

# Oh, Say Can you CDE?\*

Promoting the Use of CDEs Across NIH

DCCPS New Grantee Workshop



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\*Common Data Element

# Current Issues in Health Research

- Proliferation of measures
  - Lack of re-use
- Dearth of harmonized data
  - Difficult to compare data
  - Difficult to integrate data
- Difficult to access and share data
  - Lack of knowledge synthesis



# What is a CDE?

- **Common Data Element (CDE)** - A data element that is common to multiple data sets across different studies
- **Typically consists of:**
  - Precisely defined question
  - Specified format or set of permissible values for responses (answers)

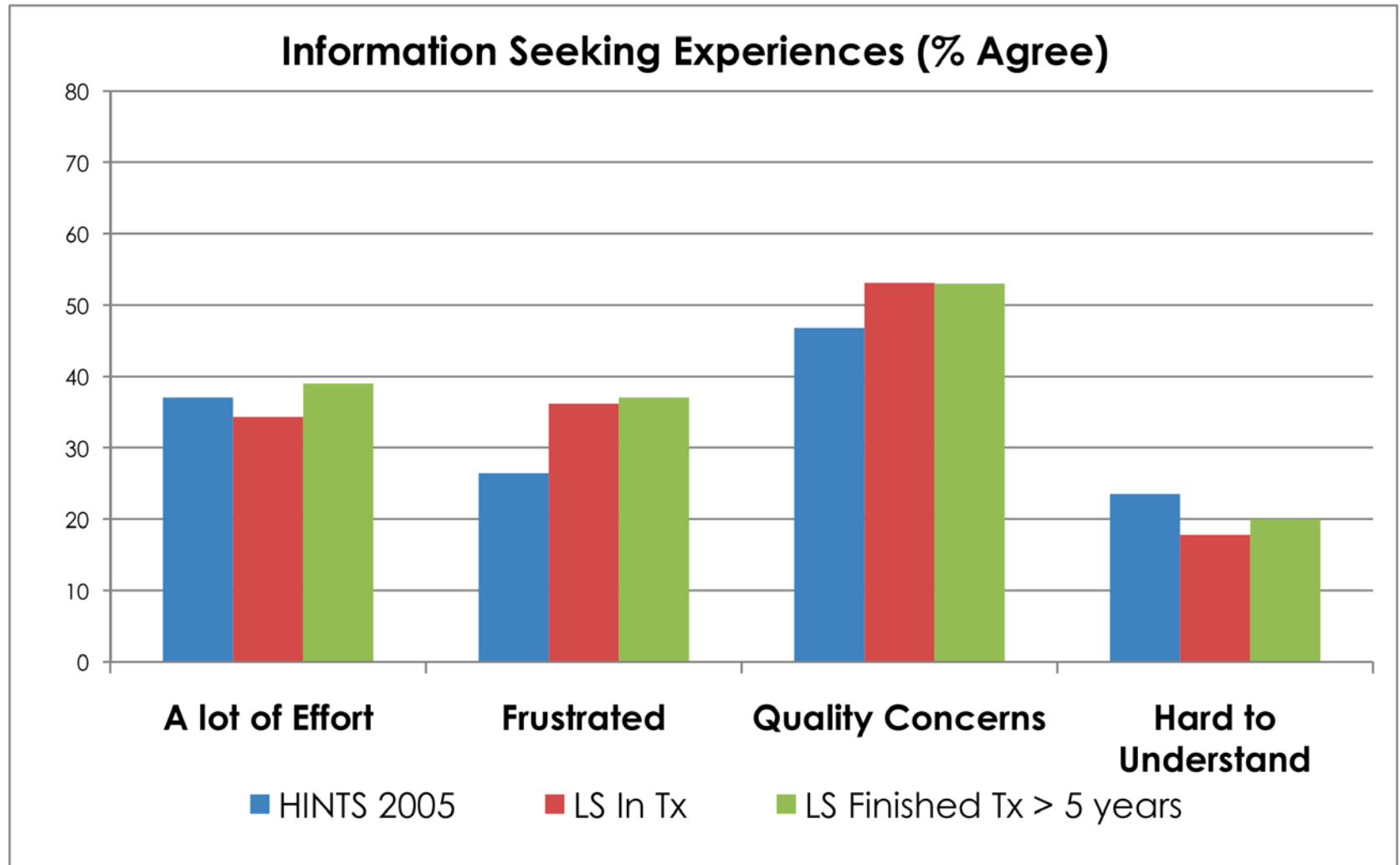
Name of Common Data Element	Definition	Query / Instructions	Provenance	Value Set
FOLLOWUP_SMOKE_HX_AVERAGE-DAY_VALUE	Average number of cigarettes participant smokes per day	Average number cigarettes currently smoked per day? (How many cigarettes do you currently smoke per day?) Record the average number of cigarettes participant currently smokes per day. This question is only asked if a positive response was received for FOLLOWUP_SMOKE-HX_CURRENT-REGULAR_CODE.	Not indicated.	Integer between 1 and 999, no unit.
Societal Sex (phenotype)	Text designations that identify gender. Gender is described as the assemblage of properties that distinguish people on the basis of their societal roles.	Self-identified gender.	This value set is from <a href="#">Health Level Seven International</a> (HL7) Table 0001 (with additions). HL7 is the global authority on standards for interoperability of health information technology.	Ambiguous; Female; Male; Not applicable; Other; Unknown; Male-to-female transsexual; Female-to-male transsexual

# Why Use CDEs: Facilitates Integrative Data Analysis

- Statistical analysis of a single dataset that consists of two or more separate samples
- Different than meta-analysis
- Knowledge synthesis

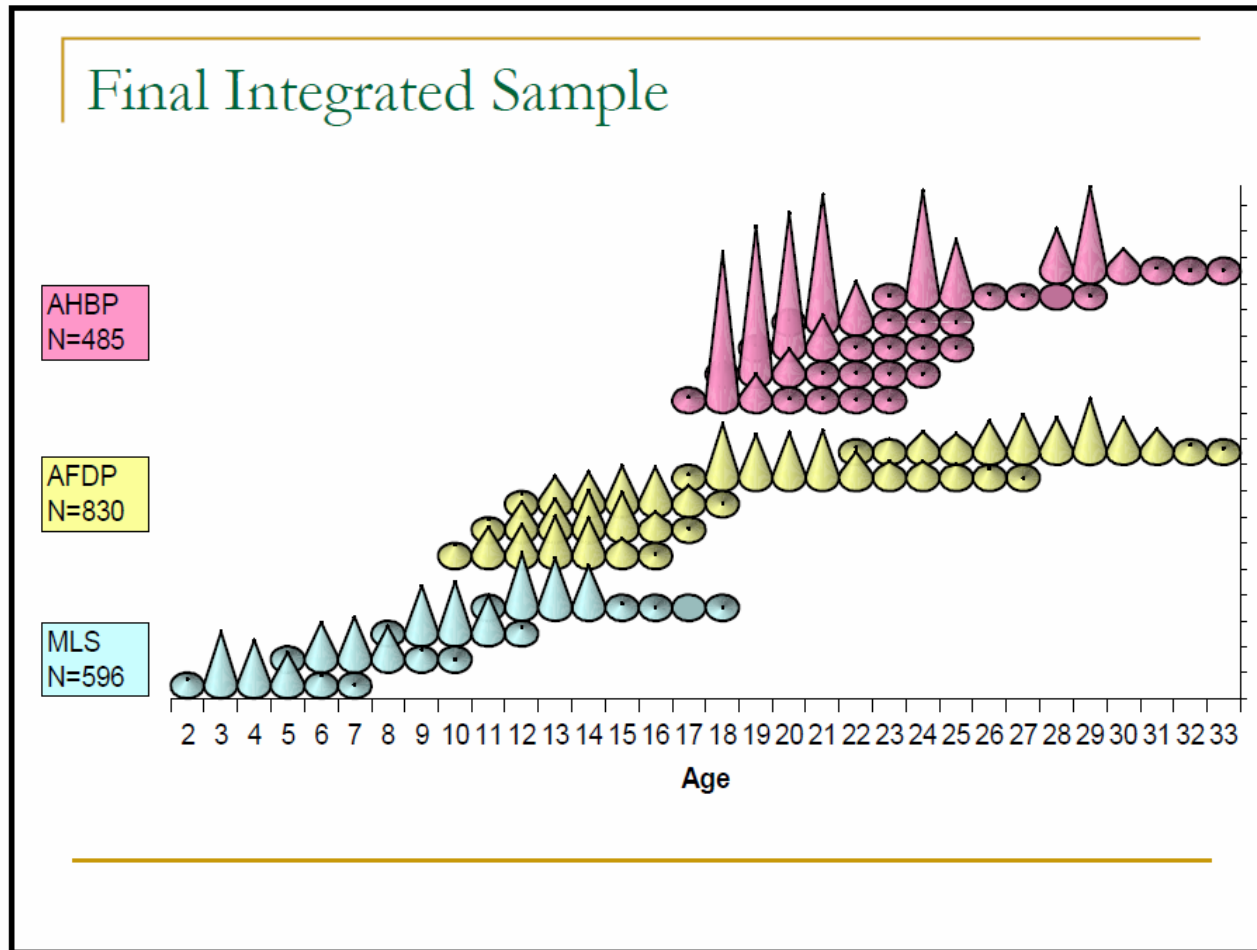


# CDE Use Case: Comparisons Across Studies



Comparing LIVESTRONG and Health Information National Trends (HINTS) 2005 Data

# Merging Data Across Studies



Slide courtesy of Patrick Curran; see Hussong, Curran & Bauer, 2013



# NIH Common Data Element Initiatives

**GEM** Grid-Enabled Measures Database  
A Community Site for Researchers

**PhenX**

**NINDS Common Data Elements**  
Harmonizing Information. Streamlining Research.  
SKIP NAVIGATION PROJECT OVERVIEW CONTACT NATIONAL INSTITUTES OF HEALTH  
▼ CDEs ▼ Tools ▼ Learn

**NDAR** National Database for Autism Research  
Serving the autism research community

**FITBIR**  
Federal Interagency Traumatic Brain Injury Research  
INFORMATICS SYSTEM

**PROMIS**<sup>®</sup>  
Dynamic Tools to Measure Health Outcomes from the Patient Perspective

**GRDR** Global Rare Diseases Patient Registry and Data Repository

**dbGaP**  
The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the results of studies that have investigated the interaction of genotype and phenotype.

**Early Detection Research Network**  
*Biomarkers: the key to early detection*

**NIH Toolbox**  
For the Assessment of Neurological and Behavioral Function

**NeuroQOL** Quality of Life in Neurological Disorders

**eyeGENE**<sup>®</sup>

Thanks to Jerry Sheehan for slide

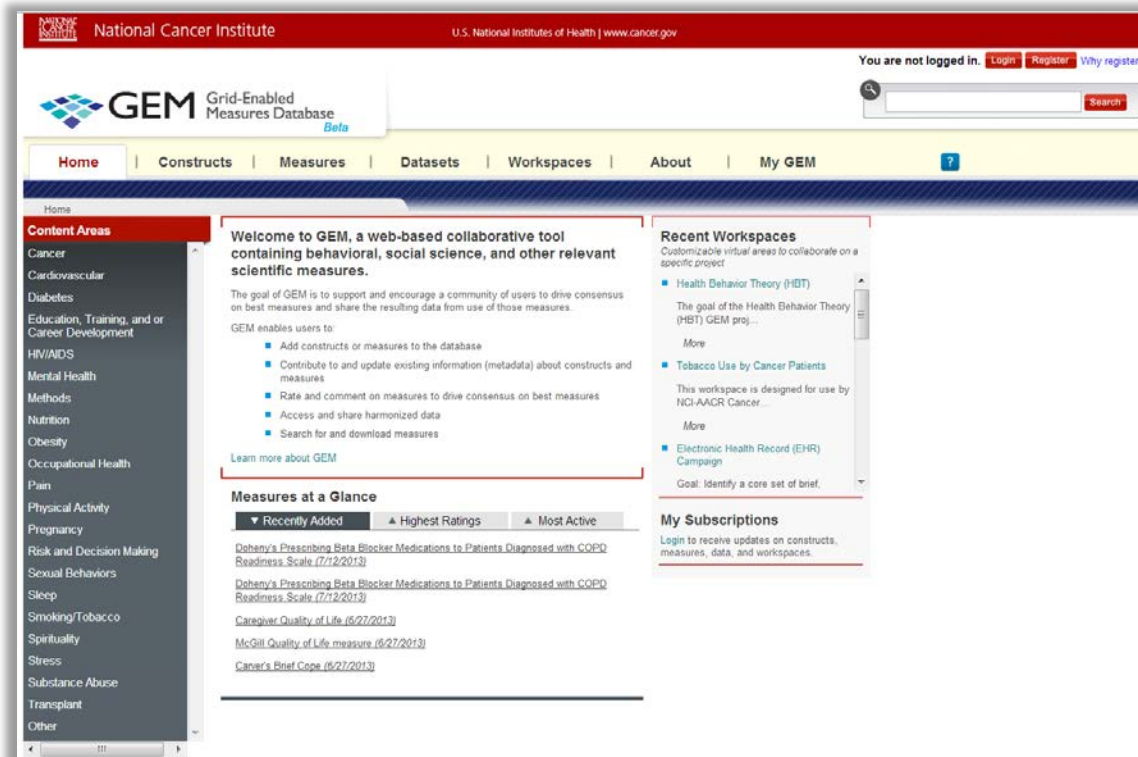


# Grid Enabled Measures (GEM)

<http://www.gem-beta.org/>

Overall Goals: To facilitate a virtual community of scientists using **technology mediated social participation (TMSP)** to:

- Vet and promote the use of theoretically-based **standardized measures** in research;
- Share the resulting **harmonized data**



- Wiki-based
- Web 2.0 functionality
- Crowdsourcing





# GEM Workspaces



National Cancer Institute

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

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## Overview

### Measures

### Datasets

### Discussion

### Uploads

### Reports

## The GEM-Care Planning Initiative (GEM-CP) (NCI/HCIRB)

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Health care policy and health information environment variables relevant to survivorship care planning (e.g., electronic and personal health records (EHRs and PHRs)) are dynamic and change rapidly. The GEM-Care Planning Initiative (GEM-CP), a project initiated by the National Cancer Institute's Health Communication and Informatics Research Branch (HCIRB) and Office of Cancer Survivorship, is intended to build consensus in the survivorship community around high-priority process and outcome measures for use in studies of survivorship care planning. Increased use of shared measures will enable comparability across studies and facilitate expeditious identification of strategies to implement optimal care planning - or barriers to that planning - for cancer survivors.

### Useful Links & Documentation

Name	Description	Type	Posted By	Date Posted
<a href="#">Examination of Survivorship Care Planning Efficacy and Impact [R21]</a>		URL	Sana Naveed	3/5/2013
<a href="#">Examination of Survivorship Care Planning Efficacy and Impact [R01]</a>		URL	Sana Naveed	3/5/2013
<a href="#">Narrative of the Presentation Describing GEM and Participation in the GEM-CP Initiative</a>		application/pdf	Brian Keefe	3/2/2012
<a href="#">Presentation Describing GEM and Participation in the GEM-CP Initiative</a>		URL	Brian Keefe	3/2/2012
<a href="#">GEM-CP Initiative Timeline 2-17-12.pdf</a>		application/pdf	Sana Naveed	2/23/2012
<a href="#">Matrix of Champions.xls</a>		application/vnd.ms-excel	Sana Naveed	2/23/2012
<a href="#">6th Biennial Cancer Survivorship Research Conference</a>		URL	Sana Naveed	2/17/2012

Workspace Administrator: Sana Naveed ( [sana.naveed@nih.gov](mailto:sana.naveed@nih.gov) )      Workspace Status: Active (02/28/12)

# National Library of Medicine: CDE Resource Portal



U.S. National Library of Medicine

<http://cde.nih.gov>

Search

Databases

Find, Read, Learn

Explore NLM

Research at NLM

NLM for You

Contact NLM



Common Data Element (CDE) Resource Portal

[Home](#) | [Resource Summaries](#) | [Glossary](#)

Home

## Home

NIH encourages the use of common data elements (CDEs) in clinical research, patient registries, and other human subject research in order to improve data quality and opportunities for comparison and combination of data from multiple studies and with electronic health records. This portal provides access to NIH-supported CDE initiatives and other tools and resources that can assist investigators developing protocols for data collection. [What is a CDE?](#)

## NIH CDE Initiatives

Collections of CDEs that have been identified for use in particular NIH-supported research projects or registries after a formal evaluation and selection processes.

Summary  
Table

Subject  
Areas

## NIH CDE Tools and Resources

Databases and repositories of data elements and case report forms that may assist investigators in identifying and selecting data elements for use in their projects.

Summary  
Table

Subject  
Areas

The CDE Resource Portal also includes [Other CDE Resources](#) and [Relevant Standards](#). Descriptions of all four groups can be found in the [Glossary](#).

The CDE Working Group of the [Trans-NIH BioMedical Informatics Coordinating Committee](#) (BMIC) developed this Portal to improve the coordination of CDEs. BMIC encourages researchers to use CDEs from the Resources in this Portal where applicable, and to consider existing CDE initiatives before starting additional initiatives.

Are we missing a CDE Resource? [Contact us](#).

# CDE Portal: Subject Areas



## Subject Areas of NIH CDE Initiatives

This table lists the [Subject Areas](#) covered by [NIH CDE Initiatives](#). More information on NIH CDE Initiatives: [Summary Table](#), [Detailed Summaries](#)

XX indicates that the subject area is a major focus, while X indicates that the subject area is a minor focus. Subject areas listed here may change as additional Resources are added to the CDE Resource Portal or as existing Resources are expanded into new subject areas (subject areas assessed in January 2013).

Show  entries

Search:

Subject Area	EDRN	eye GENE	GRDR	Neuro-QOL	NIH Toolbox	NINDS CDEs	PhenX	PROMIS
Alcohol, Tobacco, and Other Substances	X					X	XX	
Cancer	X						XX	
Demographics and Patient Contact Info.	X	X	XX			XX	XX	
Environmental Exposures	X					X	XX	
Excretory	X					X		
Gastrointestinal	X					X	XX	
Laboratory Tests	X	XX				X	X	
Medical History	X		XX			XX	X	
Medications, Devices, and Treatments	X		XX			XX	X	
Physical Function	X		X	XX	X	XX	XX	X
Reproductive	X		X			X	XX	X
Respiratory	X					X	XX	X
Study Details	X		XX			X		
Biospecimens			XX					
Anthropometrics			XX			XX	XX	
Cardiovascular and Circulatory						XX	XX	
Diabetes and Other Endocrine						X	XX	
Infectious Diseases and Immunity						X	XX	
Neurology				XX	XX	XX	XX	

# Thanks!

Rick:

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GEM:

<http://cancercontrol.cancer.gov/brp/gem.html>

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

