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.

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.