



Let's Talk

Measuring Quality of Life in ND

Wednesday, July 21, 2021

11:30 am – 12:30 pm ET



Agenda

Welcome and Project Introduction

*Greg Smiley, CEO & Founder
Adira Foundation*

11:30 – 11:35

An Analysis of Quality-of-Life Assessment Tools

*Report presentation by Zainab Mahmood, MPH Candidate
The Milken Institute School of Public School*

11:35 – 11:50

Breakout Rooms

- *Purpose of Measuring QOL in ND*
- *Practicalities of Measuring QOL in ND*
- *Practices of Measuring QOL in ND*

11:50 – 12:25

Wrap-up

12:25 – 12:30



About Adira Foundation

At Adira, a 501(c)(3) public foundation, we envision a world where people with neurodegenerative diseases and their caregivers are living fully.

OUR MODEL

Adira’s approach drives toward one outcome: better lives for people with neurodegenerative diseases.

We Listen

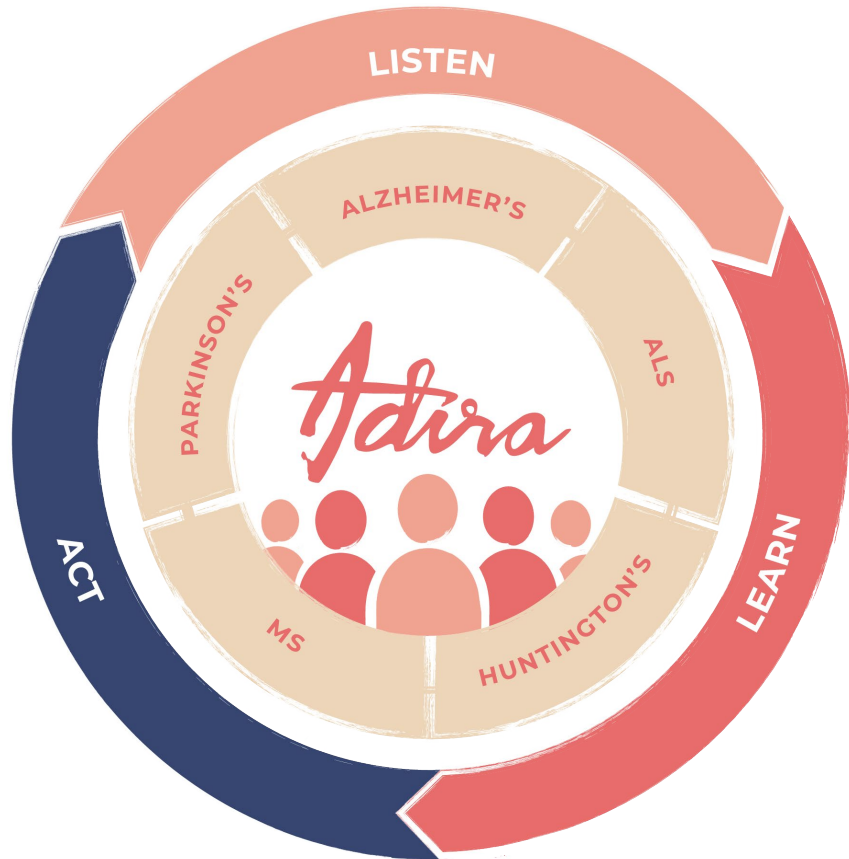
We create spaces for open conversation. We bring together everyone invested in neurodegenerative health care solutions.

We Learn

You help us learn. That’s how we find solutions to fund.

We Act

Our solutions are community based. We fund and program around priorities that rise to the top.



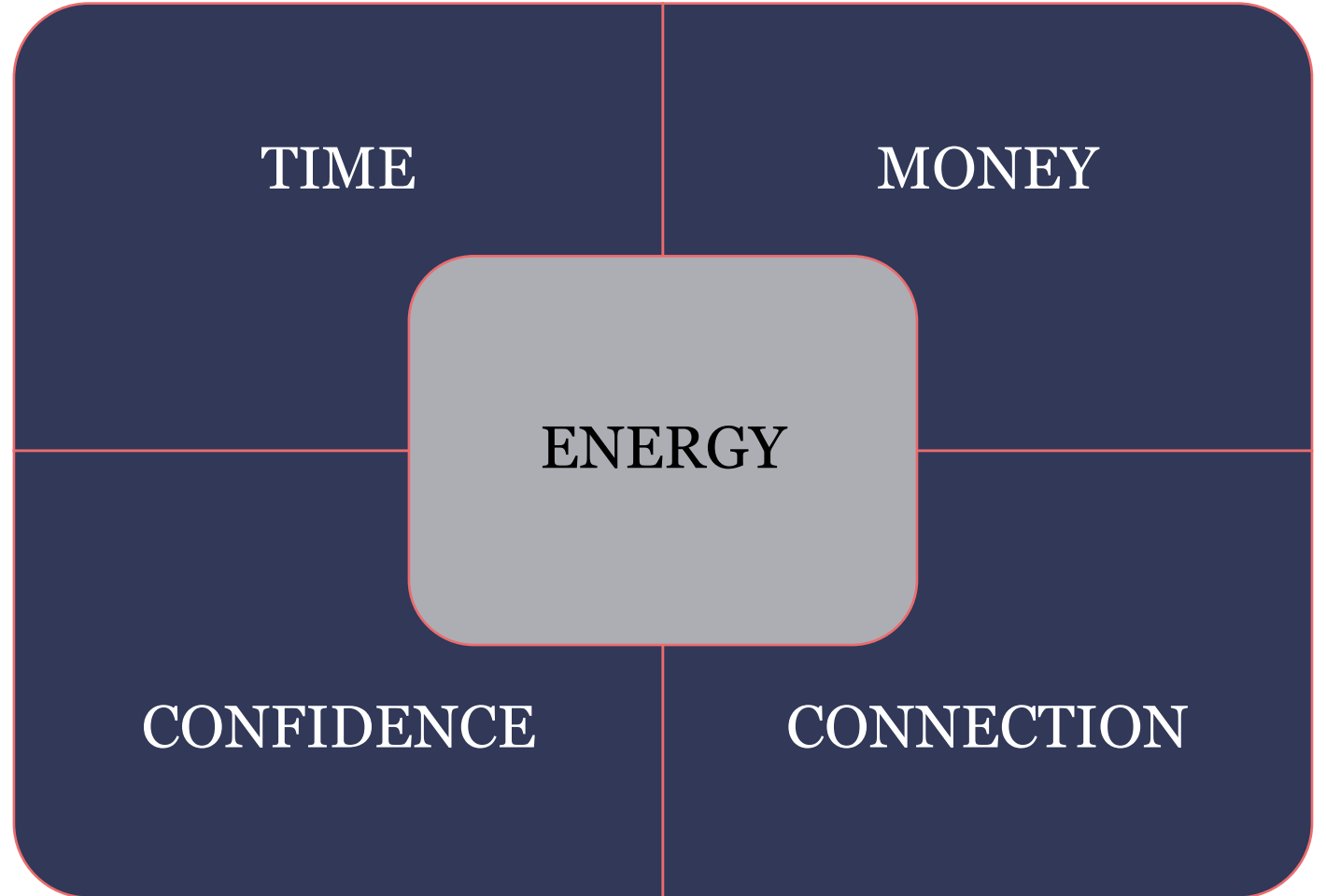


What Makes Us Different?



Better lives for people impacted by ND

- What does that mean?





Project Background



Evaluating QOL impact

- How is QOL currently measured?
- Can we show collective impact across ND groups?



Bring together experts and best practices

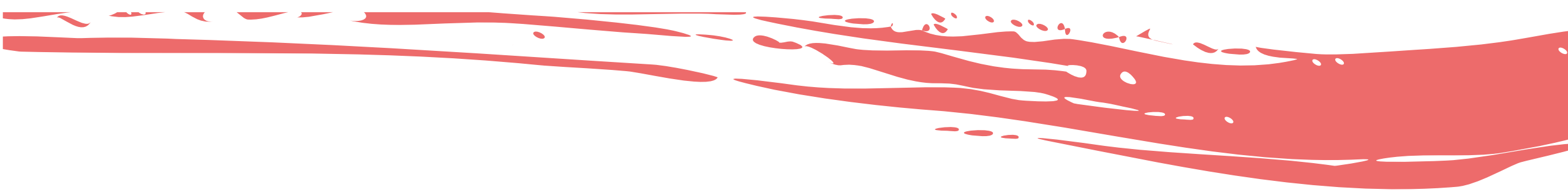
- What are the benefits of a common tool?



Convening Goals

We hope by the end of the convening that,

- You have a better understanding of the current landscape of assessment tools measuring QOL
- We have a better understanding of your experiences with these and other tools in your daily work
- You take part in co-creating resources and tools to evaluate QOL in people most impacted by ND on a broad scale
- We can agree to speak again to further explore this topic





An Analysis of Quality-of-Life Assessment Tools



Report Overview

Purpose

This paper examines the metrics defined in assessment tools currently used to evaluate QOL. It also aligns current metrics with a suggested set of common metrics to evaluate QOL in ND.

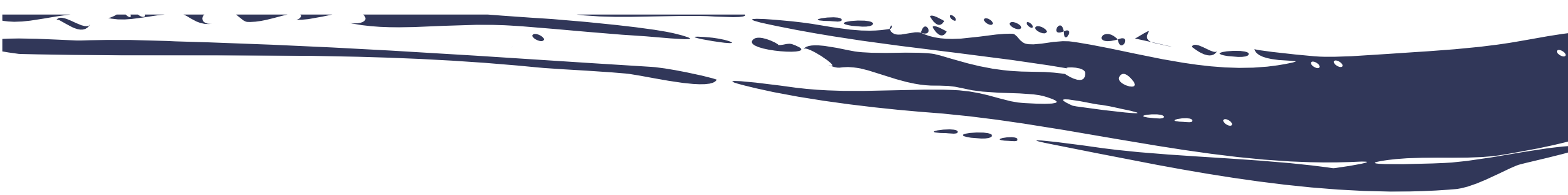
Design

We conducted a systematic literature review.

Results

The review found strong alignment between the specific metrics used in these tools to describe QOL inputs and the distinct QOL metrics Adira recommends as a common standard for QOL evaluation (time, money, energy, confidence, connection).

The evidence presented suggests that these 5 QOL metrics can be successful in defining and evaluating QOL impact on a broad scale.





Report Design

Selecting QOL Assessment Tools

Tested in..., Validity, Reliability

50

Analyzing QOL Assessment Tools

Critical features



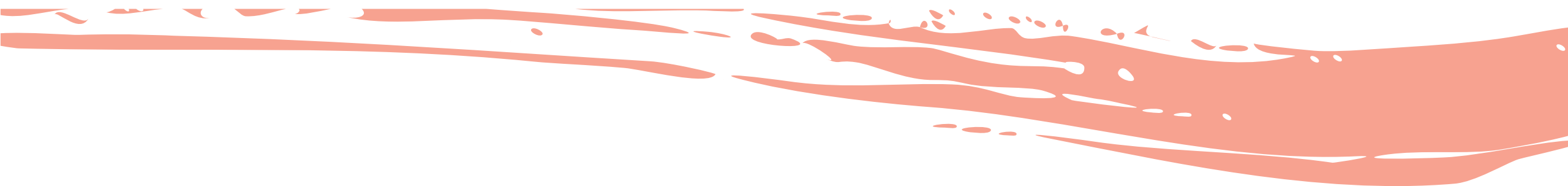
Metrics



Language

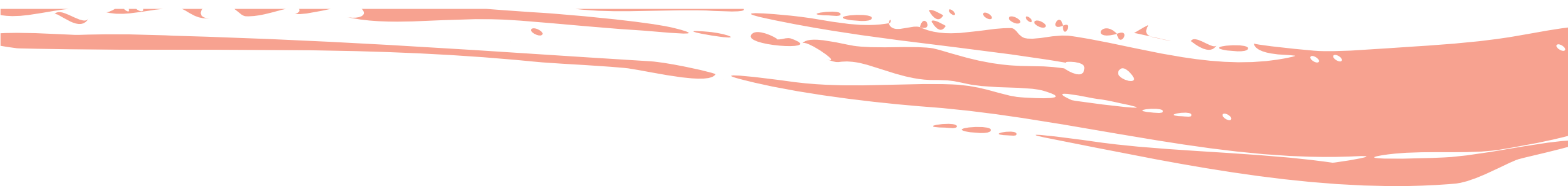
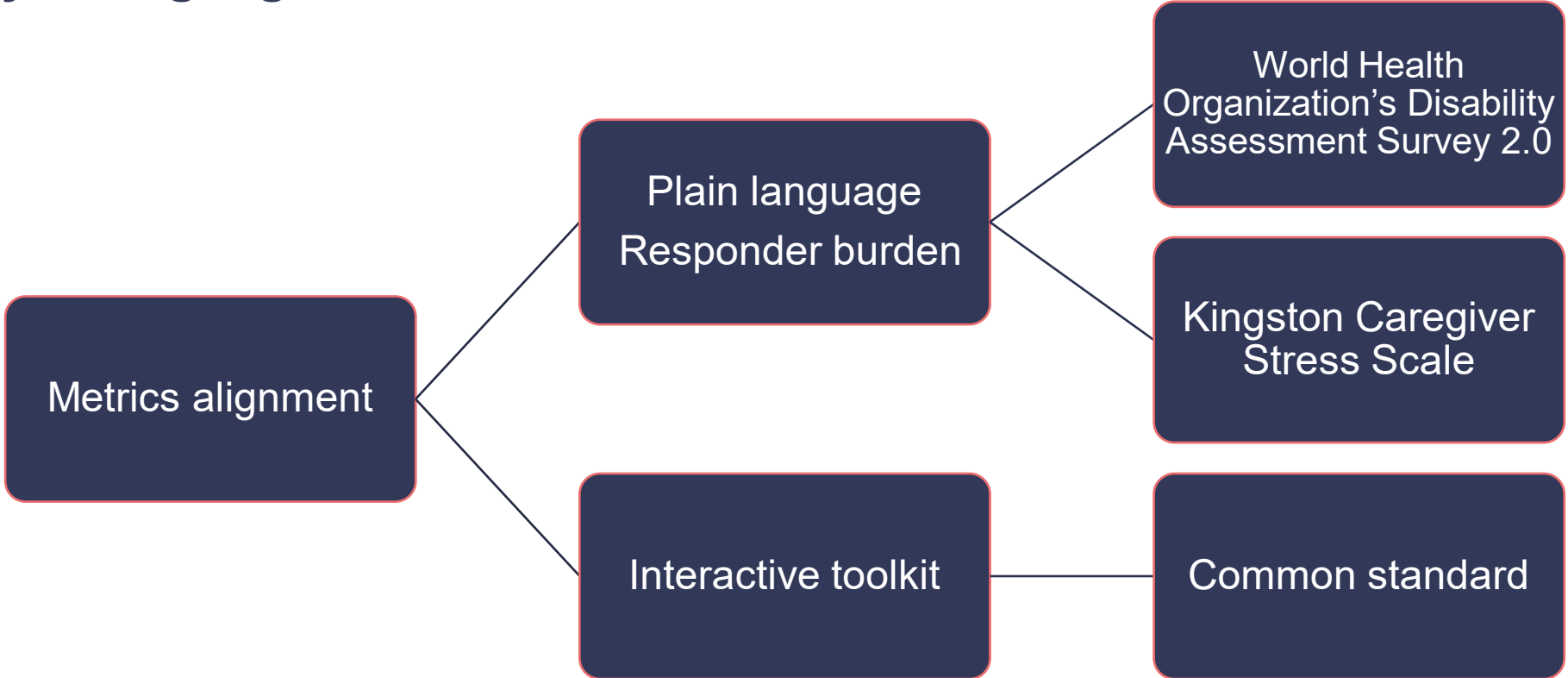


Length





Analysis Highlights





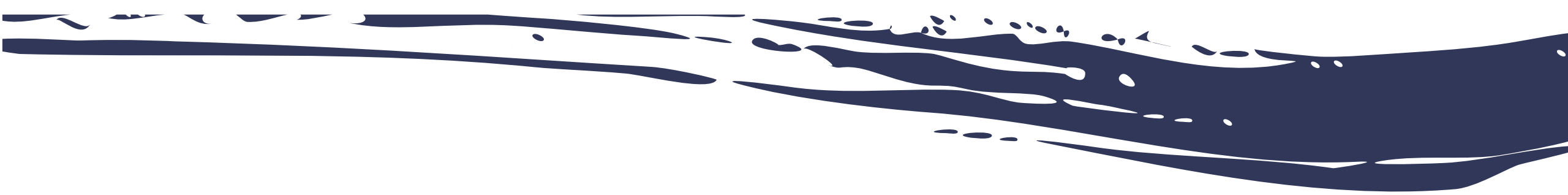
Recommendations

Create a common standard to understand and evaluate QOL

- Provide resources to evaluate QOL to ND stakeholders
- Align understanding of QOL in ND with human-related QOL measures

Build a collective strategy of ND stakeholders to implement shared evaluation

- Show impact of the ND support network on QOL in ND on a broad scale





Breakout Discussions

Measuring QOL in ND



35 minutes

Discussion 1 **Purpose**

- Understanding & defining QOL
- Value of QOL evaluation in PMI by ND

Discussion 2 **Practicalities**

- QOL evaluation challenges & solutions
- Value of project recommendations to your work

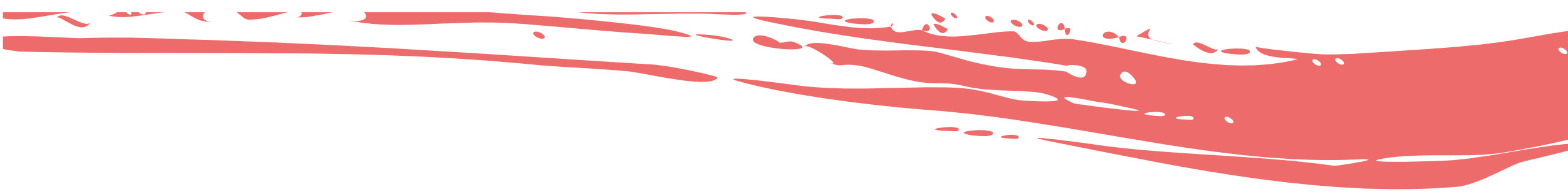
Discussion 3 **Practices**

- Critical features selection & discussion
- Establishing a strategy for report recommendations



What's Next?

- Event materials
 - Comment on the report
 - Send thoughts to programs@adirafoundation.org
- Follow-up survey
 - Contribute insights from your organization
 - Share with other professionals in your field providing care to ND communities





Announcements

- Sounding board (for people most impacted by ND)
 - Learn more at - <https://adirafoundation.org/join/shape-change-for-nd/>
- Round 3 – Fall Grants
 - 2021 grants cycle
 - Sign up for our e-newsletter to stay informed
- ND Congress
 - *Event coming soon! – January 2022*
 - Join us to help priority set and advance conversations around our collective work





Thank you!

www.adirafoundation.org

programs@adirafoundation.org