To: Matt Quinn, NIST
From: John Wasson, MD
Re: Measures that Matter to

Thank you for the opportunity to comment on "Measures that Matter."

I have three comments related to:

1) The medium matters.
2) The measures should matter.
3) The "right" measures?

The Medium

All of us experience obnoxious methods for obtaining measures. When we are confronted with these obnoxious methods, we usually will not respond. The measurer may need to offer incentives to increase response rates.

- ❏ The measurers do not serve directly our needs or interests: (e.g. service industry surveys or pop-up surveys on the internet). The measurers may promise to use the measures in quality improvement to serve our future needs but we surmise (rightly) that measurement is often marketing.
- ❏ The measurers often usurp control of private information (e.g. through patient portals or electronic "cookies")
- ❏ The measurers waste our time. Even if we might find immediate value in the objectives of the measures we may experience wasteful:
    - Layouts (e.g. readability)
    - Delivery methods (e.g. passwords on the internet or inadequate IVR that repeatedly asks "I'm sorry, did you mean?")
    - Convoluted or excessive items

In summary, in most respects, the medium is the health measure.(1) Avoidance of an obnoxious method is foundational for "what matters".

The Measures in Cross-Section

Measures that matter most are those that reliably and accurately assess consumer/patient needs – such as symptoms, dysfunctions, concerns, and immediate risks – and lead to effective action for these needs. (2)

- ❏ Because many needs are interrelated (as are effective actions) only a few measures may be necessary. For example, a few measures can be used as "high leverage" for clinical action and these few measures will correlate with many other measures. (1)
- ❏ Because consumers/patients generalize their experiences when measures of care quality are used to rank clinical practices for quality improvement, only a few measures are needed. (1)
- ❏ Because consumers/patients often care about risks, they are often quite good at reporting bio-clinical measures of which they have been informed. (3)

The Measures Over Time

Change in disease specific and functional measures over time can be used to assess the impact of actions. These measures are called outcome measures. The British have gathered consumer/patient-reported outcome measured for about 300,000 procedures a year since April, 2009. (The procedures are varicose veins, hernias, knee replacement and hip replacement.) There are plans to expand coverage to chronic conditions in primary care and cancer interventions. Because the British have a health budget they can also assign costs and derive estimates of "best value" hospitals. Thus, though they do not directly benefit from participating in the measurement process, over time all consumers benefit by learning about the highest value health care providers. Providers are able to learn about their technical efficiency and outcome variations. (4)

Clearly, since the British have many years more experience, it might be prudent for U.S. measurers to follow their lead. Of note is the fact that they have kept the measurement simple (since the analysis can be quite complex). As an example, their measures for overall quality of life (Euroqual 5) are very similar to the simple measures we have offered for many years over on our publically available website (HowsYourHealth.org) to assess and address patient needs in primary care and hospitals.(5)

The "Right" Measures?

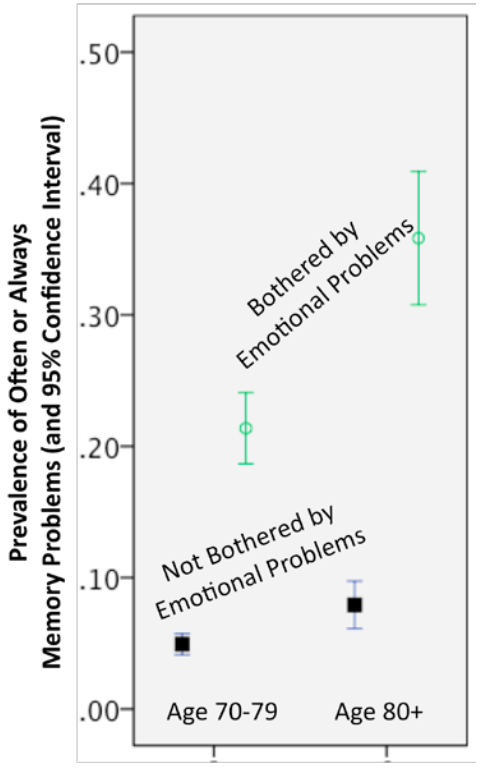
Many factors influence the choice of a measure: the social situation of the respondents, their desires and language, the effectiveness of the actions that might be taken based on their responses, and the interactions of the measures with other important domains of health. To illustrate the problem of picking the "right" measure consider two options for measurement: a single item in the left hand column and any combination of the 38 candidate measures in the right hand column.

From HowsYourHealth.org	Candidate Items from NIHPROMIOS.org
How often during the PAST FOUR WEEKS have you been bothered by Trouble thinking or remembering Never Seldom Sometimes Often Always	a. I have had trouble forming thoughts b. My thinking has been slow c. My thinking has been foggy d. I have had trouble adding or subtracting numbers in my head e. I have made mistakes when writing down phone numbers f. AND ON IT GOES THROUGH: GHIJKLMNOPQRSTUVWXYZQQBBCCDDEEFF gg. I have had to use written lists more often than usual so I would not forget things hh. I have trouble keeping track of what I was doing when interrupted ii. I have had trouble shifting back and forth between different activities that require thinking jj. I have hidden my problems with memory, concentration, or making mental mistakes so that others would not notice kk. I have been upset about my problems with memory, concentration, or making mental mistakes ll. My problems with memory, concentration, or making mental mistakes have interfered with my ability to work

The single item may be clinically sufficient for assessing how the consumer feels about their memory and whether or not action might be indicated. However, a pharmaceutical company might want much more precision so that subtle changes over time are reliably detected. To develop an index sensitive for small changes several psychometrically "best" items (Cronbach's alpha, etc.) from the right column might be chosen.

Which measure is "right"? The single measure or the multi-item index. Both and neither! It depends on the context.

As an example, the following Figure is based on 5000 consumers/patients age 70+ who answered the single item. It demonstrates that age and emotional state makes a big difference; if you were comparing the prevalence of memory problems across several practices or patients using a new drug, you would have to include measures of age and emotional state.



Furthermore, studies suggest that: • the likelihood of actual dementia in a person who self-reports memory problems is about twice as likely than someone who does not report memory problems.
• when a family member reports memory problems the likelihood of dementia goes up over 6 fold.
• if a person can recall four items after 5 minutes of distraction the likelihood is reduced dramatically; conversely the likelihood of dementia is increased 30 fold if they cannot remember the items.

Thus, neither measure would be "right" if one were trying to identify persons having a high likelihood of dementia. Either might be fine to assess "thinking" but other measures (emotions and age in particular) would be needed to make sense of the results.

When seeking the "right" measure many factors must be considered and tested. Determining the interactions of the measures and factors can be a formidable challenge. Fortunately, internet-based information and communication technologies are very good tools for delivering measures for consumer/patient-reporting. These tools can easily tailor measures by using branching logic or computerized adaptive testing (based on respondent characteristics and prior responses). These tools can also test the utility of the measures for different patients with particular conditions in specific contexts.

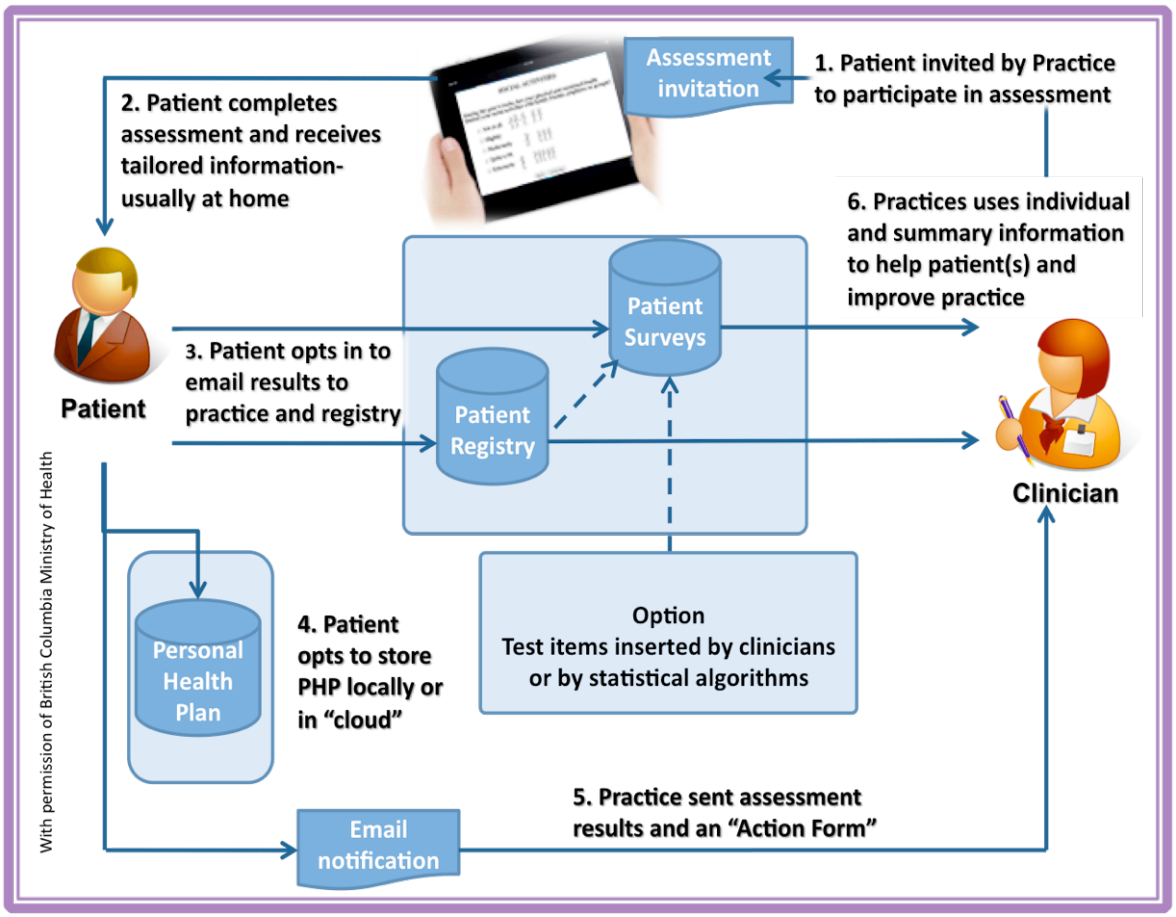
As one example we used a statistical algorithm to randomly administer a small number of patient experience measures from the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) survey. The analysis enabled us to determine the marginal value of multi-item measures for ranking practices. As another example we asked patients what they had been told about specific decisions in a particular context. Their "crowd-sourced" responses were used to tailor a new version of the website to better assess and meet their needs. (1)

As show by the "memory example above, NIHPROMIS.org would like to "create an opportunity for clinicians and patients to develop a common language around self–reported health status and in the process allow better assessment of the unique information from patients thereby enabling improved quality of care and quality of clinical research". However, NIHPROMIS.org is not designed in a user-friendly way to efficiently assess what matters to patients and serve their needs. For this reason we have designed methods whereby patients who complete HowsYourHealth.org could be offered the opportunity to go to NIHPROMIS.org and complete additional measures to further the science of measurement.

In summary, new media enable the healthcare system to create ever better measures using "crowd sourcing" and statistical algorithms to evaluate test items. Absent this new capacity the costs of developing, testing, distributing, analyzing and reporting measures using traditional mail or phone methods would undoubtedly inflate an already unsustainable healthcare budget… and burden patients unnecessarily.

1. The Medium is the (Health) Measure: Patient Engagement Using Personal Technologies. John H. Wasson, MD Helena Hvitfeld Forsberg Staffan Lindblad Garey Mazowita Kelly McQuillen Eugene C. Nelson. Jamb Care Mngmnt. 2012;35: 109-117.
2. Wasson JH, Baker NJ. Balanced Measures for Patient-Centered Care. Jamb Care Mngmnt. 2009;32: 44-51.
3. Wasson JH, Benjamin R, Johnson D, Moore LG, and Mackenzie T. Patients Use the Internet to Enter the Medical Home. J.Amb.Care.Mgmt. 2011; 34:38-46
4. Devlin N and Appleby J (2010) Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision making. The king's Fund, London http://www.kingsfund.org.uk/publications/proms.html
5. Nelson EC, Landgraf JM, Hays RD, Wasson JH, Kirk JW. The functional status of patients: How can it be measured in physicians' offices? Med Care 1990;28(12):1111-1126

An example of an Internet-based Information and Communication Technology



John H. Wasson, MD is a practicing geriatrician and Professor Emeritus of Community and Family Medicine at Dartmouth Medical School. Under license with the Trustees of Dartmouth College, Dr. Wasson leads the development and distribution of www.HowsYourHealth.org.

The Dartmouth Institute Patient-Reported Data Trust is committed to the sharing of results from these technologies to guide improvement so that everyone benefits: patient, providers, and communities. A specific goal of the Patient-Reported Data Trust is to enable front-line clinicians and their patients to test the value of patient report in the field (about "what matters", risks, experiences and outcomes). In addition to www.HowsYourHealth.org for the Medicare Annual Wellness Visit are integrated HowsYourHealth tools for children, adolescents, and adults, the very ill and frail, hospital care, problem-solving, care transitions and personal health planning, and quality certification based on patient experience measures.