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.

<table>
<thead>
<tr>
<th>Country, City/Region</th>
<th>Project Description (all adults with type 2 diabetes)</th>
<th>Organizations and Principal Investigators</th>
</tr>
</thead>
<tbody>
<tr>
<td>San Antonio, Texas</td>
<td>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</td>
<td>American Academy of Family Physicians National Research Network (with Latino Health Access, LA Net, WellMed Medical Group): Lyndee Knox, PhD</td>
</tr>
<tr>
<td>Hong Kong SAR, China</td>
<td>Examining peer support, empowerment and remote communication linked by telephone information technology</td>
<td>Asia Diabetes Foundation and Hong Kong Institute of Diabetes and Obesity, The Chinese University of Hong Kong: Juliana C.N. Chan, MD, FRCP</td>
</tr>
<tr>
<td>Cambridgeshire, England</td>
<td>Comparing group-based with individually provided peer support</td>
<td>Cambridge University Hospitals NHS Foundation Trust, Institute of Metabolic Science: David Simmons, MD</td>
</tr>
<tr>
<td>Victoria, Australia</td>
<td>Examining expansion of existing peer support programs focused on improved daily management, linkages to care and implications for national dissemination</td>
<td>Monash University, School of Public Health &amp; Preventive Medicine: Brian Oldenburg, PhD</td>
</tr>
<tr>
<td>Southern California</td>
<td>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</td>
<td>San Diego State University, Graduate School of Public Health, Center for Behavioral and Community Health Studies and Clínicas de Salud del Pueblo: Guadalupe X. Ayala, PhD, MPH</td>
</tr>
<tr>
<td>Rural Alabama</td>
<td>Examining community peer advisors linked to rural health centers serving African Americans</td>
<td>University of Alabama at Birmingham, School of Medicine: Monika M. Safford, MD</td>
</tr>
<tr>
<td>San Francisco, California</td>
<td>Examining integration of peer supporters/peer coaching into nurse/doctor treatment teams among clinics serving Latino, Caucasian, and African American populations</td>
<td>University of California at San Francisco, School of Medicine, Department of Family and Community Medicine: Thomas Bodenheimer, MD, MPH</td>
</tr>
<tr>
<td>Ypsilanti and SW Detroit, Michigan</td>
<td>Examining peer-led self-management support in &quot;real-world&quot; clinical and community settings among Latinos and African-Americans, respectively</td>
<td>University of Michigan Medical School, Depts Medical Education &amp; Internal Medicine and the University of Michigan School of Public Health: Tricia S. Tang, PhD &amp; Michele Heisler, MD, MPA</td>
</tr>
</tbody>
</table>
Part I. Summary Matrix by Component

Part II. Table of Measures/Indicators by Component

Part III. REFERENCES
## PART I: Summary Matrix by Component

<table>
<thead>
<tr>
<th>Component</th>
<th>Consensus Measures (see References)</th>
</tr>
</thead>
</table>
| Clinical Endpoints and Demographic Measures | On injectables (insulin and/or other), since when, dose  
On oral tablets, since when, dose  * if available, select type of meds  
HbA1c(%)  * also note if assay is NGSP certified and designate the normal range  
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) \(^8,10\) *(PHQ-9 minus suicide question)*                                                                                                                                                   |
| Process Evaluation                    | 17-items for perceived availability of peer support by core functions and sub-elements \(^11,12,13\)                                                                                                                           |
| Mediator and Moderators               | **Mediator:** Nondirective vs. Directive Support (Fisher et al., 8-item) \(^14\)  
**Moderator:** Health Literacy (3-item, Lisa Chew measures) \(^15\)  
**Moderator:** Availability, satisfaction with diabetes-support from family and friends (2-item) \(^16\) and health care team (2-item) |
| Cost Effective Analysis               | **System Costs:**  
# visits past 6 months to diabetes clinician *(regular chronic care visits to a diabetes physician/other health care provider)*  
# 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 Measures/Indicators by Component

<table>
<thead>
<tr>
<th>Consensus Measures and Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CLINICAL ENPOINTS</strong></td>
</tr>
<tr>
<td>Date(s) of data collection</td>
</tr>
<tr>
<td>On injectables (insulin)</td>
</tr>
<tr>
<td>If yes, when (year), x units, y times per day</td>
</tr>
<tr>
<td>On injectables other than insulin</td>
</tr>
<tr>
<td>If yes, pramlintide, exenatide, liraglutide, other?</td>
</tr>
<tr>
<td>If yes, since when (year), x units, y times per day</td>
</tr>
<tr>
<td>On oral hypoglycemic or antihyperglycemic agents</td>
</tr>
<tr>
<td>If yes and details available, designate type/select from list</td>
</tr>
<tr>
<td>If yes, since when (year), and x mg daily dose</td>
</tr>
<tr>
<td>HbA1c(%)</td>
</tr>
<tr>
<td>Is the assay NGSB approved? <a href="http://www.ngsp.org/index.asp">link</a></td>
</tr>
<tr>
<td>What is the normal range of the assay for the laboratory? Min/max</td>
</tr>
<tr>
<td>Blood pressure (mmHg)</td>
</tr>
<tr>
<td>Weight (measured, not self-reported)</td>
</tr>
</tbody>
</table>

| **DEMOGRAPHICS**                  |
| Age (year of birth)               |
| Sex (F/M)                         |
| Height                            |
| Year at diagnosis                 |
| Highest education                 |
| Marital Status                    |

**DATE OF DATA COLLECTION (survey/interview items)**

<table>
<thead>
<tr>
<th><strong>BEHAVIORS (SDSCA and BRFSS items)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
</tr>
<tr>
<td>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</td>
</tr>
<tr>
<td>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 0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Over the past 7 days, which of the following best describes your usual daily activities at home or work? Stand or walk quite a lot during the day but don’t have to carry or lift things very often 0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Over the past 7 days, which of the following best describes your usual daily activities at home or work? Usually life or carry light loads, or have to climb stairs or hills often 0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Over the past 7 days, which of the following best describes your usual daily activities at home or work? Do heavy work or carry very heavy loads 0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>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</td>
</tr>
<tr>
<td>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</td>
</tr>
<tr>
<td>On how many of the last 7 days did you test your blood sugar? 0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>On how many of the last 7 days did you check your feet? 0 1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>
**Consensus Measures and Indicators**

Have you smoked a cigarette, even a puff, in the past 7 days? Yes/No

If No, have you smoked a cigarette, even a puff, in the past 30 days? Yes/No

**MEDICATION ADHERENCE (Morisky)**

Do you ever forget to take your [condition] medicine? Yes/No

Are you careless at times about taking your [condition] medicine? Yes/No

When you feel better, do you sometimes stop taking your [condition] medicine? Yes/No

Sometimes, if you feel worse when you take the [condition] medicine, do you stop taking it? Yes/No

**QUALITY OF LIFE – GENERAL (EQ5-D)**

**Mobility**

- I have no problems in walking about □
- I have some problems in walking about □
- I am confined to bed □

**Self-Care**

- I have no problems with self-care □
- I have some problems washing or dressing myself □
- I am unable to wash or dress myself □

**Usual Activities (e.g. work, study, housework, family or leisure activities)**

- I have no problems with performing my usual activities □
- I have some problems with performing my usual activities □
- I am unable to perform my usual activities □

**Pain/Discomfort**

- I have no pain or discomfort □
- I have moderate pain or discomfort □
- I have extreme pain or discomfort □

**Anxiety/Depression**

- I am not anxious or depressed □
- I am moderately anxious or depressed □
- I am extremely anxious or depressed □

**Visual Analogue Scale (image of “thermometer”)**

Indicate where on the scale (from 0-100) how good or bad your own health is today

**QUALITY OF LIFE – DIABETES (DDS4)**

Feeling overwhelmed with the demands of living with diabetes 1 2 3 4 5 6

Feeling that I am often failing with my diabetes routine. 1 2 3 4 5 6

Not feeling motivated to keep up my diabetes self-management. 1 2 3 4 5 6

Feeling angry, scared, and/or depressed when I think about living with diabetes. 1 2 3 4 5 6

**QUALITY OF LIFE – DEPRESSION (PHQ-8)**

Little interest or pleasure in doing things 0 1 2 3

Feeling down, depressed, or hopeless 0 1 2 3
### Consensus Measures and Indicators

<table>
<thead>
<tr>
<th>Measure</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trouble falling or staying asleep, or sleeping too much</td>
<td>0-3</td>
</tr>
<tr>
<td>Feeling tired or having little energy</td>
<td>0-3</td>
</tr>
<tr>
<td>Poor appetite or overeating</td>
<td>0-3</td>
</tr>
<tr>
<td>Feeling bad about yourself — or that you are a failure or let yourself</td>
<td>0-3</td>
</tr>
<tr>
<td>or your family down</td>
<td></td>
</tr>
<tr>
<td>Trouble concentrating on things, such as reading the newspaper,</td>
<td>0-3</td>
</tr>
<tr>
<td>watching television</td>
<td></td>
</tr>
<tr>
<td>Moving or speaking so slowly that other people could have noticed?</td>
<td>0-3</td>
</tr>
<tr>
<td>Or the opposite — being so fidgety or restless that you have been</td>
<td></td>
</tr>
<tr>
<td>moving around a lot more than usual</td>
<td></td>
</tr>
</tbody>
</table>

### PROCESS EVALUATION  (Note – peer support group may be substituted for peer supporter)

<table>
<thead>
<tr>
<th>Availability (&quot;... being present and ready to help &quot;)</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 6 months, how many times did you talk to</td>
<td></td>
</tr>
<tr>
<td>or meet with your peer supporter? (# contacts)</td>
<td>1-4</td>
</tr>
<tr>
<td>Are you able to contact your peer supporter when you</td>
<td></td>
</tr>
<tr>
<td>need to? (1 = never; 2 = sometimes; 3 = usually;</td>
<td></td>
</tr>
<tr>
<td>4 = almost always)</td>
<td></td>
</tr>
<tr>
<td>In the past six months, how often did your peer</td>
<td></td>
</tr>
<tr>
<td>supporter contact you? (specify # of contacts)</td>
<td>1-4</td>
</tr>
<tr>
<td>Has your peer supporter adapted his or her approach</td>
<td></td>
</tr>
<tr>
<td>to meet your particular diabetes management needs?</td>
<td>1-4</td>
</tr>
<tr>
<td>(1 = not at all; 2 = a little; 3 = a moderate amount;</td>
<td></td>
</tr>
<tr>
<td>4 = a great deal)</td>
<td></td>
</tr>
</tbody>
</table>

| Assistance In Daily Management ("... the actions you need | Scale |
| to take every day to control your diabetes and protect   |       |
| your health")                                           | 1-4   |
| 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)        |       |
| 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)                |       |
| 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)                    |       |
| 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 ("... addressing the          | Scale |
| emotional aspects of living with diabetes")             |       |
| Has your peer supporter helped you figure out how to    | 1-4   |
| deal with stress? (1 = not at all; 2 = a little; 3 = a   |       |
| moderate amount; 4 = a great deal)                      |       |
| Has your peer supporter helped you become confident to  |       |
| manage your diabetes? (1 = not at all; 2 = a little;    | 1-4   |
| 3 = a moderate amount; 4 = a great deal)                |       |
| Has your peer supporter helped you get support from...  |       |
| Family? (1 = not at all; 2 = a little; 3 = a moderate    | 1-4   |
| amount; 4 = a great deal)                                |       |
| Has your peer supporter helped you get support from...  |       |
| Friends? (1 = not at all; 2 = a little; 3 = a moderate   | 1-4   |
| amount; 4 = a great deal)                                |       |
| Has your peer supporter helped you get support from...  |       |
| Others? (1 = not at all; 2 = a little; 3 = a moderate    | 1-4   |
| amount; 4 = a great deal)                                |       |

### Linkage to Clinical Care ("... making regular and effective use of health services ")

<table>
<thead>
<tr>
<th>Measure</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your peer supporter encouraged you to get regular diabetes care?</td>
<td>1-4</td>
</tr>
<tr>
<td>(1 = not at all; 2 = a little; 3 = a moderate amount; 4 = a great deal)</td>
<td></td>
</tr>
<tr>
<td>Has your peer supporters helped you get the care you need from doctors</td>
<td></td>
</tr>
<tr>
<td>and nurses? (1 = not at all; 2 = a little; 3 = a moderate amount;</td>
<td></td>
</tr>
<tr>
<td>4 = a great deal)</td>
<td></td>
</tr>
<tr>
<td>Has your peer supporter helped you find other resources in your</td>
<td></td>
</tr>
<tr>
<td>community to help you take care of your diabetes? (1 = not at all;</td>
<td></td>
</tr>
<tr>
<td>2 = a little; 3 = a moderate amount; 4 = a great deal)</td>
<td></td>
</tr>
<tr>
<td>Has your peer supporter helped you communicate effectively with your</td>
<td></td>
</tr>
<tr>
<td>doctor or nurse about your diabetes? (1 = not at all; 2 = a little;</td>
<td></td>
</tr>
<tr>
<td>3 = a moderate amount; 4 = a great deal)</td>
<td></td>
</tr>
</tbody>
</table>
### Consensus Measures and Indicators

**MEDIATOR: Nondirective vs. Directive Support** (8 item) *(Fisher)*

Please circle the number that best indicates how typical each statement is of the support you receive from your diabetes peer supporter (1 – not at all to 5 - very typical):

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Show interest in how you are doing</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Push you to get going on things</td>
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<td></td>
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</tr>
<tr>
<td>Cooperate with you to get things done</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Take charge of your problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Point out harmful or foolish ways you view things</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make it easy for you to talk about anything you think is important</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tell you what to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offer a range of suggestions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**MODERATOR: Health Literacy** *(Chew)*

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you have someone like a family member, hospital worker, clinic worker, or caregiver help you read hospital materials?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often do you have problems learning about medical conditions because of difficulty understanding written information?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How confident are you filling out health care forms by yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**MODERATOR: Availability, satisfaction with diabetes-support from family and friends and your health care team** *(Tang)*

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much support do you get from friends and family dealing with your diabetes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How satisfied are you with the support you get from family and friends for dealing with your diabetes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much support do you get from your health care team to deal with your diabetes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How satisfied are you with the support you get from your health care team for dealing with your diabetes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**COSTS (SYSTEM)**

- # visits past 6 months to diabetes clinician
- # 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 III. REFERENCES

1 Toobert DJ, Hampson SE, Glasgow RE. The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. Diabetes Care 2000; 23(7):943-950.


14 Fisher EB, Earp JA, Maman S, Zolotor A. Cross-cultural and international adaptation of peer support for diabetes management. Family Practice 2010. 27 (Supplement 1): i6-i16.
