New Roles for Academic Health Centers in Clinical Research

Patient Centered Opportunities and Imperatives

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New Roles for AHCs in Research: Using Health Care Data To Catalyze Translation

- Partnering with patients to definite clinical research endpoints
- Data capture on a health care system level from beyond our walls and technology
- The development of true AHC networks as growing sources of data
- Patient, Government, AHC collaboration in the development of regulatory policies
Patient Reported Outcomes: Empowering Each Patient in Informing Care and Creating New Sources of Data For Translational Science

Develop and track performance metrics to demonstrate unparalleled patient experience, outcomes and value
Patient Reported Outcomes: Goals

1. To orient care toward outcomes that matter to patients, creating a health system that *learns*

2. To use PRO to improve the care of individual patients through better monitoring and improved responsiveness.

3. To use population-level data to set patient expectations and improve joint medical decision-making.

4. To use aggregate data as the basis for internal comparative effectiveness research.

5. To publically report outcome measures in order to demonstrate quality and value.
1. Initial *Snapshot*  
On-Site

- A. Enrollment
- B. Initial *Snapshot* Data
- C. Follow-up Modality

Remote

iPad

2. Follow-up *Snapshots*

On-Site

iPad

Remote

Patient Portal

3. Reporting

Provider Reporting

- A. PDF Report
- B. Raw Data

Patient Reporting

- iPad
- Patient Portal
- Mail

The Technology Backbone
**1. Initial Snapshot**

On-Site

- iPad

**2. Follow-up Snapshots**

On-Site

- iPad

Remote

- Patient Gateway
- Patient Portal

**3. Reporting**

Provider Reporting

- LMR
- Electronic Health Record

Patient Reporting

- iPad
- Patient Portal
- Mail

**The Technology Backbone**

- A. Enrollment
- B. Initial Snapshot Data
- C. Follow-up Modality

Follow-up Snapshot Data

- A. Follow-up interval
- B. Follow-up modality
- C. “Bloodhound” Algorithm

QDM Vendor

- A. PDF Report
- B. Raw Data
Thank you for completing the Patient-Reported Outcomes Snapshot for Patients with Diabetes. Below are scores calculated from your answers. Your score is reported in comparison to the national average which includes people of all ages and all levels of health.

**Physical Function** is one's ability to carry out various activities, ranging from everyday activities to more strenuous activities. A higher score is better. Most people report a score between 19 and 82 with an average of approximately 50.

**Mental health** refers to emotional symptoms including depression, anxiety or irritability, as well as joyfulness. It also refers to your satisfaction with social interactions and your impressions of yourself. A higher score is better. Most people report a score between 19 and 82 with an average of approximately 50.

**Anxiety** is described as self-reported fear (fearfulness, panic), anxious misery (worry, dread), hyperarousal (tension, nervousness, restlessness). Most people report a score between 17 and 100 with an average of approximately 50 for normal level of anxiety.
In general, would you say your health is:
- Poor
- Fair
- Good
- Very Good
- Excellent

In general, would you say your quality of life is:
- Poor
- Fair
- Good
- Very Good
- Excellent

In general, how would you rate your physical health?
- Poor
- Fair
- Good
- Very Good
- Excellent

In general, how would you rate your mental health including your mood and your ability to to think?
- Poor
- Fair

In general, how would you rate your satisfaction with your social activities and relationships?
- Poor
- Fair

To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a table?
- Not at all
- A little
- Moderately
- Mostly
- Completely

In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?
- Always
- Often
- Sometimes
- Rarely
- Never

Fatigue on average?
- Very severe
- Severe
- Moderate
- Mild
- None

In the past 7 days, how would you rate your pain on a scale of zero to ten where zero is no pain

5

My worries overwhelmed me.

<table>
<thead>
<tr>
<th>Question</th>
<th>Always</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found it hard to focus on anything other than my anxiety.</td>
<td></td>
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<tr>
<td>My worries overwhelmed me.</td>
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<td>I felt uneasy.</td>
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<tr>
<td>Overall, how much of a problem is it to live a normal life and take care of your diabetes?</td>
<td>Very much a problem</td>
<td>Somewhat of a problem</td>
<td>A little bit of a problem</td>
<td>Not a problem</td>
<td>Does not apply</td>
</tr>
<tr>
<td>In your opinion, how good or bad is your own health today?</td>
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<tr>
<td>0</td>
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<td>50</td>
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<tr>
<td>100</td>
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</tbody>
</table>
Depression in Diabetes

- Diabetics are twice as likely as non-diabetics to suffer from Major Depressive Disorder

- Mortality is 50% higher in depressed vs. not depressed diabetics over 10 years

- Total health care expenditures for diabetics with depression are 4.5 times higher than those without

- *New Research from MGH:* Collecting and reporting Patient Reported Outcomes to PCPs *doubles* the odds of patients responding to treatment [OR of 2.02 response to treatment (n=915)]

Yeung AS. Depression and Anxiety, 2012 29:865–873.