

Consensus Evaluation for Research on Self Management and Peer Support in Diabetes

Evaluation Measures, Indicators,
Tools/Instruments, and Reference Information

Peers for Progress

*MISSION: to accelerate and promote best practices in peer support
as a regular part of health care and prevention around the world*

PREFACE

Peers for Progress is a program of the American Academy of Family Physicians Foundation dedicated to promoting peer support in health, health care, and prevention around the world. It is supported by the Eli Lilly and Company Foundation. Using diabetes as an excellent model of chronic disease management, it has funded a set of evaluation grants to build the evidence base for peer support's contributions to health and provide models of approaches to implementing and organizing peer support programs.

Using rigorous methods, the eight evaluation grantees listed below are conducting their own research projects testing the effectiveness of peer support in management of type 2 diabetes. They are also pooling data in a cross-site evaluation. Investigators and key staff collaborated with the Peers for Progress Program Development Center at the University of North Carolina at Chapel Hill to identify key evaluation indicators of their peer support programs that could be applied across all projects. The aim was for a core set of shared evaluation indicators that could strengthen evidence from, yet not add burden to, their individual and collective projects.

It is hoped that, beyond these eight grants, these consensus evaluation measures may serve the broader community of researchers examining peer support and self management in diabetes. Additionally, most of the measures included are not diabetes-specific and, so, may serve the broader community of research in chronic disease management and health promotion.

Country, City/Region	Project Description (all adults with type 2 diabetes)	Organizations and Principal Investigators
San Antonio, Texas	Examining the application of a peer support intervention shown to be effective among low-income, Latino populations in Los Angeles, CA to an older, insured, mixed racial and middle class population	American Academy of Family Physicians National Research Network (with Latino Health Access, LA Net, WellMed Medical Group): <i>Lyndee Knox, PhD</i>
Hong Kong SAR, China	Examining peer support, empowerment and remote communication linked by telephone information technology	Asia Diabetes Foundation and Hong Kong Institute of Diabetes and Obesity, The Chinese University of Hong Kong: <i>Juliana C.N. Chan, MD, FRCP</i>
Cambridgeshire, England	Comparing group-based with individually provided peer support	Cambridge University Hospitals NHS Foundation Trust, Institute of Metabolic Science: <i>David Simmons, MD</i>
Victoria, Australia	Examining expansion of existing peer support programs focused on improved daily management, linkages to care and implications for national dissemination	Monash University, School of Public Health & Preventive Medicine: <i>Brian Oldenburg, PhD</i>
Southern California	Examining peer support intervention, with emphasis on volunteer model and navigating family, community, and clinical environments, among Mexican/ Mexican American adults along US-Mexico border	San Diego State University, Graduate School of Public Health, Center for Behavioral and Community Health Studies and <i>Clinicas de Salud del Pueblo: Guadalupe X. Ayala, PhD, MPH</i>
Rural Alabama	Examining community peer advisors linked to rural health centers serving African Americans	University of Alabama at Birmingham, School of Medicine: <i>Monika M. Safford, MD</i>
San Francisco, California	Examining integration of peer supporters/peer coaching into nurse/doctor treatment teams among clinics serving Latino, Caucasian, and African American populations	University of California at San Francisco, School of Medicine, Department of Family and Community Medicine: <i>Thomas Bodenheimer, MD, MPH</i>
Ypsilanti and SW Detroit, Michigan	Examining peer-led self-management support in "real-world" clinical and community settings among Latinos and African-Americans, respectively	University of Michigan Medical School, Depts Medical Education & Internal Medicine and the University of Michigan School of Public Health: <i>Tricia S. Tang, PhD & Michele Heisler, MD, MPA</i>



Part I. **Summary Matrix by Component**

Part II. **Table of Measures, Indicators, and Other Details by Component**

Part III. **REFERENCES**

PART I: Summary Matrix by Component

Component	Consensus Measures (see References)
Clinical Endpoints and Demographic Measures	On injectables (insulin and/or other), since when, dose On oral tablets, since when, dose * <i>if available, select type of meds</i> HbA1c(%) * <i>also note if assay is NGSP certified and designate the normal range</i> Blood pressure (mmHg) Weight Date(s) of data collection (clinical and survey data) Age (year of birth) Sex (F/M) Height Year of diagnosis Highest education Marital status
Behavioral – Self Care Activities	Selections from Summary of Diabetes Self Care Activities (SDSCA) ^{1,2} and Behavioral Risk Factor Surveillance System (BRFSS) ³ : 9-items (diet, exercise, blood sugar testing, foot care, smoking)
Behavioral – Medication Adherence	Morisky Scale (4-item) ^{4, 5, 6}
Quality of Life – General	EQ5-D ⁷
Quality of Life – Diabetes	Brief Diabetes Distress Screening Instrument (Fisher et al., 2008): DDS4 ^{8,9}
Quality of Life - Depression	Patient Health Questionnaire (PHQ) 8 ¹⁰ (<i>PHQ-9 minus suicide question</i>)
Process Evaluation	17-items for perceived availability of peer support by core functions and sub-elements ^{11, 12, 13}
Mediator and Moderators	<i>Mediator</i> : Nondirective vs. Directive Support (Fisher et al., 8-item) ¹⁴ <i>Moderator</i> : Health Literacy (3-item, Lisa Chew measures) ¹⁵ <i>Moderator</i> : Availability, satisfaction with diabetes-support from family and friends (2-item) ¹⁶ and health care team (2-item)
Cost Effective Analysis	<u>System Costs</u> : # visits past 6 months to diabetes clinician (<i>regular chronic care visits to a diabetes physician/other health care provider</i>) # visits past 6 months to other clinicians # visits past 6 months for emergency/acute care # overnight stays past 6 months in hospital (all cause admissions)

Part II. Table of Variables by Component

This first set of variables will be assigned by Peers for Progress or supplied by the site (as applicable). These variables will assist in identifying and differentiating the site source of data and related aspects of study design as part of the Peers for Progress cross-site evaluation database and subsequent analyses.

SID	SITE IDENTIFICATIONS
SID1	Site identification code <i>(assigned by Peers for Progress)</i>
SID2	Participant identification code <i>(assigned by Peers for Progress)</i>
SID3	Participant role (Participant, Peer Supporter, Control/Comparison)
SID4	Support ID – <i>if documented, supplied by site to denote any pairing between intervention participants and peer supporters</i>
SID5	Support Type – <i>if documented, site supplies mode as 1:1 only, group only, both, other</i>
SID6	Stratification variable 1 – <i>if applicable, supplied by site</i>
SID7	Stratification variable 2 – <i>if applicable, supplied by site</i>
SID8	Cluster variable 1 – <i>if applicable, supplied by site</i>
SID9	Cluster variable 2 – <i>if applicable, supplied by site</i>

The following items are the shared set of evaluation items that the eight Peers for Progress Evaluation Grants will be collecting.

Consensus Items	
CLI	CLINICAL ENPOINTS
CLI_MON	Month of clinical data collection <i>(if multiple, select earliest/site discretion)</i>
CLI_YR	Year of clinical data collection
CLI1A	On injectables (insulin)
	If yes, when (year), x units, y times per day
CLI1B	On injectables other than insulin
	If yes, pramlintide, other?
	If yes, since when (year), x units, y times per day
CLI2	On oral hypoglycemic or antihyperglycemic agents
	If yes and details available, select from list: <i>Tolbutamide (Orinase)</i> <i>Acetohexamide (Dymelor)</i> <i>Tolazamide (Tolinase)</i> <i>Chlorpropamide (Diabinese)</i> <i>Glipizide (Glucotrol)</i> <i>Glyburide (Diabeta, Micronase, Glynase)</i> <i>Glimepiride (Amaryl)</i> <i>Rapaglinide (Prandin)</i> <i>Nateglinide (Starlix)</i> <i>Metformin (Glucophage)</i> <i>Rosiglitazone (Avandia)</i> <i>Pioglitazone (Actos)</i> <i>Miglitol (Glyset)</i> <i>Acarbose (Precose/Glucobay)</i> <i>Vildagliptin (Galvus)</i> <i>Sitagliptin (Januvia)</i> <i>Saxagliptin (Onglyza)</i>
	If yes to any above, since when (year), and x mg daily dose

Consensus Items	
CLI3	HbA1c(%)
	Is the assay NGSB approved? http://www.ngsp.org/index.asp
	What is the normal range of the assay for the laboratory? Min/max
CLI4	Blood pressure – systolic and diastolic (mmHg)
CLI5	Weight (measured, not self-reported; reported in kg)
DEM	DEMOGRAPHICS
DEM1	Age (year of birth)
DEM2	Sex (F/M)
DEM3	Height (reported in centimeters)
DEM4	Year at diagnosis
DEM5	Highest education
DEM6	Marital Status
SVY_MON	Month of other data collection by survey, interviews, etc. <i>(if multiple, select earliest/site discretion)</i>
SVY_YR	Year of other data collection by survey, interviews, etc. <i>(if multiple, select earliest/site discretion)</i>
BEH	BEHAVIORS (SDSCA and BRFSS items)
	<i>INSTRUCTIONS: The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.</i>
BEH1	On how many of the last 7 days did you eat five or more servings of fruits and vegetables? A serving of fruit is ½ cup; a serving of vegetables is ½ to 1 cup) 0 1 2 3 4 5 6 7
BEH2	On how many of the last 7 days did you eat high-fat foods, such as red meat, full-fat dairy products, full-fat pastries or other desserts? 0 1 2 3 4 5 6 7
BEH3	Over the past 7 days, which of the following best describes your usual daily activities at home or work? Usually sit during the day and don't walk around very much Stand or walk quite a lot during the day but don't have to carry or lift things very often Usually lift or carry light loads, or have to climb stairs or hills often Do heavy work or carry very heavy loads
BEH4	Now, other than your regular job or what you do around the house, on how many of the last 7 days did you participate in a specific exercise session (such as swimming, walking, running, biking)? 0 1 2 3 4 5 6 7
BEH5	Again, other than your regular job or what you do around the house, on how many of the past 7 days did you participate in at least 30 minutes total (one session, or several smaller sessions) of physical activity? 0 1 2 3 4 5 6 7
BEH6	On how many of the last 7 days did you test your blood sugar? 0 1 2 3 4 5 6 7
BEH7	On how many of the last 7 days did you check your feet? 0 1 2 3 4 5 6 7
BEH8	Have you smoked a cigarette, even a puff, in the past 7 days? Yes/No

Consensus Items	
BEH9	If No, have you smoked a cigarette, even a puff, in the past 30 days? Yes/No
MED	MEDICATION ADHERENCE (Morisky)
	INSTRUCTIONS: Thinking about the medications PRESCRIBED to you by your doctor(s), please answer the following questions:
MED1	Do you ever forget to take your [condition] medicine? Yes/No
MED2	Are you careless at times about taking your [condition] medicine? Yes/No
MED3	When you feel better, do you sometimes stop taking your [condition] medicine? Yes/No
MED4	Sometimes, if you feel worse when you take the [condition] medicine, do you stop taking it? Yes/No
QGE	QUALITY OF LIFE – GENERAL (EQ5-D)
	EQ-5D is a standardized instrument for use as a measure of health outcome. Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status. It contains two parts: five self-classifier items and one visual analogue. Overall information about this tool can be found at http://www.ahrq.gov/rice/ceoutc.htm and http://www.euroqol.org/ : INSTRUCTIONS: By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.
QGE1	Mobility
	I have no problems in walking about <input type="checkbox"/>
	I have some problems in walking about <input type="checkbox"/>
	I am confined to bed <input type="checkbox"/>
QGE2	Self-Care
	I have no problems with self-care <input type="checkbox"/>
	I have some problems washing or dressing myself <input type="checkbox"/>
	I am unable to wash or dress myself <input type="checkbox"/>
QGE3	Usual Activities (e.g. work, study, housework, family or leisure activities)
	I have no problems with performing my usual activities <input type="checkbox"/>
	I have some problems with performing my usual activities <input type="checkbox"/>
	I am unable to perform my usual activities <input type="checkbox"/>
QGE4	Pain/Discomfort
	I have no pain or discomfort <input type="checkbox"/>
	I have moderate pain or discomfort <input type="checkbox"/>
	I have extreme pain or discomfort <input type="checkbox"/>
QGE5	Anxiety/Depression
	I am not anxious or depressed <input type="checkbox"/>
	I am moderately anxious or depressed <input type="checkbox"/>
	I am extremely anxious or depressed <input type="checkbox"/>
QGE6	Visual Analogue Scale (see “thermometer”)

Consensus Items	
	<p>To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.</p> <p>We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale that indicates how good or bad your health state is today.</p> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid black; width: 50px; height: 50px; background-color: black; margin: 10px;"></div> <div style="text-align: right;"> <p>Best imaginable health state</p> <p>100</p> <p>90</p> <p>80</p> <p>70</p> <p>60</p> <p>50</p> <p>40</p> <p>30</p> <p>20</p> <p>10</p> <p>0</p> <p>Worst imaginable health state</p> </div> </div>
<u>QDI</u>	<u>QUALITY OF LIFE – DIABETES (DDS4)</u>
	<p>INSTRUCTIONS: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are four potential problem areas that people with diabetes may experience. Consider the degree to which each of the four items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.</p> <p>Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle “1.” If it is very bothersome to you, you might circle 6.</p>
QDI1	Feeling overwhelmed with the demands of living with diabetes 1 2 3 4 5 6
QDI2	Feeling that I am often failing with my diabetes routine. 1 2 3 4 5 6
QDI3	Not feeling motivated to keep up my diabetes self-management. 1 2 3 4 5 6
QDI4	Feeling angry, scared, and/or depressed when I think about living with diabetes. 1 2 3 4 5 6
<u>QDE</u>	<u>QUALITY OF LIFE – DEPRESSION (PHQ-8)</u>
	<p>The Patient Health Questionnaire (PHQ) is a self-administered version of the PRIME-MD diagnostic instrument for common mental disorders. The PHQ was developed by Drs. Robert L. Spitzer, Janet BW Williams, Kurt Kroenke, and colleagues. More information can be found here: http://www.mapi-trust.org/services/questionnairelicensing/cataloguequestionnaires/129-phq</p> <p>INSTRUCTIONS: Over the last 2 weeks, how often have you been bothered by any of the following problems? 0 - Not at all, 1 – Several days, 2 – More than half the days, 3 – Nearly every day</p>
QDE1	Little interest or pleasure in doing things 0 1 2 3
QDE2	Feeling down, depressed, or hopeless 0 1 2 3

Consensus Items	
QDE3	Trouble falling or staying asleep, or sleeping too much 0 1 2 3
QDE4	Feeling tired or having little energy 0 1 2 3
QDE5	Poor appetite or overeating 0 1 2 3
QDE6	Feeling bad about yourself — or that you are a failure or let yourself or your family down 0 1 2 3
QDE7	Trouble concentrating on things, such as reading the newspaper, watching television 0 1 2 3
QDE8	Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual 0 1 2 3
PEV	PROCESS EVALUATION NOTE: “Peer support group” may be substituted for “peer supporter.”
	The following items were integrated from the Resources and Supports for Self Management (RSSM) instrument of the Robert Wood Johnson Foundation’s Diabetes Initiative ¹¹ , the Patient Assessment of Chronic Illness Care (PACIC) instrument, ^{12,13} or developed for use with Peers for Progress. INSTRUCTIONS: We would like to ask what you think about particular ways that your [term for peer supporter or peer support group] interacted with you and may have helped you.
Availability (“By available, we mean being present and ready to help . . .”)	
PEV1	In the past 6 months, how many times did you talk to or meet with your peer supporter? (specify # of contacts)
PEV2	Are you able to contact your peer supporter when you need to? (1 = never; 2 = sometimes; 3 = usually; 4 = almost always)
PEV3	In the past six months, how often did your peer supporter contact you? (specify # of contacts)
PEV4	Has your peer supporter adapted his or her approach to meet your particular diabetes management needs? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
Assistance In Daily Management (“By assistance with daily management, we mean the actions you need to take every day to control your diabetes and protect your health”)	
PEV5	Has your peer supporter asked what would be helpful to you in managing your diabetes? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV6	Has your peer supporter helped you set specific goals to manage your diabetes? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV7	Has your peer supporter helped you learn skills to achieve your goals? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV8	Has your peer supporter helped you solve problems that arise in managing your diabetes? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
Social & Emotional Support (“By social and emotional support, we mean addressing the emotional aspects of living with diabetes”)	
PEV9	Has your peer supporter helped you figure out how to deal with stress? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV10	Has your peer supporter helped you become confident to manage your diabetes? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV11	Has your peer supporter helped you get support from... Family? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV12	Has your peer supporter helped you get support from... Friends? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV13	Has your peer supporter helped you get support from... Others? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)

Consensus Items	
Linkage to Clinical Care (“By linkage to care, we mean making regular, effective use of health services “)	
PEV14	Has your peer supporter encouraged you to get regular diabetes care? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV15	Has your peer supporters helped you get the care you need from doctors and nurses? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV16	Has your peer supporter helped you find other resources in your community to help you take care of your diabetes? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
PEV17	Has your peer supporter helped you communicate effectively with your doctor or nurse about your diabetes? (1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)
MND	MEDIATOR: Nondirective vs. Directive Support (8 item) (Fisher) INSTRUCTIONS: Different people provide support in different ways. We want to get an idea of exactly how your [term for peer supporter] supports you. For each statement below, please circle the number that best indicates how typical it is of the support you receive from [term for peer supporter]. Remember, all of these statements reflect ways that your [term for peer supporter] <i>could</i> be supportive to you. But please answer so that we can tell which ways are really typical of the support you receive from your [term for peer supporter] and which ways are not so typical. Please circle the number that best indicators how typical each statement is of the support you receive from your diabetes peer supporter (1 – not at all to 5- very typical):
MND1	Show interest in how you are doing 1 2 3 4 5
MND2	Push you to get going on things 1 2 3 4 5
MND3	Cooperate with you to get things done 1 2 3 4 5
MND4	Take charge of your problems 1 2 3 4 5
MND5	Point out harmful or foolish ways you view things 1 2 3 4 5
MND6	Make it easy for your to talk about anything you think is important 1 2 3 4 5
MND7	Tell you what to do 1 2 3 4 5
MND8	Offer a range of suggestions 1 2 3 4 5
MHL	MODERATOR: Health Literacy (Chew)
	INSTRUCTIONS: Many people have difficulty reading and filling out forms when they go for medical care. The next set of questions will ask you about paperwork and information that you receive from your doctor.
MHL1	How often do you have someone like a family member, hospital worker, clinic worker, or caregiver help you read hospital materials? 1-always, 2-often, 3-sometimes, 4-rarely, 5-never
MHL2	How often do you have problems learning about medical conditions because of difficulty understanding written information? 1-always, 2-often, 3-sometimes, 4-rarely, 5-never
MHL3	How confident are you filling out health care forms by yourself? 1-not confident at all, 2-not very confident, 3-somewhat confident, 4-confident, 5-extremely confident
MDS	MODERATOR: Availability, satisfaction with diabetes-support from family and friends and your health care team (Tang)
	INSTRUCTIONS: Managing diabetes on your own can be challenging. We would like to learn a little more about what types of help and support you might like to get to help with your diabetes.
MDS1	How much support do you get from friends and family dealing with your diabetes?
	<i>No Support</i> <i>A great deal of support</i>
	1 2 3 4 5

Consensus Items	
MDS2	How satisfied are you with the support you get from family and friends for dealing with your diabetes?
	<i>Not Satisfied</i> <i>Very Satisfied</i>
	1 2 3 4 5
MDS3	How much support do you get from your health care team to deal with your diabetes?
	<i>No Support</i> <i>A great deal of support</i>
	1 2 3 4 5
MDS4	How satisfied are you with the support you get from your health care team for dealing with your diabetes?
	<i>Not Satisfied</i> <i>Very Satisfied</i>
	1 2 3 4 5
<u>COS</u>	<u>COSTS (SYSTEM)</u>
COS1	# visits past 6 months to diabetes clinician (regular chronic care visits to a diabetes physician/other health care provider)
COS2	# visits past 6 months to other clinicians
COS3	# visits past 6 months for emergency/acute care
COS4	# overnight stays past 6 months in hospital (all cause admissions)

PART III. REFERENCES

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