

# Grid-Enabled Measures (GEM): Overview and Lessons Learned

*Advancing Data Sharing for Implementation Science*

*in Cancer Control Workshop Day 3*

*June 13, 2022*

# What is GEM?

<https://www.gem-measures.org>

The image shows a screenshot of the National Cancer Institute's GEM (Grid-Enabled Measures Database) website. The page features a red header with the NCI logo and the text "National Cancer Institute" and "U.S. National Institutes of Health | www.cancer.gov". Below the header, the GEM logo is displayed, followed by a navigation menu with links for Home, Constructs, Measures, Datasets, Workspaces, About, My GEM, Admin, and Glossary. A search bar is located in the top right corner. A large blue rectangular overlay is positioned in the center of the page, containing three bullet points. Below the overlay, a news section titled "Inaugural GEM-inar! GEM Care Planning: Advancing Survivorship Care Planning" is visible, along with a list of measures such as the Center for Epidemiologic Studies Depression Scale (CES-D) and the Subjective Numeracy Scale (SNS).

National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov

Hello Rick Moser [Logout](#)

**GEM** Grid-Enabled Measures Database

[Home](#) | [Constructs](#) | [Measures](#) | [Datasets](#) | [Workspaces](#) | [About](#) | [My GEM](#) | [Admin](#) | [Glossary](#)

- A collaborative, online tool to support a prospective measure (CDE) consensus process for research and clinical settings
- Utilizes collaborative workspaces
- Encourages use of CDEs across projects

**Inaugural GEM-inar! GEM Care Planning: Advancing Survivorship Care Planning**

In case you missed it, click the link below to watch the first GEM-inar that highlights real-world application and use of GEM. NCI's Carly Perry, PhD, MA, MSW and University of Pittsburgh's Ellen Beckjord, PhD, MPH presented on the GEM-Care... [More](#)

[Click here to watch the Gem-inar](#)

Center for Epidemiologic Studies Depression Scale (CES-D) (Updated on 04/25/2011)

Subjective Numeracy Scale (SNS) (Updated on 11/16/2010)

[More Community News](#)

# What is GEM?

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National Cancer Institute

U.S. National Institutes of Health | [www.cancer.gov](http://www.cancer.gov)

## • Wiki-based and

### ■ Assessment of Cancer Patient Symptoms and Needs

#### Survey

## Evaluation - UK Cancer Concerns Assessment

Instructions: Please complete this survey about the "UK Cancer Concerns Assessment" please answer regardless of whether you have used the measure or not. Question #8 instrument for clinical or research purposes. You may decline to answer any question.

#### 1. With regard to the "UK Cancer Concerns Assessment", please rate the following

	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall rating of the instrument	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rating of quality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rating of ease of administration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rating of ease of completion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rating of availability (e.g. is it publicly available or do you have to purchase rights to use it?)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 2. In what context is the "UK Cancer Concerns Assessment" used? (Or could it be used? Please check all that apply)

## Custom Measure Evaluations

#### 1. With regard to the "UK Cancer Concerns Assessment", please rate the following:

- Overall rating of the instrument
- Rating of quality
- Rating of ease of administration
- Rating of ease of completion
- Rating of availability (e.g., is it publicly available or do you have to purchase rights to use it?)

#### 2. In what context is the "UK Cancer Concerns Assessment" used? (Or could it be used? Please check all that apply)

- Clinical Practice
- Basic/Applied/Clinical Research
- Surveillance/Epidemiology

#### 3. How useful is the "UK Cancer Concerns Assessment" for identifying otherwise unknown or undetected patient needs?

- Very useful
- Somewhat useful
- Not very useful
- Not at all useful

#### 4. How useful is the "UK Cancer Concerns Assessment" to oncology and survivorship clinicians to help generate referrals to cancer rehabilitation, psychosocial care, exercise interventions, and palliative care/symptom management?

- Very useful
- Somewhat useful
- Not very useful
- Not at all useful

#### 5. What domains of functioning or symptoms are missing (if any) from the "UK Cancer Concerns Assessment"?

#### 6. Can the "UK Cancer Concerns Assessment" be used for patients with all types of cancers or only specific types of cancers?

- All cancers
- Only specific types, please specify:

#### 7. In your opinion, will the "UK Cancer Concerns Assessment" meet the Commission on Cancer psychosocial distress screening accreditation standard?

- Yes
- No
- Unsure

#### 8. For those who have used the "UK Cancer Concerns Assessment," in what ways has the instrument affected clinical practice (positive or negative)?

Smoking/tobacco

Spirituality

Stress

Substance Abuse

More Community News

Criteria

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(NS)

# Past GEM Initiatives



ACCUMULATING DATA TO OPTIMALLY PREDICT OBESITY TREATMENT



# What worked? What did not work?



- Consensus tool using crowdsourcing
  - Multiple stakeholders
- Collaborative workspaces
- Ability to find/access measures



- Wiki aspects
  - Missing/non-standard information
- Lack of data entry
  - Discomfort from users
  - Burdensome
- Disparate evaluation methods
- Data repository
- Other available resources-e.g.:
  - Data (ICPSR; CRDC)
  - Measures (NCCOR; NIH CDE Repository; PhenX; HealthMeasures)
  - Collaboration (Teams; Slack)

# Lessons Learned

- Reduce burden/barriers
- Need tools and resources
- Need clear benefit to user (win/win)
  - What's the need/problem?
  - Incentivize reuse of CDEs/data
- Foster collective attitude
- Prospective vs. retrospective data harmonization
- A trusted source is important



<https://here2there.ca/developing-lessons-learned/>

A screenshot of the NIH Common Data Elements (CDEs) search interface. The page title is "Use Common Data Elements for More FAIR Research Data". Below the title is a search bar with three buttons: "Search NIH-Endorsed CDEs", "Search All CDEs", and "Search Forms". The search bar contains the text "Search by topic, keyword, or organization". A red circle highlights the "Search NIH-Endorsed CDEs" button and the search bar. Below the search bar is a note: "NIH-endorsed CDEs have been reviewed and approved by an expert panel, and meet established criteria. They are designated with a gold ribbon." The background of the page is light blue with a pattern of overlapping white shapes.

<https://cde.nlm.nih.gov/home>

# GEM Transition



**GEM** Grid-Enabled  
Measures Database



Group-Evaluated Measures (GEM)


- Rebrand as cancer- and behaviorally-focused
- Shift to dissemination of existing measures
- Start with GEM initiatives then do outreach
- Search for constructs and/or measures
  - Download where possible
  - Trusted source
- Connect to other systems (e.g., HealthMeasures; PhenX; NIH CDE Repository; NCCOR)

# For more information about GEM . . .

Supplement  
THE ADOPT PROJECT

Obesity

## The Accumulating Data to Optimally Predict Obesity Treatment (ADOPT) Core Measures Project: Rationale and Approach

Paul S. MacLean<sup>1</sup>, Alexander J. Rothman<sup>2</sup>, Holly L. Nicastro<sup>3</sup>, Susan M. Czajkowski<sup>4</sup>, Tanya Agurs-Collins<sup>4</sup>, Elise L. Rice<sup>4</sup>, Anita P. Courcoulas<sup>5</sup>, Donna H. Ryan <sup>6</sup>, Daniel H. Bessesen<sup>1</sup>, and Catherine M. Loria<sup>3</sup>

MacLean et al. (2018)  
*Obesity*

Rabin et al. *Implementation Science* 2012, 7:119  
<http://www.implementationscience.com/content/7/1/119>

### METHODOLOGY

Open Access

## Advancing the application, quality and harmonization of implementation science measures

Borsika A Rabin<sup>1\*</sup>, Peyton Purcell<sup>2</sup>, Sana Naveed<sup>2</sup>, Richard P Moser<sup>2</sup>, Michelle D Henton<sup>1</sup>, Enola K Proctor<sup>3</sup>, Ross C Brownson<sup>4,5</sup> and Russell E Glasgow<sup>2</sup>

Rabin et al. (2012)  
*Implementation Science*

## Standardized Measures

## Using Science 2.0 to Standardize Measures and Share Data

Richard P. Moser, PhD, Bradford W. Hesse, PhD, Abdul R. Shaikh, PhD, MHSc, Paul Courtney, MS, Glen Morgan, PhD, Erik Augustson, PhD, MPH, Sarah Kobrin, PhD, Kerry Y. Levin, PhD, Cynthia Helba, PhD, David Garner, Marsha Dunn, MPH, Kisha Coa, MPH

Moser et al. (2011) *AJPM*





**NATIONAL  
CANCER  
INSTITUTE**

[www.cancer.gov](http://www.cancer.gov)

[www.cancer.gov/espanol](http://www.cancer.gov/espanol)