

Patient-reported outcomes: the better to know you with

Chris Weiss is the Co-founder, President & Chief Executive Officer of Dynamic Clinical Systems. The DCS secure Web-based solution, Integrated Survey System® (ISS), enables patients to provide health history and outcomes data electronically, lowering the cost of data management, improving the value of data collected, enhancing control in decision making, and documenting empirical measurement of outcomes tailored to care. DCS's vision is to enable outcomes-based care over a patient's journey through the healthcare system.

What are "patient-reported outcomes" and why does DCS believe they are important?

We use the term "patient-reported outcomes" (sometimes referred to as PROs) to differentiate them from medical outcomes. That is, data that can best be provided by the patient and cannot typically be derived from a medical test, reading, or measurement. For example, a patient may be asked about his ability to function in daily life or the level of pain he is feeling. PROs tend to be subjective measures that can be asked in a consistent manner so they can be analyzed and even scored. Shown graphically over time, PROs help a patient and his treating clinician understand the long-term results of care that go beyond typical medical outcomes like mortality rates or surgical complications.

Not just those of us at DCS believe patient-reported outcomes are important. The medical, research, and payor communities have all increased their focus on PROs in recent years. For example, the Food and Drug Administration now requires PROs in certain drug trials. Outside the realm of research, we see feeding real-time PROs to clinicians at the point of care as a way to impact treatment decisions. Our collaborators in the Spine Center at Dartmouth-Hitchcock Medical Center would say that patient-reported outcomes are the equivalent of a "blood test for spine patients" – that is, the most useful indicator of long-term outcomes for this class of patients.

Since the patient provides the key data, the process can be much more efficient for the clinician. And patients say they would prefer their clinicians have this data to help paint a more complete picture of their background and current condition.

Are there any particular health conditions that lend themselves more to the use of PROs?

We don't believe there is a condition that should *not* be tracked using patient-reported outcomes. But of course that's a biased position! We see that collaboration between PROs and other data types is particularly effective when a patient is under long-term care for a chronic condition. In those situations, being able to analyze and compare PROs over a long period of time allows the patient and her clinician to detect variations in her health.

A cancer or spine patient's ability to function in daily life may be impacted by increasing depression or anxiety, or by gradually building pain levels. Again by contrast to a medical outcome using a blood test, these types of shifts can be detected only by asking the patient herself.

If PROs are that important, why aren't they more broadly adopted in healthcare today?

Patient-reported outcomes have been around healthcare for many years. However, their use has typically been confined to clinical studies and trials, and they have been collected mostly on paper. Forces such as the push for more transparency in healthcare, the need to meaningfully measure clinical performance, and the tremendous adoption of the Web by patients and clinicians alike, have begun to unlock the value of PROs in the process of care.

How does DCS make it possible for PROs to be used in the process of care?

When a patient makes an appointment with the clinic, an interface downloads relevant appointments into ISS. Surveys are automatically scheduled according to appointment characteristics (e.g., specialty, clinician, appointment type), patient information (e.g., gender, age, past and current survey responses), and pre-defined timing parameters. Based on the

specific implementation, the patient may be notified via email to sign on and take the survey from home or he may come into the clinic early to take the survey in the waiting room.

While the process described above implies integration to local information systems, ISS can be operated completely stand alone without such integration.

The patient may be asked about health status, history, outcomes, expectations and satisfaction, understanding and preferences of treatment options. This in-depth knowledge about the individual patient allows for better targeted care and education and for a more active role of the patient in collaboration with the clinician.

Based on the individual patient responses, a number of actions may be automatically triggered to ensure whole patient care, including referrals to specialists (e.g., nutritionist, behavioral health, smoking cessation, etc.), real-time patient education (via links clinician-approved Web sites or streaming video), or follow-up protocols for future data collection.

An individual patient summary report is then printed for the clinician to view prior to the patient visit. This report includes a summary of patient survey answers, color coding for easy scanning, longitudinal comparisons of previous surveys, red flags and warnings, clinical protocols, quality measures, billing documentation, and shared decision making information. The clinician uses this report during the visit to focus the discussion on highlighted items rather than routine questioning.

You mention patient preferences. Does that type of data really fit your description of PROs?

Strictly speaking, no. However, once a patient and her clinician are collaborating in this way, there are other types of data not related to outcomes that can be useful. For example, it is typical for a DCS customer to collect a patient's health history (e.g., past surgeries, medications) using our Web-based system. Those data are not really patient-reported outcomes either, but it is essential for a clinician to have at-hand when providing care.

Further, since the collaboration is two-way, it is possible for clinicians to provide healthcare education through links to other Web sites or even by streaming video to a patient's computer

ISS is Web-based. How does that work? Aren't patients concerned about privacy?

A patient can provide PROs and other information either in the clinic or at home, or for that matter wherever he has access to the Internet. We see a rapidly dwindling number of patients who cannot get on the Web somehow. Most of the questions we ask a patient do not require the use of a keyboard. That allows our customers to offer tablet computers or touch screen kiosks to their patients in the clinic, although those technologies are not required for our system to work.

Patients are focused on privacy, to be sure. We provide information about the system before the patient uses the system, and we ask for patient consent when required by Federal, state, or site regulations. With the Internet increasingly infused in daily life, patients have become informed online consumers. Patients ask questions of their clinicians and they have the ability to just say "no" if that seems like the best choice for them.

Is ISS difficult for patients who have no computer experience to use?

DCS has tested its system with patients of all computer skills, ages, education levels. Many patients who have never used a computer have suggested that it's actually easier to tap the answers to one question at a time than it is to fill out busy paper forms requiring patients to figure out which sections apply to them. Some patients are incapable of completing the survey due to physical, mental, or language limitations. In these cases, patients typically have family members or other caregivers assist them, as they do with paper forms.

Shifting topics slightly, it sounds like ISS provides abilities that other healthcare information technologies already provide. How do you fit with things like electronic medical record (EMR) or personal health record (PHR) systems?

Yes, the healthcare IT landscape is dotted with would-be options. It is common for us to integrate with other systems. A growing number of our customers – who are clinicians

providing care in practices or hospitals – have systems they use for scheduling appointments, documenting care, and billing for services. These systems serve the needs of the practice, but do not typically create the ability for patients and clinicians to collaborate in the way we have been talking about it, nor do they have any particular focus on patient-reported outcomes. Further, since local practice systems are oriented toward a patient who has an appointment, these systems are limited in their ability to interact with the patient outside of the clinic, or when care is not actively being provided in the clinic.

Our view is that the PHR of today does not yet provide enough value to the key stakeholders in the provision of healthcare – the patient *and* the clinician. Just as clinical documentation is trapped within the confines of the EMR, so is the patient's information locked in the vault of the typical PHR where it is not able to influence the care process. The notion of true healthcare collaboration is difficult to achieve without connected, context-sensitive systems.

It is important to have a system like ours that enforces rules about what data is required within the context of a patient's episode of care. To improve not only an individual patient's care but to impact a community of patients, PROs need to be collected routinely and consistently.

You mention that EMR systems are limited in their ability to interact with the patient when the patient is not being treated in the clinic. How would ISS be used when a patient is not being treated in the clinic?

It is misleading to track outcomes only for patients with appointments in the clinic because patients tend to return for follow-up appointments if their condition is still bothering them. In other words, the healthier patients – ones with arguably better outcomes – may not return to the clinic and therefore would not be properly represented in the PROs dataset.

The DCS process seeks to continue collecting patient-reported outcomes data from all patients whether they return to the clinic or not. Those patients who enter their PROs data after a treatment intervention can help clinicians understand which treatments are best suited for the various patient populations.

Another scenario for interacting with patients who do not currently have appointments in the clinic is to monitor and assist patients with long-lasting illnesses or disease threats, such as diabetic patients or cancer survivors. Those patients can be prompted to regularly enter information into ISS and – based on their responses – may be given education for symptom self-management or advised to make an appointment with the clinic.

Your slogan is “A patient-centered approach to clinical information management.” That sounds like an important mantra in general, but who gets value out of using your system?

This is an important question with a multi-tiered answer. The practice or hospital gets value through outcomes reporting available for quality management, marketing, or payor negotiation, more efficient research processes, and better patient data. The clinician gets value through less routine interviewing, less time documenting the visit, and assistance in providing quality care through red flags, clinical protocols, and longitudinal reports. Patients get value using the system through reduced paperwork, more-complete information for the clinician, shared decision-making, and real-time, tailored education.