



# **Advancing research on emotional well-being: Introducing a family well- being research network**

**ISPOR 2022**

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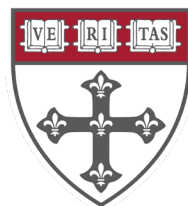
**FAMNET**  
Family Well-Being Research Network

# Presenters

- 👤 **Eve Wittenberg, PhD, Harvard University**
- 👤 **Janel Hanmer, MD, PhD, University of Pittsburgh**
- 👤 **Lisa Prosser, PhD, University of Michigan**

# Family Well-being Research Network FAM-NET

- 👤 Collaborative project
  - 👤 University of Michigan
  - 👤 Harvard University
  - 👤 University of Pittsburgh
  - 👤 National Institutes of Health
- 👤 Funded by Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD),  
U24HD107562





# EWB Networks

- 👤 **Emotional Well-Being and Economic Burden Research Network** (Univ of Alabama at Birmingham, Univ of Tennessee)
- 👤 **Network to Advance the Study of Mechanisms Underlying Mind-Body Interventions and Measurement of Emotional Well-Being** (Univ of Connecticut, Storrs)
- 👤 **The Plasticity of Well-Being: A Research Network to Define, Measure, and Promote Human Flourishing** (Univ of Wisconsin-Madison)
- 👤 **Advancing Psychosocial & Biobehavioral Approaches to Improve Emotional Well-Being** (Univ of California, San Francisco, Univ of California, Berkeley, Harvard)
- 👤 **Network for Emotional Well-Being and Brain Aging** (Univ of Rochester)
- 👤 **Family Well-Being Research Network** (Harvard, Univ of Michigan, Univ of Pittsburgh)



# FAM-NET goal

To support and advance research on the measurement of family well-being and pediatric quality of life, by funding new areas of study, supporting and mentoring the next generation of scholars, and providing education and resources for researchers

# Why family well-being?

# Expanded unit of analysis



individual



family



# Expanded construct



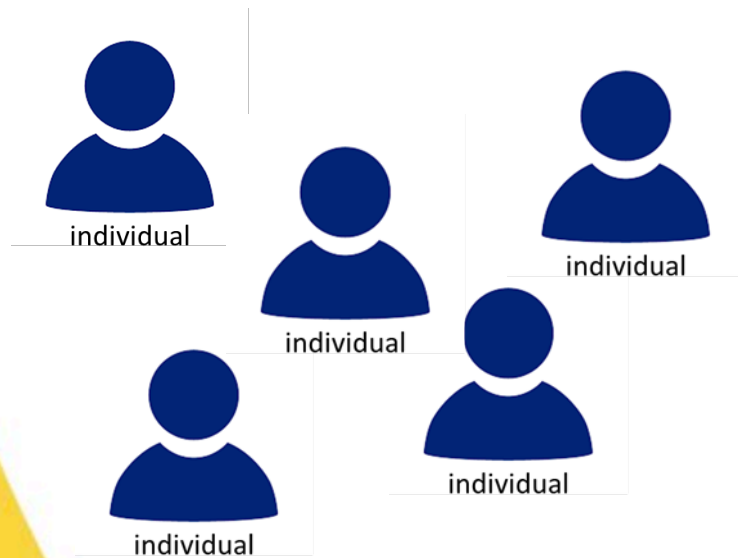
**HRQOL**



**Well-being**

# Measuring family-level outcomes

 Combination of individual metrics



 Group-specific metric






family





Implies who responds/provides 'data'  
Implies what is being measured

# Potential constructs

## Individual metrics

-  Health—physical, emotional
-  HRQOL—health-related quality of life
-  Individual well-being

## Group-specific metrics

-  Family functioning/cohesion
-  Family ‘harmony’
-  Family ‘quality of life’
-  Satisfaction with family life

# If individual-level metrics

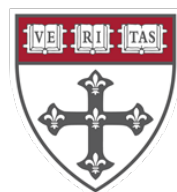
- 👤 How to combine?
  - 👤 Sum
  - 👤 Mean
  - 👤 Who is included
  - 👤 Equal weights or differential weighting
- 👤 Same or different metric for all or different metric for different ages or roles?
  - 👤 Child/adult
  - 👤 Caregivers/non-caregivers

# If family-level metrics

- 👤 Same ‘content’ for all families?
  - 👤 With/without children
  - 👤 Spouses
  - 👤 Within a residence/across households (e.g., adult children)
- 👤 Who responds/provides ‘data’
  - 👤 One for family/all members
  - 👤 Proxies—for children/older adults/patients

# FAM-NET

**A collaborative project to support and advance research on measurement of family well-being and pediatric quality of life. We will build knowledge by funding new research, supporting and mentoring the next generation of scholars, and providing education and training.**



# FAM-NET Focus

- 👤 Family well-being
  - 👤 childhood to older ages
- 👤 Measurement
- 👤 Catalyzing research: providing resources and creating connections

# “Family”

- 👤 Two+ individuals connected by:
  - 👤 Shared financial responsibility/dependence
  - 👤 Legal/blood relationship
  - 👤 Shared household residence
  - 👤 (any 2 of these at minimum)



family



# “Well-being”

- 👏 To be determined...part of focus

# FAM-NET components

- 👤 Research resources: Web-based Repository
- 👤 Research funding: Pilot Project Grants
- 👤 Research mentorship: Research Scholar Corps

# Research resources: Web-based resource repository ([www.fam-net.org](http://www.fam-net.org))



**Databases**



**Instruments**



**Videos**






# Databases



- 👤 Curated catalog of datasets containing data elements relevant to families, family members, outcomes—well-being and related
- 👤 Publicly accessible and proprietary
- 👤 Cataloged for searching/easy-identification

# Example: HRS Childhood Family and Child Health Aggregated Data

## Description

-  HRS respondent data from 1992-2016 aggregated to highlight childhood background—family and health
  -  Retrospective reports
  -  n=38,654
  -  74 variables
  -  Household and person-level identifiers
- ## Link to dataset

# Instruments



- 👤 Two catalogs under development:
  - 👤 Family outcomes measures/instruments
  - 👤 Pediatric quality-of-life and well-being instruments
  - 👤 Annotated and tagged for searching
- 👤 Links to other catalogs, annotated with descriptions, contents, scope: e.g., Harvard's Lee Kum Sheung Center for Health and Happiness, well-being measurement: <https://www.hsph.harvard.edu/health-happiness/well-being-measurement-2021/>
- 👤 Links to partner networks' measures repositories: e.g., EWB Subjective Measures Repository: <https://m3ewb.research.uconn.edu/ewb-subjective-measures-repository/>

# Educational videos






- 👤 All open-access
- 👤 Cataloged and annotated for content
  - 👤 FAM-NET meetings
  - 👤 FAM-NET sponsored research symposia
  - 👤 Reports from funded pilot projects/scholars' research
- 👤 Partner networks' events
- 👤 Externally-produced recorded events

# Research Funding

## **Pilot project grants**

-  Projects that lead to further work/research
-  Maximum \$15,000/award
-  Any level of investigator

## **Research Scholar Corps**

-  Mentored projects
-  \$6,000 stipend
-  Junior faculty, trainees, graduate students





# Pilot Project Grants

## Objective

- 👤 To develop and advance new ideas and scalable approaches to contribute to the measurement and foundational knowledge of family well-being

## Focus: lifespan perspective

- 👤 childhood quality of life through and including older adults' well-being, with a focus on family-focused metrics and analytic strategies



# Research Scholar Corps

## Objectives

- 👤 To support and foster a scholar pipeline for future research on family well-being measurement
  - 👤 Intended for trainees and junior faculty
- 👤 To provide multidisciplinary mentoring and training
- 👤 To create a peer network of like-minded researchers
- 👤 Promote Corps members
  - 👤 Highlight on FAM-NET website
  - 👤 Include in annual symposia



# All grantees

- 👤 Participate in network symposia, workshops, and webinars
- 👤 Receive regular feedback from FAM-NET investigators
- 👤 Have access to support for research translation/dissemination
- 👤 Contribute to and access FAM-NET on-line research resources

# Award Priorities

- 👏 Contributing to FAM-NET impact & theme
- 👏 Advancing methods
- 👏 Developing investigators
- 👏 Contributing to network: connections with FAM-NET sponsoring institutions, research resources, research scholar corps, and partner networks

# Request for Applications

- 👏 All awards for 12-month period
- 👏 Rolling applications—awards made every 3 months
- 👏 2022 schedule: June 30, Sept 30, Dec 31 deadlines
- 👏 [www.fam-net.org](http://www.fam-net.org)
- 👏 Funding Opportunities page
- 👏 Pilot projects and Scholar abstracts/descriptions

# Current grantees

- 👤 **“Natural experimentation approaches to explore family well-being: A scoping review”**, University of Utah College of Nursing—research scholar
- 👤 **“Health-related quality of life and family well-being in pediatric patients with genetic conditions and their families: A scoping review of the literature”**, Baylor College of Medicine—research scholar
- 👤 **“Using PROMIS measures to Characterize the Emotional Well-Being of Family”**, University of Pittsburgh School of Medicine—pilot project
- 👤 **“Beyond ‘Survival’: Patient and Caregiver Well-being in Pediatric Heart Failure”**, University of Utah, Department of Pediatrics--dual pilot and research scholar
- 👤 **“Parent and Adolescent Perspectives on Adolescent Well-Being”**, Northwestern University, Feinberg School of Medicine--dual pilot and research scholar

# Questions

- 👏 Follow us on Twitter [@famnetresearch](https://twitter.com/famnetresearch)
- 👏 Join our email list: [contact@fam-net.org](mailto:contact@fam-net.org)
- 👏 Website: [www.fam-net.org](http://www.fam-net.org)