



Key considerations when selecting family carer outcome measures



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What is the Caregiver Core of the Palliative Care Research Cooperative Group?

The screenshot shows the website for the Palliative Care Research Cooperative Group (PCRC). The header includes the PCRC logo and the text "PALLIATIVE CARE RESEARCH COOPERATIVE GROUP". A navigation menu lists: About, Membership, Research, Funding Opportunities, Cores/Centers, News & Publications, Who We Are, Resources. A search icon is visible in the top right. The main content area is titled "Caregiver Core". Under "Core Leadership:", there are two profiles: Betty Ferrell, PhD, MA, FAAN, FPCN (Core Lead) and J. Nicholas Dionne-Odom, PhD RN ACHPN (Consultant). Below the profiles is the text "Contact Betty Ferrell for a core consultation." The "Roles and Responsibilities of the Caregiver Core:" section lists: Discuss opportunities to include caregivers in palliative care studies involving patients; Explore areas of science needed to advance understanding of caregiving in palliative care; Assist investigators in the selection of conceptual models, study designs, outcome variables and measurement tools for use in caregiver research. On the right side, there are sections for "ANNOUNCEMENTS" (listing funding opportunities), "TWEETS FROM @PCRCGROUP", and "NIH EXTRAMURAL NEXUS" (listing grant updates).

PCRC website: <https://palliativecareresearch.org/>

PCRC Core page: <https://palliativecareresearch.org/corescenters/caregiver-core>

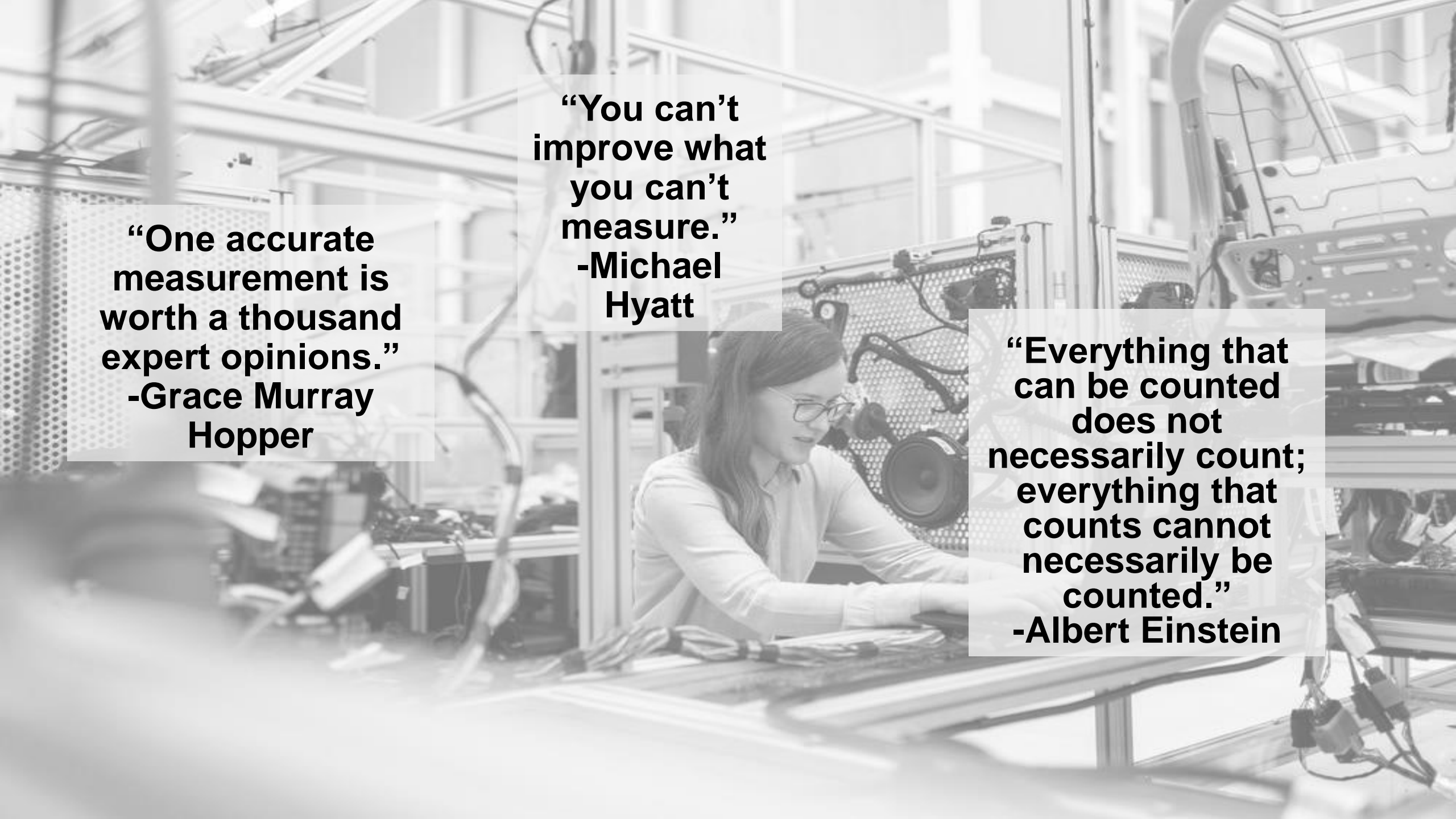
What does the PCRC Caregiver Core do?

Discuss opportunities to include caregivers in palliative care studies involving patients

Explore areas of science needed to advance understanding of caregiving in palliative care

Discuss opportunities for inclusion of qualitative data in caregiver research

Assist investigators in the selection of conceptual models, study designs, outcome variables and measurement tools for use in caregiver research

A grayscale photograph of a woman with long hair and glasses, wearing a light-colored long-sleeved shirt, working at a workstation in a factory or laboratory. She is looking down at her work. The background shows industrial equipment, including a large metal structure with a speaker and various cables.

**“One accurate measurement is worth a thousand expert opinions.”
-Grace Murray Hopper**

**“You can’t improve what you can’t measure.”
-Michael Hyatt**

**“Everything that can be counted does not necessarily count; everything that counts cannot necessarily be counted.”
-Albert Einstein**

5 measurement considerations in family carer research

1. What instrument(s) best operationalize concepts in my research question/aims?
2. Does the instrument link my study's larger theoretical framework?
3. What instruments should I use?
4. What carer demographics should I collect?
5. What are some good resources to find instruments?

1

What instrument best operationalizes concepts in my research question?



Caregiver Focused Constructs



Patient Focused Constructs



Relationship Focused Constructs



Caregiver Focused Outcomes

Health and well-being outcomes

- Quality of life
- Distress
- Burden/strain
- Mood (depression/anxiety)
- Physical health
- Grief/bereavement

Caregiver skills

- Communication
- Preparedness
- Decision-making
- Knowledge (beware of Dunning-Kruger effect)
- Nursing task (e.g., med administration, wound care)

Caregiver health utilization

- Out of pocket costs
- Primary care/wellness visits
- Caregiver hospital days/ED visits
- Work time off
- Paid help

Patient Focused Outcomes

Health and well-being outcomes

- Quality of life
- Physical health
- Mood (depression/anxiety)
- Symptoms
- Mortality

Patient healthcare utilization

- Hospital/ICU days
- ED visits
- ACP behaviors/living will completion/DPOAH designation

End of life outcomes

- QOL at EOL
- Medical treatment intensity (last 30/last 7 days)
- Place of death
- Symptoms at end of life



Relationship Focused Outcomes

Patient-family healthcare clinician relationships

- Patient-family-provider quality of communication
- Satisfaction with care
- Patient-family-healthcare clinician concordance

Caregiver-patient relationship

- Relationship strain
- Marital satisfaction
- Intimacy
- Serious illness conversation

Caregiver health utilization

- Out of pocket costs
- Primary care/wellness visits
- Use of community and other professional support services



2

Does the instrument link to a construct within my study's larger theoretical framework?

—

What is a conceptual model or theory?

National Cancer Institute

Theory at a Glance

A Guide For Health Promotion Practice

“A theory presents a systematic way of understanding events or situations. It is a set of concepts, definitions, and propositions that explain or predict these events or situations by illustrating the relationships between variables.”
(p. 4)

—
What is a
conceptual
model or
theory?

Identify a theory or conceptual framework

Step 1:

“A theory presents a systematic way of understanding events or situations. It is a set of concepts, definitions, and propositions that explain or predict these events or situations by illustrating the relationships between variables.”
(p. 4)

Caregiver Core

Core Leadership:



ANNOUNCEMENTS

- May 2019, Issue 36 PCRC Newsletter
- Open Position: NIH DIRECTOR OF THE NINR DIVISION OF EXTRAMURAL SCIENCE PROGRAMS
- PCRC's Heart Failure Special Interest Group to host a Work-in-Progress meeting
- New NIH Administrative Supplements
- Submission Abstracts Based Abstract Database for

Caregiving Research Resources.

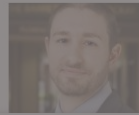
- [Selecting a Conceptual Model of Caregiving Research](#)
- [Methodological Considerations for Caregiver Research References](#)
- [Case Western Reserve University's Distance Caregiver Study website](#)
- [Latino Family Caregiving at End of Life video: A video-soap opera, telenovela entitled Cuidadores como yo/Caregivers Like Me for the education of family caregivers. Available in English or Spanish.](#)
 - Cruz-Oliver DM, Fernandez N, Parikh M, Malmstrom TK, Gonzalez J, Sanchez-Reilly S. [Education Intervention "Caregivers Like Me" for Latino Family Caregivers Improved Attitudes Toward Professional Assistance at End-of-life Care](#). *American Journal of Hospice and Palliative Medicine*. 2015 May 27. pii: 1049909115584315. [Epub ahead of print]
 - Cruz- Oliver DM, Ellis K, Sanchez-Reiley S. [Caregivers Like Me: An Education Intervention for Family Caregivers of Latino Elders at End-of-Life](#). *MedEdPORTAL Publications*. 2016;12:10448. http://dx.doi.org/10.15766/mep_2374-8265.10448.
 - Cruz-Oliver DM, Parikh M, Wallace C. [What did Latino Family Caregivers expect and learn from Education Intervention "Caregivers Like Me?"](#) *Am J Hosp Palliat Care*. 2017 Jan 1:1049909117709550.
 - Cruz-Oliver DM, Malmstrom TK, Roegner M, Gwen Y. [Evaluation of a video-based seminar to raise healthcare professionals' awareness of culturally sensitive end-of-life \(EOL\) care](#). *J Pain Symptom Manage*. 2017 Jul 14.

PCRC Caregiver Core Resources for Theory/Conceptual Frameworks

<https://palliativecareresearch.org/corescenters/caregiver-core>

Caregiver Core

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Caregiving Research Resources:

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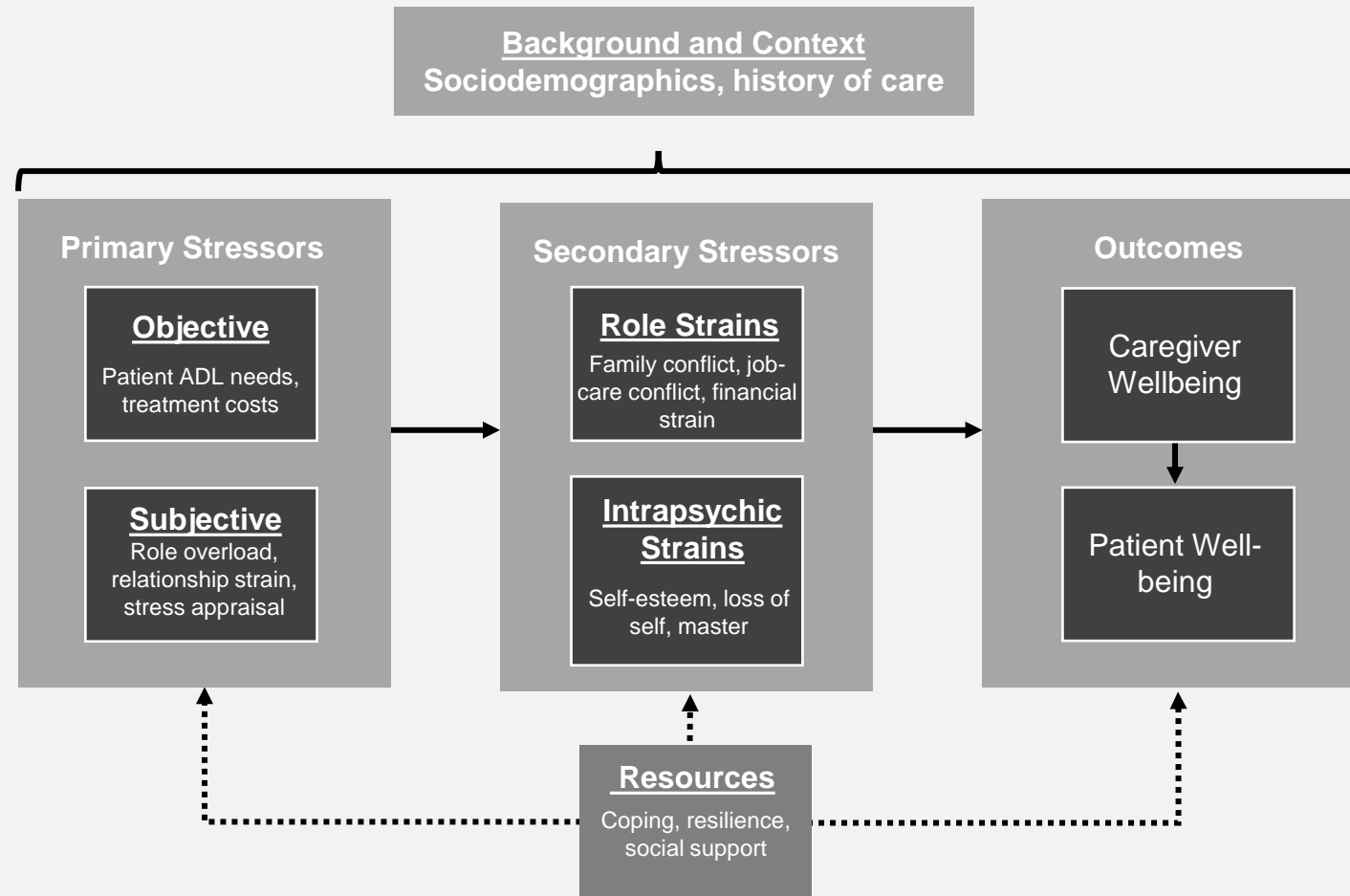
Step 2:

Link constructs in your theoretical model to instruments

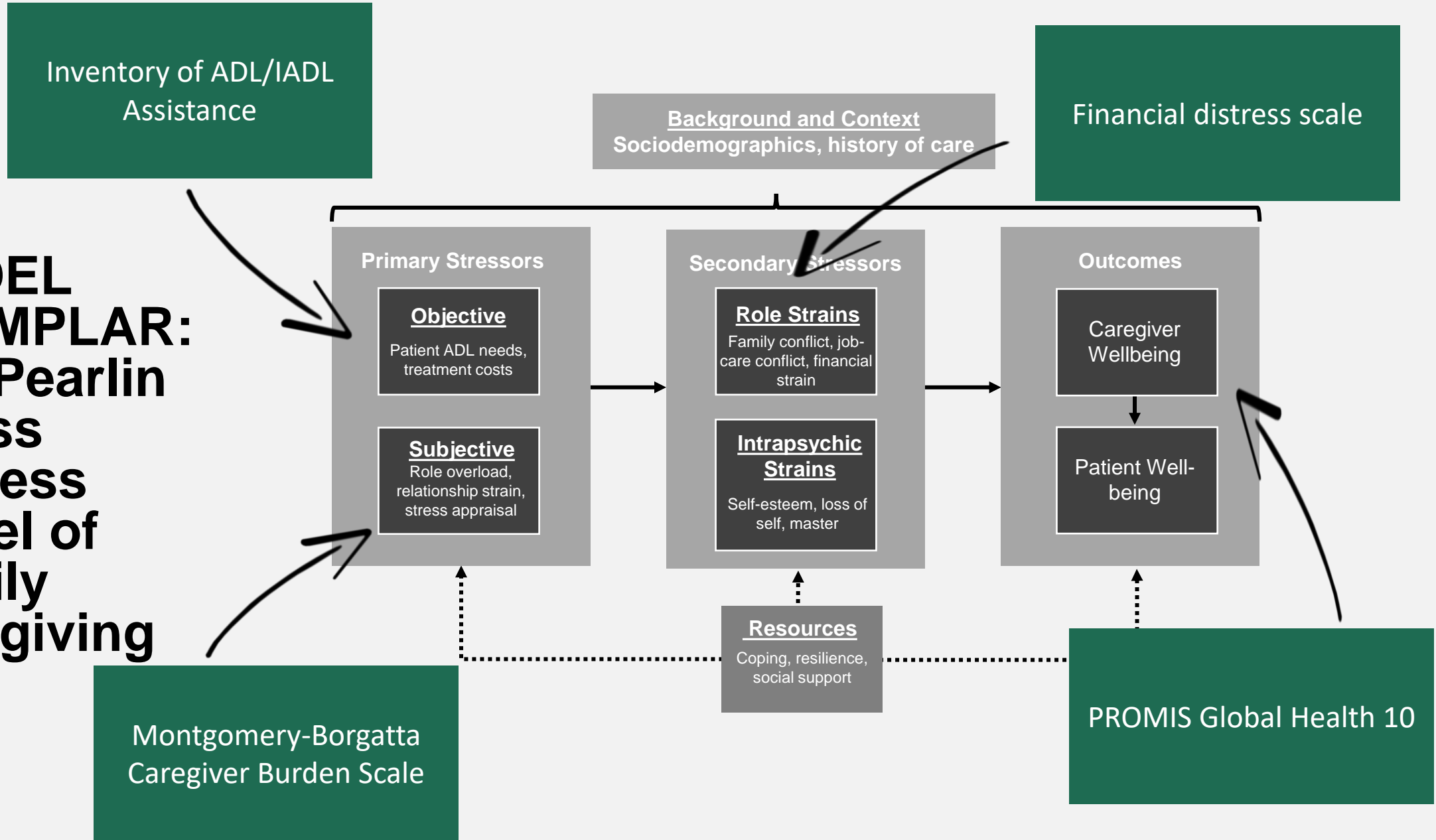
PCRC Caregiver Core Resources for Theory/Conceptual Frameworks

<https://palliativecarereseach.org/corescenters/caregiver-core>

MODEL EXEMPLAR: The Pearlin Stress Process Model of Family Caregiving



MODEL EXEMPLAR: The Pearlin Stress Process Model of Family Caregiving





3


What instruments should I use?

What instruments should I use?

General considerations:

- What has been documented in systematic reviews?
- What have similar studies used?
- Unless you're a psychometrician, don't develop a new instrument

A Review of Family Caregiving Intervention Trials in Oncology

Betty Ferrell, RN, PhD, MA, FAAN, FPCN, CHPN ¹; Elaine Wittenberg, PhD²

¹Director, Division of Nursing Research and Education, City of Hope National Medical Center, Duarte, CA; ²Associate Professor, Division of Nursing Research and Education, City of Hope National

Abstract: This article contains a review of literature published from 2010 to 2016 on family caregiving in oncology. An analysis of 810 citations resulted in 50 randomized trials. These trials describe the need to prepare family caregivers for the complex role

of life for general students. An

Heart Fail Rev (2017) 22:543-557
DOI 10.1007/s10741-017-9597-4



Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review

J. Nicholas Dionne-Odom¹ · Stephanie A. Hooker² · David Bekelman³ · Gwen McGhan⁴ · Lisa Kitko⁴ · Anna Strömberg⁵ · Rachel Wells¹ · M. Zehra Gok Metin⁷ · Gisella Mancarella¹ · Salpy V. Pamboukian⁸ · Lorraine Evangelista⁹ · Harleah G. Buck¹⁰ · Marie A. Bakitas¹ · On behalf of the IMPACT-HF National Workgroup

Published online: 4 February 2017
© Springer Science+Business Media New York 2017

Abstract Many of the 23 million individuals with heart failure (HF) worldwide receive daily, unpaid support from a family member or friend. Although HF and palliative care practice are closely related, little is known about HF with

Department of Veterans Affairs Health Services Research & Development Service | Evidence-based Synthesis Program

QUERI

Effectiveness of Family and Caregiver Interventions on Patient Outcomes among Adults with Cancer or Memory-Related Disorders: A Systematic Review

April 2013

Prepared for:
Department of Veterans Affairs
Veterans Health Administration
Quality Enhancement Research Initiative
Health Services Research & Development Service
Washington, DC 20420

Prepared by:
Evidence-based Synthesis Program (ESP) Center
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Nancy Greer, Ph.D.
Agnes Jensen, B.S.
Roderick MacDonald, M.S.
Indulis Rutks, B.S.

A young child with light brown hair, wearing a blue jacket, is sitting in a blue and black toy car. A yellow strap is attached to the front of the toy car and extends towards the front of a real dark-colored car parked on a gravel driveway. The scene is outdoors with green grass and trees in the background.

Don't worry I got this...

**...developing this new
instrument will be easy.**

What instruments should I use?

General considerations:

- Identify instruments that are valid and reliable

Validity: how well specific instruments measure what they are intended to measure

Reliability: extent to which a measure yields the same results on repeated trials

Understanding the error of our ways: Mapping the concepts of validity and reliability

Patricia A. Higgins, RN, PhD
Andrew J. Straub, ANP, GNP

Nurs Outlook 2006;54:23-29.

0029-6554/06/\$—see front matter

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doi:10.1016/j.outlook.2004.12.004

Clinicians increasingly desire evidence upon which to base their practice decisions. One of the difficulties in their decision-making, however, is answering the fundamental question, "How do I evaluate the relevance and applicability of the findings?" There are a number of factors involved in such an evaluation and, frequently, readers can easily determine the usefulness

straightforward than others; for example, the timeliness, research setting, cultural relevance, and/or types of subjects involved. On the other hand, evaluating the methodology (design and instruments) that produced those findings may not be as easily accessible, in part because of the complexity of the terms and relation-

External Validity, Generalizability, and Knowledge Utilization

Linda Ferguson

Purpose: To examine the concepts of external validity and generalizability, and explore strategies to strengthen generalizability of research findings, because of increasing demands for knowledge utilization in an evidence-based practice environment.

Framework: The concepts of external validity and generalizability are examined, considering theoretical aspects of external validity and conflicting demands for internal validity in research designs. Methodological approaches for controlling threats to external validity and strategies to enhance external validity and generalizability of findings are discussed.

Conclusions: Generalizability of findings is not assured even if internal validity of a research study is addressed effectively through design. Strict controls to ensure internal validity can compromise generalizability. Researchers can and should use a variety of strategies to address issues of external validity and enhance generalizability of findings. Enhanced external validity and assessment of generalizability of findings can facilitate more appropriate use of research findings.



4

**What demographics on carers
should I collect?**



What demographics on carers should I collect?

RESEARCH REPORT

MAY 2020

2020 Report

Caregiving in the U.S.



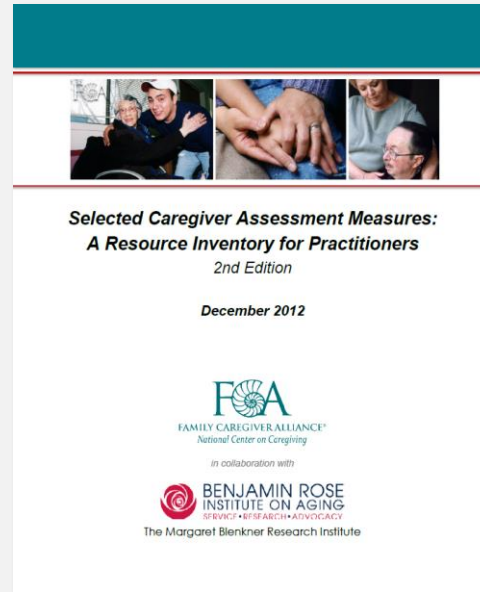
- Age
- Gender
- Race/Ethnicity
- Care recipient relationship (This person is my...)
- Education
- Employment status
- Relationship status
- Religious preference
- Care recipient dwelling status
- Household status (Who lives with you? Who lives with care recipient?)
- Caregiver socioeconomic status
- Month/year started caregiving
- Days/week providing support
- Hours/day providing support
- Medical insurance status



5

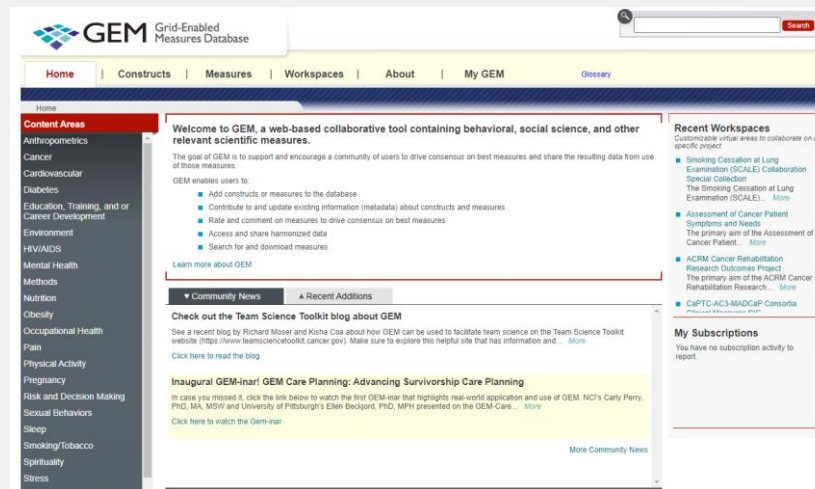
What are some good resources to find instruments?

National Alliance for Caregiving Assessment Measures

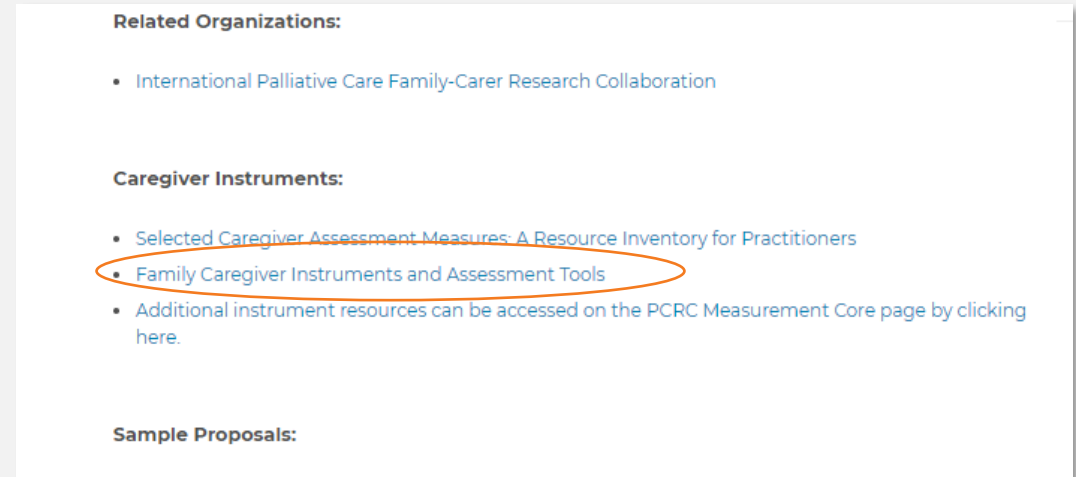


Instrument libraries and databases

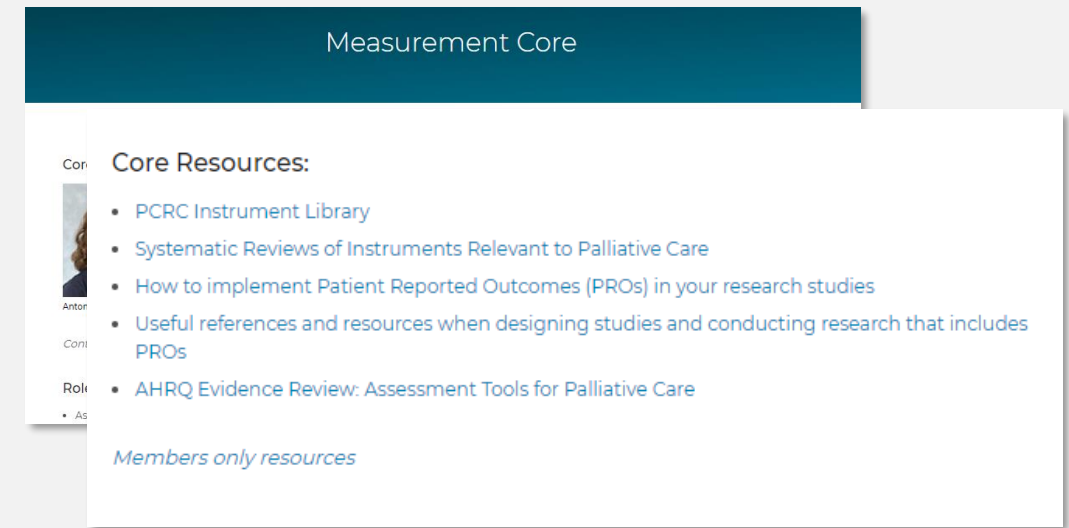
GEM: Grid-Enabled Measures Database



PCRC Caregiver Core Instrument library

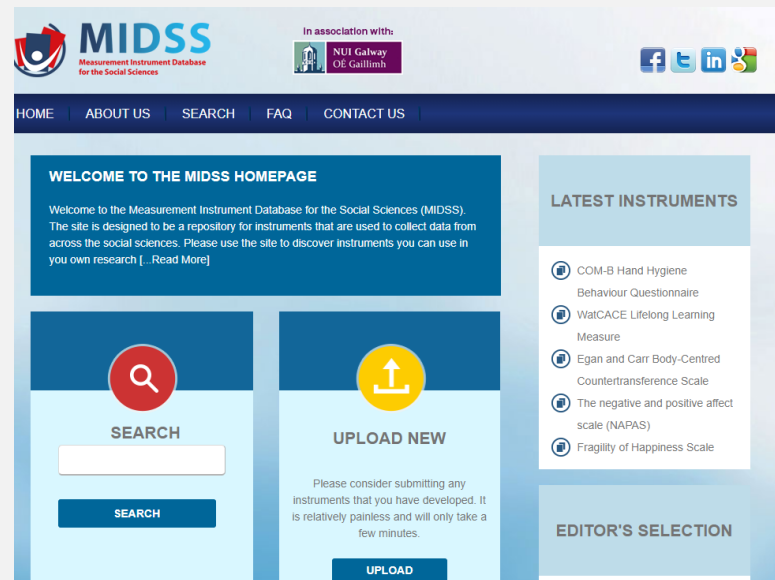


PCRC Measurement Core Instrument library:



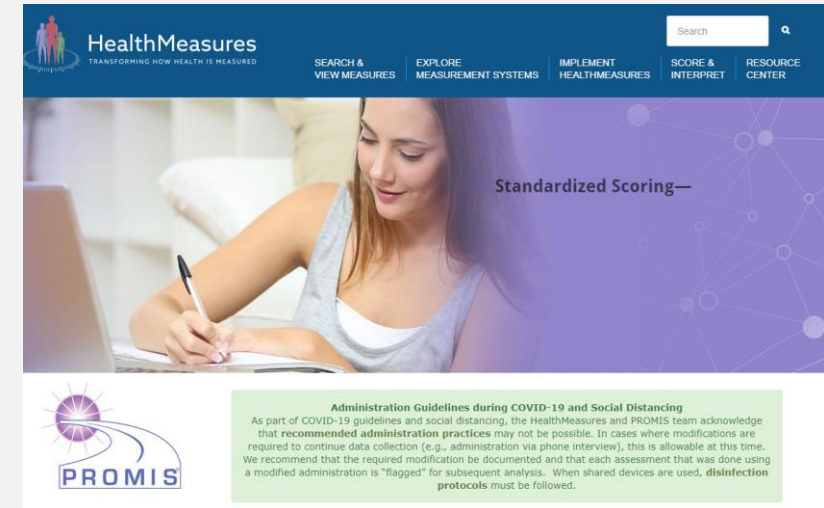
Instrument libraries and databases

MIDSS: Measurement Instrument Database for the Social Sciences



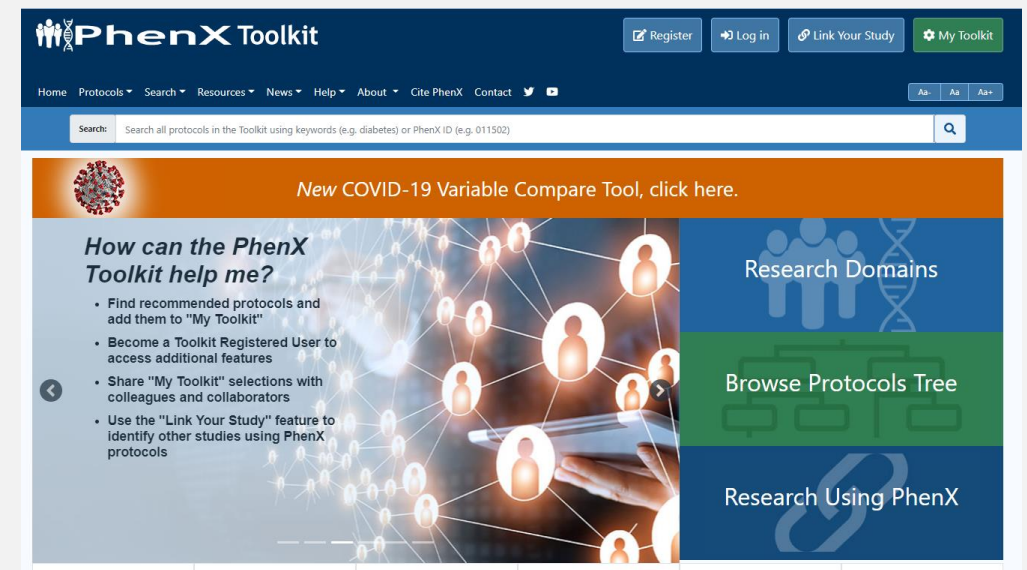
The screenshot shows the MIDSS homepage with a navigation bar (HOME, ABOUT US, SEARCH, FAQ, CONTACT US) and a main content area. The main content includes a 'WELCOME TO THE MIDSS HOMEPAGE' section, a 'SEARCH' box with a magnifying glass icon, an 'UPLOAD NEW' box with an upload icon, and a 'LATEST INSTRUMENTS' section listing various questionnaires and scales. The 'LATEST INSTRUMENTS' list includes: COM-B Hand Hygiene Behaviour Questionnaire, WatCACE Lifelong Learning Measure, Egan and Carr Body-Centred Countertransference Scale, The negative and positive affect scale (NAPAS), and Fragility of Happiness Scale. There is also an 'EDITOR'S SELECTION' section at the bottom.

PROMIS®



The screenshot shows the HealthMeasures website with a navigation bar (SEARCH & VIEW MEASURES, EXPLORE MEASUREMENT SYSTEMS, IMPLEMENT HEALTHMEASURES, SCORE & INTERPRET, RESOURCE CENTER) and a main content area. The main content features a banner for 'Standardized Scoring' and a section for 'Administration Guidelines during COVID-19 and Social Distancing'. The guidelines state that as part of COVID-19 guidelines and social distancing, the HealthMeasures and PROMIS team acknowledge that recommended administration practices may not be possible. In cases where modifications are required to continue data collection (e.g., administration via phone interview), this is allowable at this time. We recommend that the required modification be documented and that each assessment that was done using a modified administration is "flagged" for subsequent analysis. When shared devices are used, disinfection protocols must be followed.

PhenX Toolkit



The screenshot shows the PhenX Toolkit homepage with a navigation bar (Home, Protocols, Search, Resources, News, Help, About, Cite PhenX, Contact) and a main content area. The main content includes a search bar, a 'New COVID-19 Variable Compare Tool, click here.' banner, a 'How can the PhenX Toolkit help me?' section with a list of features, and a 'Research Domains' section with a 'Browse Protocols Tree' button. The 'How can the PhenX Toolkit help me?' section lists the following features: Find recommended protocols and add them to "My Toolkit", Become a Toolkit Registered User to access additional features, Share "My Toolkit" selections with colleagues and collaborators, and Use the "Link Your Study" feature to identify other studies using PhenX protocols.

In summary:

1. Choose instruments that operationalize specific carer constructs in your research aims
2. Identify a theoretical framework containing both the concept you desire to measure and other concepts of interest named in your research aims
3. Choose validated and reliable instruments that have ideally been used by others in the area
4. Collect carer demographic information that allows you to make comparisons to other work
5. Utilize established instrument databases and expert guidance to help find optimal instruments

Thank you!

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