my relationship with my partner, either regarding our sexual or emotional relationship."

The emotional impact scale measures the impact the patient's condition has on the mental and emotional well-being of the caregiver. Taking care of a patient, especially a family member, can increase stress and worry, particularly when it comes to planning for the future. The emotional ramifications of these ND conditions can decrease the energy a caregiver has to live their life and keep a positive outlook. Questions under this subscale include:

"I worry about the fatigue of the person with multiple sclerosis whom I care for."
"I feel sad as a consequence of the multiple sclerosis of the person whom I care for."
"I am scared about the progress and the consequences of multiple sclerosis."

- **Confidence** - How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?

Aligning subscale: none

- **Connection** - How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?

Aligning subscale: physical burden and global health, need of support, emotional reactions

The physical burden and global health scale also includes an item that gauges how supported the caregiver feels in caring for their patient by those around them. Being the sole caretaker for someone with a complex condition can be overwhelming and isolating, leading to a decreased QOL for the caregiver. Questions under this subscale include:

"I feel alone regarding my tasks of caring for, watching, and supporting a person with multiple sclerosis."

The need of support scale measures how important having others who are acquainted with the disease is for the caregiver. As mentioned previously, caretaking can be

overwhelming, especially without a support system. Having a support group that understands the complexities of the ND condition of the patient can increase the caregiver's QOL by making them more confident in their role as a caregiver. Questions under this subscale include:

"I believe that my situation might improve through the collaboration of other caregivers."
"I miss the company of persons outside the family circle who are acquainted with the disease, so I can share my current situation with them."
"I believe that some psychological aid would help me provide better care for the person with multiple sclerosis."

The emotional reactions scale measures how the patient's condition makes the caregiver feel. Having to provide for someone with a complex ND condition can lead to negative emotional reactions that the caregiver cannot control. A support system that validates these feelings can help the caregiver make sense of these negative emotions and improve their QOL by providing an outlet. Questions under this subscale include:

"The attitude of the person with multiple sclerosis whom I care for elicits mood changes in me."
"The nervousness of the person with multiple sclerosis whom I care for irritates me."

Kingston Caregiver Stress Scale (KCSS)

The KCSS was created by the Kingston Scales Institute in Canada as a way of measuring a caregiver's stress level in real-time and assessing the source of the stress. It was designed to be used by community caregivers, such as family members of patients, to measure stress over time and attribute the stress to a specific factor in their lives. The KCSS, along with many other Kingston Scales, have been translated into multiple languages and used in studies around the world, including the U.S. The KCSS consists of 10 items divided into 3 subscales: caregiving issues, family issues, and financial issues. Items from these subscales align with 4 out of the 5 QOL metrics Adira recommends.

- **Time** - How does the project give people most impacted by ND more time to spend doing the things they enjoy?

  Aligning subscales: none

- **Money** - How does the project put more money in the pockets of people most impacted by ND?

  Aligning subscales: financial issues

  > The financial issues subscale consists of a single item used to assess whether the patient's condition has any financial consequences for the caregiver. Since the KCSS is meant to be utilized by family caregivers, financial concerns of the patient often need to be addressed by the caregiver and the rest of their family. Questions under this subscale include:

  > *"Are you having any financial difficulties associated with care giving?"*

- **Energy** - How does the project provide people most impacted by ND with more physical and mental energy to live their lives?

  Aligning subscales: caregiving issues

  > The caregiving issues subscale mainly covers items that gauge whether the caregiver is overwhelmed, having trouble keeping up with their daily lives due to their caregiving

responsibilities, or worried about the future needs of the person they are taking care of. The worry that comes along with caregiving can have a severe impact on the caregiver's mental health by increasing stress and thereby decreasing their energy levels and QOL. Questions under this subscale include:

"Are you having feelings of being overwhelmed, over worked, and/or overburdened?"
"Are you having any conflicts with your previous daily commitments (work/volunteering)?"
"Do you have concerns regarding the future care needs of your spouse/relative?"

- **Confidence** - How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?

Aligning subscale: caregiving issues, family issues

The caregiving issues subscale contains an item that addresses how confident the caregiver is in providing care for their patient. By directly asking about their confidence, this subscale helps gauge whether the caregiver feels like they have the information and tools they need to make good decisions for their patient when it comes to their condition. Questions under this subscale include:

"Do you ever have feelings related to a lack of confidence in your ability to provide care?"

The family issues subscale also contains an item to gauge how easily decisions about the patient's care are made but tackles it from a group decision standpoint. It addresses the issue of needing to make important health decisions for a family member as a group and acknowledges that different members of the family may have different views about how the patient's condition should be managed. By having access to better information and better health services, these joint family decisions can be made from a more informed perspective, thereby increasing the caregiver's and the patient's QOL. Questions under this subscale include:

"Are you having any conflicts within your family over care decisions?"

- **Connection** - How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?

Aligning subscale: caregiving issues, family issues

The caregiving issues subscale also contains items that measure how the caregiver's responsibilities have changed their social life and their relationship with their spouse. Complex ND conditions can have a negative impact on the patient's life but also the lives of those around them. With more time spent taking care of the patient, caregivers can have less time to make connections with others or spend time away from the stresses of caregiving to enjoy themselves with friends and other family members. Questions under this subscale include:

"Has there been a change in your relationship with your spouse/relative?"
"Have you noticed any changes in your social life?"

The family issues subscale also contains items that evaluate how much support a caregiver gets from other family members. As the primary caregiver for a family member, caregivers can often feel overburdened by their roles and feel isolated when others in the family do not offer as much support in caregiving as they need. A lack of support from other family members can place too much burden on a single caregiver and decrease their

QOL, as well as the quality of care the patient receives. Questions under this subscale include:

"Are you having any conflicts within your family over the amount of support you are receiving in providing care?"

Use of Plain Language in Tools to Measure QOL in People Living with ND

The language used by an assessment tool is important for clarity and usability. When using a self-reported questionnaire, it is important to state questions in plain, simple words rather than complicated jargon that can lead to confusion and unreliable data collection. Assessment tools that use plain, simple language include the Parkinson's Disease Questionnaire-39 (PDQ-39), the Medical Outcomes Study 36-item Short Form Health Survey (SF-36), and the World Health Organization Disability Assessment Survey 2.0 (WHODAS 2.0).

Parkinson's Disease Questionnaire-39 (PDQ-39)

The PDQ-39 is a 39-item tool divided into 8 subscales: mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort. It was originally created in the U.K. to measure the QOL of Parkinson's disease patients and has been adapted into a U.S. version to better capture the language that most Americans understand. It has also been translated into 40 other languages and is one of the most widely-used disease-specific measures for Parkinson's disease patients. The PDQ-39 uses everyday language to ask about specific scenarios that a patient might encounter to make it easy for patients to understand what the question is referring to. Examples of plain and simple language include:

"How often have you had difficulty carrying shopping bags?"
"How often have you had difficulty cutting up your food?"
"How often have you felt depressed?"
"How often have you had difficulty speaking?"

Medical Outcomes Study 36-item Short Form Health Survey (SF-36)

The SF-36 is a 36-item tool divided into 8 subscales: general health, limitations of physical activities, limitations in social activities, physical health problems effects, emotional health problem effects, bodily pain, energy and emotions, and general health perception. It was originally created as part of the Medical Outcomes Study as a general self-reported measure to assess QOL but has been used extensively across many disease populations around the world. The SF-36 is available in multiple languages and consists of questions that give examples of experiences the individual may be facing to gauge their physical and mental health. It uses simple, easy-to-understand language and includes everyday tasks within the question to further explain what the question is asking, making it easier to understand than questionnaires that use broad language.

"Does your health now limit you in these activities? e.g. Lifting or carrying groceries, climbing one flight of stairs, walking more than a mile"
"Have you felt so down in the dumps that nothing could cheer you up?"

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World Health Organization Disability Assessment Survey 2.0 (WHODAS 2.0)

As mentioned previously, the WHODAS 2.0 consists of 36 items divided into 6 subscales: cognition, mobility, self-care, getting along, life activities, and participation. The WHODAS 2.0 was created by the World Health Organization as a self-administered general assessment of health and disability and has been validated in multiple disease populations around the world, in both clinical and general population settings. It has been translated into multiple languages and uses specific but plain language to make questions easy to understand.

> *"In the past 30 days, how much difficulty did you have in concentrating on doing something for ten minutes?"*
> *"In the past 30 days, how much difficulty did you have walking a long distance such as a kilometre [or equivalent]?"*
> *"In the past 30 days, how much difficulty did you have washing your whole body?*

Use of Plain Language in Tools to Measure QOL in ND Caregivers

Assessment tools made for caregivers that use plain, simple language include the Caregiver Quality Of Life for dementia (CGQOL-80), the Parkinson Disease Questionnaire for Carers (PDQ-Carer), and the Kingston Caregiver Stress Scale (KCSS).

Caregiver Quality of Life for Dementia (CGQOL-80)

As previously stated, the CGQOL-80 consists of 80 items divided into 10 subscales: assistance with instrumental activities of daily living (IADLS), assistance with activities of daily living (ADLS), role limitations due to caregiving, personal time, family involvement, demands of caregiving, worry, spirituality and faith, benefits of caregiving, and caregiver feelings. It was created by researchers at the University of California Los Angeles as the first assessment tool meant to measure the QOL of informal caregivers of patients with dementia from a variety of ethnic backgrounds. The CGQOL-80 consists of questions that ask the caregiver about specific tasks, activities, and decisions the patient may need help with or specific emotions they may feel. By asking a general question and giving a list of things that the caregiver may have difficulty with, it decreases ambiguity in the questions and makes them easier to understand and answer.

> *"During the last 4 weeks, did you have any of the following problems with your work or other regular daily activities as a result of being a caregiver?*
> *Cut down on the amount of time you spent on work or other activities?*
> *Accomplished less than you would like?*
> *Were limited in the kind of or other activities?"*

Parkinson Disease Questionnaire for Carers (PDQ-Carer)

The PDQ-Carer consists of 29 items divided into 4 subscales: social and personal activities, anxiety and depression, self-care, and strain. It was created by researchers at the University of Oxford in the United Kingdom as a disease-specific measure of QOL for caregivers of patients with Parkinson's disease. It has been validated in the U.K and shown to have good internal consistency, reliability, and construct validity. The PDQ-Carer contains simple questions that ask about specific facets of caregiving that could potentially affect the QOL of the caregiver, such as difficulties with daily activities due to the stresses and time commitment of caregiving and negative emotions that can arise from having to take care of another person for an extended period. The specificity of these questions makes them easy to understand and interpret.

> *"Found it difficult to see friends and family?"*
> *"Felt anxious because of the responsibility of caring?"*
> *"Found it difficult to get out, for example, to do the shopping?"*
> *"Felt less in control of your temper than before you became a carer?"*

Kingston Caregiver Stress Scale (KCSS)

As mentioned previously, the KCSS consists of 10 items divided into 3 subscales: caregiving issues, family issues, and financial issues. It was created by the Kingston Scales Institute in Canada as a way of measuring a caregiver's stress level in real-time and assessing the source of the stress. It has been translated into 7 languages other than English, including French, Greek, and Hebrew. The English version has been used in studies around the world, including the U.S. The KCSS aims to tie a caregiver's stress level to a specific source of stress by asking targeted questions about where the caregiver's stress is originating from – whether it's from family issues, worries about the caregiver's ability to provide adequate care, changes to the caregiver's social life etc. These targeted questions are asked in specific, plain language that leaves little room for ambiguity and makes it easy for the caregiver to respond using the 5-point Likert-type scale.

> *"Are you having feelings of being overwhelmed, over worked, and/or over burdened?"*
> *"Do you have feelings of being confined or trapped by the responsibilities or demands of care giving?"*
> *"Are you having any financial difficulties associated with care giving?"*

Tools to Measure QOL in People Living with ND that Minimize Responder Burden

The length of an assessment tool is an important consideration because it has an impact on the burden placed on the respondent. Longer assessment tools can be cumbersome to fill out completely, ask repetitive questions, and lead to inaccurate or incomplete data collection. Shorter assessment tools that measure the same dimensions of QOL but can do so with fewer items decrease the burden placed on the respondent and make it more likely to get fully completed questionnaires returned. Assessment tools that cover a range of QOL metrics but take minimal time to complete include the World Health Organization's Disability Assessment Survey 2.0 (WHODAS 2.0), the Parkinson's Disease Questionnaire-39 (PDQ-39), and the World Health Organization's Quality of Life Instrument – Abbreviated Version (WHOQOL-BREF).

World Health Organization's Disability Assessment Survey 2.0 (WHODAS 2.0)

As mentioned previously, the WHODAS 2.0 consists of 36 items divided into 6 subscales: cognition, mobility, self-care, getting along, life activities, and participation. The WHODAS 2.0 was created by the World Health Organization as a self-administered general assessment of health and disability and has been validated in multiple disease populations around the world, in both clinical and general population settings. The WHODAS 2.0 is a short questionnaire that takes approximately 5-20 minutes to complete and has fewer items than other general health measures such as the WHOQOL-100.

> *Number of items: 36*
> *Time to complete: 5-20 minutes*

Parkinson's Disease Questionnaire-39 (PDQ-39)

As mentioned previously, the PDQ-39 is a 39-item tool divided into 8 subscales: mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort. It was originally created in the U.K. to measure the quality of life of Parkinson's disease patients and has been adapted into a U.S. version. The shorter PDQ-39 was created from an original 65-item questionnaire using items that had the most statistical correlation to the domains being measured. It takes roughly 10-20 minutes to complete and can be used in both younger and older adult age groups.

> *Number of items: 39*
> *Time to complete: 10-20 minutes*

World Health Organization's Quality of Life Instrument – Abbreviated Version (WHOQOL-BREF)

As mentioned previously, the WHOQOL-BREF is a 26-item tool divided into 4 subscales: physical, psychological, social, and environmental. It was created by the World Health Organization as a shorter, but still reliable, version of the WHOQOL-100 after researchers found that the initial six-domain structure could be condensed into a shorter, four-domain structure that was more appropriate and less time intensive. The WHOQOL-BREF takes roughly 10-15 minutes to complete and contains one item from each of the 24 facets of the WHOQOL-100, along with 2 items that gauge general health and well-being.

> *Number of items: 26*
> *Time to complete: 10-15 minutes*

Tools to Measure QOL in ND Caregivers that Minimize Responder Burden

Assessment tools made for caregivers that cover a range of QOL metrics but take minimal time to complete include the Kingston Caregiver Stress Scale (KCSS), the Caregiver health-related quality of life in multiple sclerosis (CAREQOL-MS), and the Parkinson Disease Questionnaire for Carers (PDQ-Carer).

Kingston Caregiver Stress Scale (KCSS)

As mentioned previously, the KCSS consists of 10 items divided into 3 subscales: caregiving issues, family issues, and financial issues. It was created by the Kingston Scales Institute in Canada as a way of

measuring a caregiver's stress level in real-time and assessing the source of the stress. It has been used in studies around the world in multiple languages. Because it was made to be administered multiple times to measure a caregiver's stress over time, the questionnaire was created to be short and succinct. It takes approximately 5-10 minutes to complete and can be self-administered or administered by a professional.

Number of items: 10
Time to complete: 5-10 minutes

Caregiver health-related quality of life in multiple sclerosis (CAREQOL-MS)

As mentioned previously, the CAREQOL-MS consists of 24 items divided into 5 subscales: physical burden and global health, social impact, emotional impact, need of support, and emotional reactions. It was created in Spain as the first instrument to specifically measure QOL in family caregivers of patients with multiple sclerosis (MS) and has only been validated in a Spanish population. The CAREQOL-MS is a relatively short questionnaire takes approximately 10-15 minutes to complete.

Number of items: 24
Time to complete: 10-15 minutes

Parkinson Disease Questionnaire for Carers (PDQ-Carer)

As mentioned previously, the PDQ-Carer consists of 29 items divided into 4 subscales: social and personal activities, anxiety and depression, self-care, and strain. It was created by researchers at the University of Oxford in the United Kingdom as a disease-specific measure of QOL for caregivers of patients with Parkinson's disease. The PDQ-Carer started as a 45-item questionnaire that took on average 11 minutes to complete. After testing with a population of caregivers, the questionnaire was shortened to 29 items that takes under 10 minutes to complete.

Number of items: 29
Time to complete: less than 10 minutes

Highlighted Assessment Tools

The assessment tools that best fit all three critical features stated in this report are the WHODAS 2.0 and the KCSS. The ideal tool measures the majority of the five QOL metrics Adira recommends for impact, uses plain, simple language, and is short enough to minimize responder burden.

Assessment tool for ND individuals:

World Health Organization's Disability Assessment Survey 2.0 (WHODAS 2.0)

The WHODAS 2.0 measures four out of the five QOL metrics Adira recommends: time, money, energy, and connection. Its six subscales match well to these four measures to create a holistic view of patient QOL. Although it does not contain items that measure the confidence dimension, a few additional items can be added from the more extensive WHOQOL-100 to encompass this domain. It uses direct, specific language to help the responder easily understand and answer questions and with only 36 items, the WHODAS 2.0 takes roughly 5-20 minutes to complete. This general assessment of health and disability has also been tested in multiple populations and settings in various languages, making it a globally validated and well-accepted assessment tool.

Assessment tool for caregivers of ND individuals:

Kingston Caregiver Stress Scale (KCSS)

The KCSS also measures four out of the five QOL metrics Adira recommends: money, energy, confidence, and connection. Its three subscales match well to these four measures to create a more or less holistic view of caregiver QOL. Although it does not contain items that measure the time dimension, a few additional items can be added from the more extensive CGQOL-80 to encompass this domain. By using targeted questions written in plain terms to match a caregiver's stress level to a specific source of stress and only taking 5-10 minutes to complete the 10 items, the KCSS minimizes responder burden and makes the tool easy to fill out for caregivers. Although not as widely tested as other global scales, the KCSS has been validated in multiple countries and languages around the world and provides a succinct but robust view of caregiver QOL.

Key Findings

Metrics Analysis

- Strong alignment was found between the specific metrics, which describe factors affecting QOL, of the 50 tools analyzed and the distinct QOL metrics Adira recommends as a common standard of QOL evaluation (**time, money, energy, confidence, connection**).

- Energy and connection are the QOL areas most often evaluated by existing assessment tools. Every tool we analyzed asked questions which aligned with these areas of QOL.

- Our analysis suggests that the QOL areas of time, money, and confidence are under-evaluated by existing assessment tools.

  - Further information is needed to determine if we are simply not capturing evidence of QOL impact in these areas or if we, as a system, are failing to adequately address these needs for people most impacted by ND.

Critical Features

Two tools stood out in our analysis as those that most closely met all the critical features we considered for this report – metrics which aligned with the 5 QOL areas of time, money, energy, confidence, and connection, the use of plain and simple language, and minimal responder burden.

- For people living with ND the World Health Organization's Disability Assessment Survey 2.0 (WHODAS 2.0)

- For ND caregivers the Kingston Caregiver Stress Scale (KCSS)

Assessment Tools Library

The database we created to organize our analysis can act as a library for organizations to easily identify assessment tools which best meet their evaluation needs and program goals. A searchable library of tools aligned with QOL measures can provide an actionable evaluation process for organizations who have historically struggled to define the QOL impact their programs have through related interventions.

Organizations can interact with the library to find tools with the features most important to their communities and project goals. Tools can be identified by

- Alignment of evaluation metrics with the QOL areas of **time, money, energy, confidence,** and **connection**

- Populations the tool has been tested in

- Length of assessment

- Simplicity of language

Recommendations

We recommend a coordinated, strategic effort among ND stakeholders to:

1. Create a common standard of metrics to evaluate QOL in ND
2. Build a stronger, living library of assessment tools to facilitate QOL evaluation
3. Implement a shared evaluation process across ND programs to measure total system impact on QOL for people living with ND and ND caregivers

Create a common standard

- Adira is proposing to start with the 5 metrics identified in this report – **time, money, energy, confidence, and connection.**

As shown through our analysis these metrics align well with the specific measures used to evaluate impact on factors affecting QOL found in assessment tools today

- We recommend creating a framework which describes the relationship between factors affecting QOL (*ex. reduction in pain, improvement of sleep*) and universal, QOL measures *(time, money, energy, confidence, connection)*

The framework will help define the conceptual nature of QOL. It will also show the inherent need and value of assessing both the unique factors affecting QOL and QOL impact on a broad scale

- We recommend creating further opportunities for conversation among ND stakeholders to further test the validity of the 5 measures of time, money, energy, confidence, and connection as a common standard for QOL evaluation for people impacted by ND.

These conversations must include people living with ND and ND caregivers.

Build a living library of assessment tools

The assessment tools library (Appendix 2) can act as a valuable resource for organizations interested in measuring QOL.

- We recommend the creation of iterative and enhanced versions of the assessment tools library, based on the feedback and input of ND stakeholders

- We recommend the utility of the library be assessed for use in the shared evaluation process

We describe the immediate applications of the assessment tools library in our Key Findings. Those, and other applications of the library, can be made stronger through your contributions and feedback as you use the library in your own QOL work.

Implement a shared evaluation process

- Adira recommends the creation of a tool that will accurately translate the metrics evaluated by existing assessment tools to the metrics in the common standard for evaluating QOL we have proposed *(time, money, energy, confidence, connection)*

This tool will need to be carefully designed to ensure metrics in existing assessment tools are properly aligned with the common QOL metrics. It will also need to consider the various scales used across assessment tools to accurately translate outcomes in a standardized way.

- Using this tool, we recommend the creation of a shared evaluation process across ND programs to measure total system impact on QOL for people living with ND and ND caregivers

  We envision the shared evaluation process may include steps like these:

a. Organization serving ND group(s) engages people most impacted by ND to identify QOL goals and specific factors affecting QOL
    b. Organization designs a program to meet these needs
    c. Organization uses Adira's assessment tool library (Appendix 2) to identify tools which best relate to the QOL goals and factors affecting QOL expressed by their community
    d. Program is evaluated using identified tool, showing individual outcomes on factors affecting QOL
    e. Organization uses translational tool to quantify individual outcomes as QOL impact

- We then recommend aggregating this data across individual programs to show total system impact on QOL in ND.

With a common set of metrics and a standard process for translating program outcomes to QOL impact we can begin to understand on a broad scale how particular interventions impact QOL. We can also ensure health care and social support systems are effectively providing support for all areas of QOL.

Conclusion

We believe we can create a common set of metrics to evaluate QOL based on our shared identity as humans. Despite the unique manifestations of disruptions to our individual QOL ultimately, we all share common desires. As people, we want more time, more money, more energy, more confidence, and more connection to be able to live full lives.

Assessment tools used to measure QOL today actually measure factors affecting QOL. Historically, programs and organizations have had a hard time quantifying and effectively communicating impact on QOL itself.

With a diverse group of ND stakeholders, we seek to create and test a common standard of QOL metrics and develop a process and tools to accurately translate existing assessment tool outcomes to QOL impact. Over time this data can be used to analyze QOL impact on a broad scale and inform decision making by ND stakeholders to act in a collective and coordinated manner to support people most impacted by ND in the ways that matter to them most.

To succeed in this effort, it is critical that we gather more information from people most impacted by ND on their prioritization of the QOL metrics of time, money, energy, confidence, and connection and their perceived alignment of specific factors impacting QOL with these standard measures.

We also look to receive critical feedback and comments from professionals on the purpose, content, and recommendations of this report. Comments can be sent to programs@adirafoundation.org.

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Contact programs@adirafoundation.org to request a copy of this reference

Appendix 1

Table 1:

Definitions of Metrics Included in Common Standard

Time	How does the project give people most impacted by ND more time to spend doing the things they enjoy?
Money	How does the project put more money in the pockets of people most impacted by ND?
Energy	How does the project provide people most impacted by ND with more physical and mental energy to live their lives?
Confidence	How does the project give people most impacted by ND more confidence to navigate systems and make informed decisions?
Connection	How does the project offer more opportunities for connection and feelings of shared community to people most impacted by ND?

Appendix 2

A link to the interactive assessment tool database is available at
www.adirafoundation.org/inform-qol

Additionally, you may contact programs@adirafoundation.org to request a copy.

- Direct links to the source materials for each assessment tool analyzed in this report are included in the database.