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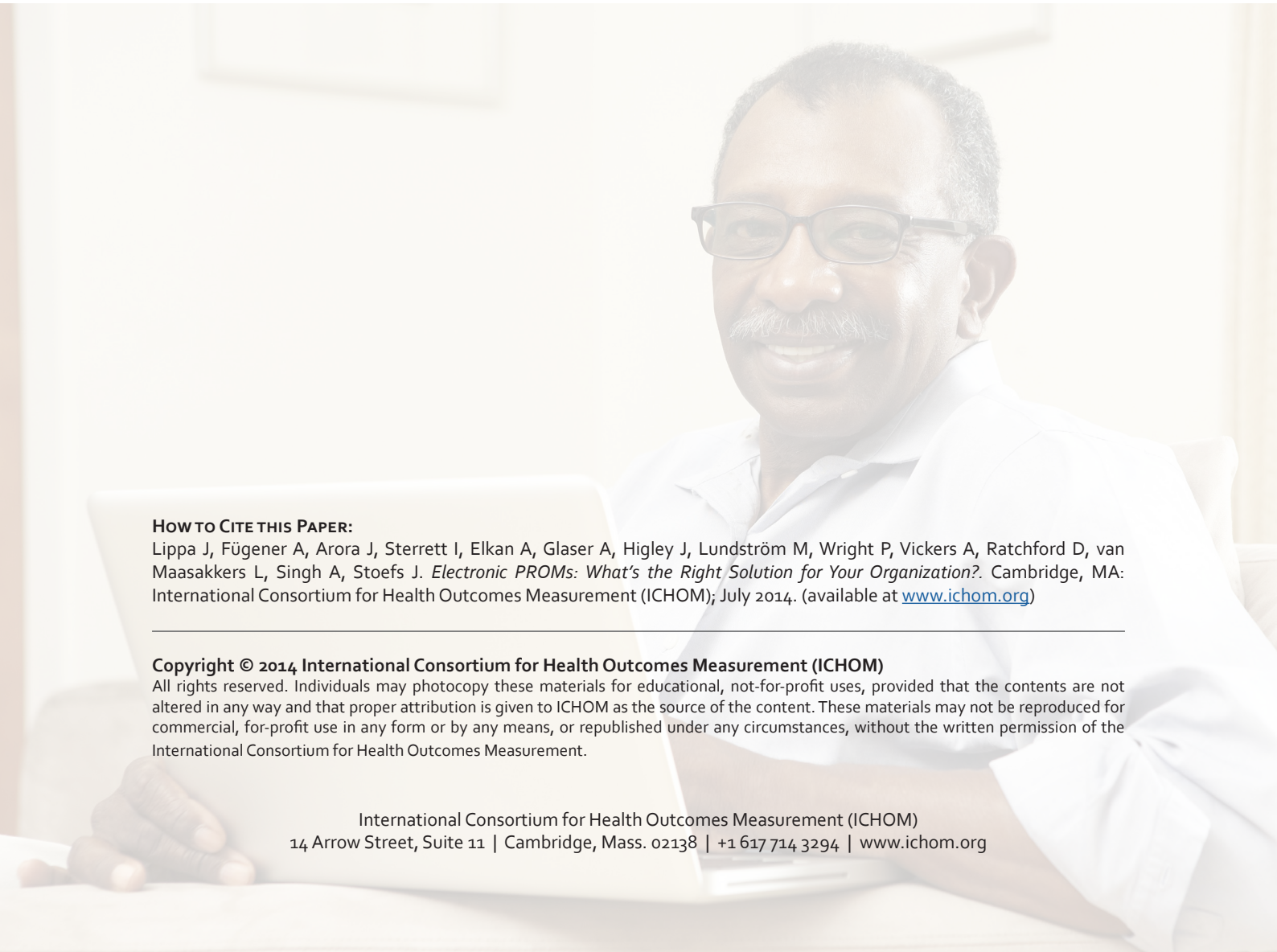
International Consortium for
Health Outcomes Measurement

ELECTRONIC PROMs:
WHAT'S THE RIGHT SOLUTION FOR YOUR ORGANIZATION?

JULY 2014



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Foreword

The International Consortium for Health Outcomes Measurement (ICHOM) is a non-profit organization dedicated to transforming health care systems worldwide. In pursuit of this goal, we work with leading physicians, registry leaders, and patient representatives to determine the most essential outcomes – that is, the results that patients care about most when seeking treatment – for specific medical conditions. Taken together, these outcomes, as well as associated risk factors, constitute an ICHOM Standard Set. We believe that care teams that measure the Standard Sets will improve the care they provide and the results their patients experience.

Because our Standard Sets are designed to measure the outcomes that matter most to patients, a majority of the outcomes we recommend are typically patient-reported, free from interpretation by clinicians. Collecting patient-reported outcomes, however, can be challenging. Capturing certain outcomes directly after a procedure is relatively straightforward, but following a patient over time to track the evolution of his or her condition can be far more difficult. Yet doing so is critically important to determine the treatment approaches and other elements of care that lead to sustained, long-term health and better value for patients.

Technology promises to help overcome this challenge. Electronic tools developed to track patients and their conditions over time are becoming more prevalent and more powerful. Numerous solutions exist in the market today, yet purchasers often lack a clear understanding of what attributes to look for and what criteria to apply when comparing these tools.

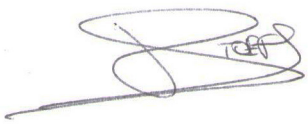
With this in mind, ICHOM recently launched an initiative to establish guidelines and identify the key attributes to consider when evaluating a tool, and to identify and assess a number of existing tools. To do so, ICHOM leveraged its international network to convene a Working Group of patient representatives and experts:

- **Ann-Charlotte Elkan** | Karolinska Institutet | Sweden
- **Adam Glaser** | Leeds Teaching Hospital | United Kingdom
- **Jim Higley** | Patient Representative & Author | United States
- **Mats Lundström** | EUREQUO/Lund University | Sweden
- **Penny Wright** | University of Leeds | United Kingdom
- **Andrew Vickers** | Memorial Sloan Kettering Cancer Center | United States
- **Daniel Ratchford** | Quality Health | United Kingdom
- **Lisa van Maasakkers** | ICHOM | Germany

The Working Group met twice over the course of the four-month project to review literature and expert interviews and to determine the minimum requirements electronic PROM (ePROM) tools should meet. The minimum requirements and conclusions presented herein were developed and unanimously agreed upon by the Working Group.

We would like to express our sincere thanks to the Movember Foundation for its generous support of the project, as well as all the Working Group members, who volunteered their time. We also want to thank the ICHOM team members who drove this work: Dr. Andreas Fügener, Mrs. Lisa van Maasakkers, Mr. Jacob Lippa, Dr. Jason Arora, Mr. Isaiah Sterrett, and Mr. Ajeet Singh.

We hope this paper enhances your understanding of the topic and helps you select the right tool for your organization. If you want to go one step further, we invite you to join the ICHOM Implementation Network, an online community and repository of resources that brings together health care providers from around the world and supports their implementation of the ICHOM Standard Sets.



Jean Stoefs
Vice-President of Implementation

What are PROMs and why they are important?

Patient-reported outcome measures (PROMs) aim to capture how patients perceive their health and the effects of the health care services they receive.

To ensure the accuracy of data and enable comparisons across settings and over time, PROMs are scientifically- and linguistically-validated instruments. They are typically captured through questionnaires or other survey instruments. Methods and modes of collection vary. PROMs can be self-administered or administered by an interviewer, and they can be administered on paper, by phone, or electronically using a computer, tablet, smart phone, or other device. PROMs are typically measured at numerous time points after a diagnosis in order to capture the evolution of a condition or particular outcome over time.

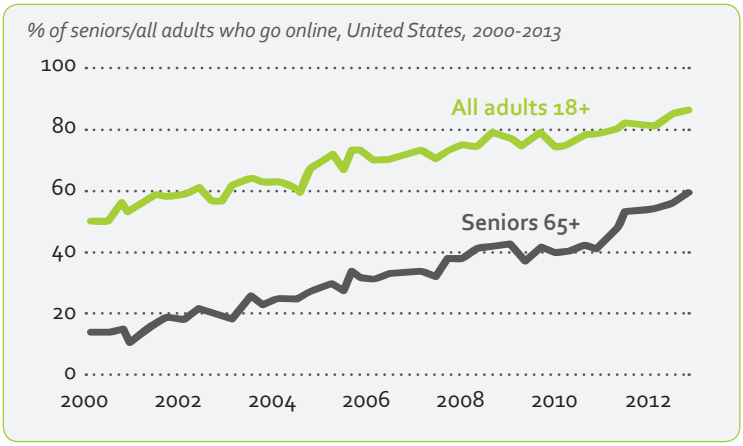
PROMs are a significant part of all ICHOM Standard Sets. They typically account for more than half of the outcomes recommended for a given medical condition. We believe they are important for a number of reasons:[1]

- **They measure what really matter to patients**
  For example, PROMs for prostate cancer measure such critical outcomes as urinary incontinence and sexual dysfunction.
- **They measure outcomes that are known only by patients**
  For example, PROMs in the Low Back Pain Standard Set measure pain, disability, and health-related quality of life.
- **They improve interaction between patients and their providers**
  PROMs provide a common language and a basis for meaningful discussion.
- **They increase patients' understanding of their condition**
  PROMs allow patients to monitor their recovery and progress over time.

Why electronic patient-reported outcome measures?

Systematic, longitudinal tracking of patient-reported outcomes can be challenging. Historically, the means by which providers could reach patients to conduct PROMs were limited to telephone calls or traditional mail. These methods, however, can be expensive for providers and inconvenient (even intrusive) for patients. Electronic PROM (ePROM) tools offer a simple, convenient, efficient method for follow-up with patients inside and outside of the hospital or clinic. With a few clicks of a mouse or taps on a touch screen, patients can fill out surveys that provide important feedback about their condition. Further, these tools can be used virtually anytime, from virtually anywhere.

Exhibit 1 | Internet adoption over time



Source: Pew Research Center's Internet Project tracking surveys

Recent studies demonstrate that the vast majority of adults now use the Internet and that usage is on the rise (Exhibit 1). And even among patients without internet access, there are other ways to capture PROMs electronically. Kiosks can be set up in clinical settings, and tablets or other touch screen devices can be provided to patients in waiting rooms. Alternatively, interactive voice response technology allows patients to speak their responses to automated prompts into their phones. PROMs can even be collected via SMS (text message) technology.

What was the scope of the project?

- **We focused on patient-reported outcomes**
  Some tools also allow capture of physician-reported outcomes, but this was not the focus of our work.
- **We limited our project to electronic tools**
  Electronic tools include computer- and web-based instruments, as well as automated phone calls and text messaging.
- **We focused on data capture and reporting**
  Our primary focus was on capturing data properly and efficiently, as well as the use of this data to improve clinical care.

Minimum Requirements for ePROM tools

When it comes to choosing an ePROM tool, providers should take care to select a robust, reliable, secure, and sustainable solution. Privacy and security are of the utmost concern, but there are many additional factors to consider when selecting a tool. Unfortunately, standards have yet to be established for ePROM tools, which is why our Working Group developed a list of minimum requirements that any tool should meet before being considered.

These requirements comprise a minimum set. Thus, a given tool may meet the requirements but still be less than ideal for a given condition or setting. In other words, the requirements set forth by our Working Group are threshold requirements. Other attributes (e.g., price, integration with electronic medical record systems, modalities of data-capture) must also be taken into consideration when selecting the right tool among all those that meet the minimum requirements.

Our Working Group established two levels of requirements: those that apply to the solution-provider (i.e., the legal entity that is commercializing the tool), and those that apply to the tool itself. The Working Group concluded that the solution-provider should meet the following requirements:

1. **Independence**
   The solution-provider should be free from conflicts of interest. For example, clinicians should avoid solution-providers that might be interested in using the raw data for commercial purposes (e.g., to extract commercial insights).
2. **Business Continuity**
   The solution-provider should be able to demonstrate the ability to sustain business operations for several years. Patient-reported outcomes measurement is a long-term endeavor, and continuity is important. Having to switch tools can be disruptive and costly for providers and, in some cases, challenging for patients.
3. **Maintenance**
   The solution-provider should commit to providing maintenance for the tool. This will ensure that problems or evolutions (e.g., changes in the questions of an instrument) are handled properly and in a timely manner.
4. **Compliance with law**
   It's important that the solution-provider complies with all local and national laws, which can vary from one country to the next. Some countries, for example, might require data to be stored domestically. Regulations like these can impact how data are handled by the solution-provider.

At the tool level, one should be attentive to a number of additional factors:

1. **Data Ownership**
   The care provider should be the sole owner of data.
2. **Data access**
   The care provider should have direct and unlimited access to the raw data (e.g., through an extraction tool). Any access to the data by the solution-provider should be pre-approved by the care provider.
3. **Data security**
   Data in transit between systems should be encrypted. Access to data must be recorded for audit purposes.
4. **System reliability**
   A Service Level Agreement should define how the tool will be maintained and the response level to be expected. The tool should be available anytime for patients, with little or no delay. It is thus critical to ensure that bugs and problems are fixed quickly.
5. **Unique patient identification**
   Since PROMs are typically tracked over time for the same patient, it is necessary that the provider be able to identify each patient and his records uniquely in the system.
6. **System adaptability**
   Finally, the tool should be customizable by care providers. This can help to reduce bias and ensure replicability and comparability of results.

It is worth noting that our Working Group extensively discussed including a requirement relating to psychometric characteristics—that is, whether a particular tool introduces a bias in the instrument it uses. Ultimately, however, we decided that this important question should not be a minimum requirement. Rather, it should remain on the agenda of those who plan to conduct comparisons or to collect data for research. Indeed, our Working Group believes that it is the responsibility of those conducting the survey–and not the tool-developers–to ensure that electronic administration of an instrument does not introduce a bias.

Landscape of Existing Tools

What are the solutions out there that meet your needs? To help answer this question, ICHOM prepared a landscape of existing tools by reaching out to more than 40 solution-providers. From this initial set, we sent a questionnaire to the 18 that responded to our inquiry, fell within the scope of the project, and agreed to participate. Ultimately, we received completed questionnaires from 11 solution-providers. Encouragingly, all of the solution-providers that participated in our landscape met the minimum requirements that had been defined by the Working Group.

The questionnaire asked about additional characteristics, as well, allowing us to develop better insight into distinguishing features and discriminating attributes. This allowed us to draw a high-level comparison, which is presented in table 1 (page 6-7).

What we have learned

Most of the tools provide a platform that can be customized and adapted to meet the needs and preferences of the user. For example, users can usually add questions to a questionnaire. Some, however, are specific to certain medical conditions or groups of pathologies. The tool developed by BCB Medical, for example, is specific to prostate cancer, while CliniCast and KEOPS offer solutions for oncology and spinal care, respectively. While these tools have the advantage of having been developed around specific medical conditions, they may not be the best choice for multi-specialty organizations interested in a single solution for administering PROMs across departments and/or adopting multiple ICHOM Standard Sets.

Another discriminating factor is price. Not all solution-providers were able to give us an estimate of the cost, but we did observe wide

Details on the methodology

We asked solution-providers to characterize their solution along the following dimensions.

Cost
This includes both the cost of setting up the tool (installation, on-site service, etc.) and of running it (price per patient, maintenance fees, and so on).

Flexibility
A flexible tool is one that can be both customized (e.g., so new instruments can be added to it or additional questions can be added to existing instruments) and can be used across a range of medical conditions.

IT Requirements
Can it run as a standalone tool? Can it be integrated with an electronic medical record (to generate automatic triggers based on a patient's visits, or to upload collected information in a central database)? Does it run on local servers or in the cloud?

Administrative Effort
The effort required to run the tool on a daily basis. Is the workflow automatically managed? For example, will the system send a specific survey at six months post-procedure?

Setting
In which environment can the tool be used—in a hospital, at the registry level, or both.

Physician Information
This refers to a tool's capacity to yield useful feedback to the physician. This includes (1) its capacity to extract data from the tool in standard and common formats (e.g., .csv, .xls); (2) its ability to report data automatically (tough the quality and depth of reporting varies a lot); (3) whether it includes advanced analytic tools, such as statistical software for risk-adjustment, and alerts that can be used to bring inadequate or unexpected answers to physicians' attention.

Patient Information
This is the tool's ability to provide educational information to the patient (e.g., information on the evolution of his disease) and a comprehensive report of the data collected on his or her behalf.

Modalities
PROMs can be captured electronically in different ways—at home or in the hospital, on the web, on a tablet or smart phone application, or even by an automated phone call. This final dimension provides an overview of the capabilities of the different solutions.

variation—from a few thousand US dollars to USD $50,000 or more. The level of complexity and integration with existing IT tools and electronic medical records plays a key role in the final price of a solution. Pricing structures also differ. In light of the great variability in pricing models and estimates of cost, we recommend exploring different options and requesting quotes from multiple solution-providers before making a decision.

All solutions in our landscape are usable on the internet or through web-enabled mobile devices. Other data-capture modalities, like automated phone calls (which utilize interactive voice response technology to capture patients' responses) and SMS are not widely supported. Most solutions can be integrated with an electronic medical record (EMR), but this usually comes at a cost. The need for integration should be assessed on a case-by-case basis. This functionality may be important for providers who wish to do more advanced analysis, such as stratifying observations by data elements contained in the medical records.

Most solutions can be integrated with an EMR, but this usually comes at a cost.

Additionally, EMR integration can facilitate the entry of patients into the system. This is likely a key consideration for larger providers with high patient volumes.

Table 1 | Results of landscape of existing ePROM tools

All information contained in the table below is self-reported by the solution provider

	Acesis	BCB Medical	CliniCast	InputHealth	KEOPS
COSTS					
Setup	Monthly inclusive service charge, by scope of project	€ 50,000	--	Variable ex. CDN $399 set up, $149/ mo. for 3 physicians & 3 questionnaires	--
Running		€ 25,000/year € 10,000/ add-on	USD $1,000 per month		€ 2,400 per year per hospital for 350 patients
FLEXIBILITY					
Customize Surveys	✔	✔	✔	✔	✔
Conditions Covered	Broad	Prostate Cancer	Oncology	Broad	Spinal Care
IT NEEDS					
Standalone	✔	✔	✔	✔	✔
EMR Integration	✔	✔	✔	✔	✔
SaaS vs. Local	SaaS	Local	SaaS	SaaS	SaaS
ADMIN. EFFORT					
Flow Management	✔	✔	✔	✔	✔
Automatic Reminders	✔	✔	✔	✔	✔
SETTING					
Hospital	✔	✔	✔	✔	✔
Registry	✔	✔	✔	✔	✔
PHYSICIAN INFO					
Extract Data	✔	✔	✔	✔	✔
Report Data	✔	✔	✔	✔	✔
Alerts	✔	✔	✔	✔	✔
PATIENT INFO					
Education Tools	✔	✘	✔	✔	✔
Basic Reporting	✘	✔	✔	✔	✔
MODALITIES					
Mobile Access	✔	✔	✔	✔	✔
SMS Questions	✔	✔	✘	✔	✘
Phone Calls	✔	✘	✔	✔	✘

MKSCC	myClinicalOutcomes	PhDx	Press Ganey	PHT	Tonic Health
Variable maximum: USD $5,000, USD $20/ patient	Variable Options at patient, hospital, provider levels	-- List price: USD $4,000 per user per year	Variable depending on departments and physicians	Variable Options at patient, hospital, provider levels	Annual license fee on expected survey volume
✔ Oncology	✔ Broad	✔ Broad	✔ Broad	✔ Broad	✔ Broad
✔ ✔ Both	✔ ✔ Both	✔ ✔ SaaS	✔ ✔ Local	✔ ✔ Local	✔ ✔ SaaS
✔ ✔	✔ ✔	✔ ✔	✔ ✔	✔ ✔	✔ ✔
✔ ✔	✔ ✔	✔ ✔	✔ ✔	✔ ✔	✔ ✔
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✔ ✔	✔ ✘	✔ ✔	✔ ✔	✔ ✔	✔ ✔
✔ ✘ ✔	✔ ✔ ✔	✔ ✘ ✘	✔ ✘ ✘	✔ ✔ ✘	✔ ✔ ✘

✔ Available/Included

✔ In Development/ Requires Purchase

✘ Not Available

All solutions allow users to extract data in common formats (e.g., .csv and .txt). They differ from each other, however, with respect to their reporting functions. Depending on your existing infrastructure, you might find these advanced reporting capabilities valuable. If your organization already has a well-established data warehouse and/or statistical programmers to run these analyses, these functions may not be a priority.

Finally, it should be noted that these tools can be deployed in different settings and for different purposes. On the one hand, ePROM tools can serve as a valuable clinical aid. The reporting functionality built into many of the tools allows physicians to monitor their patients more closely, and alerts can help clinicians identify problems and intervene before they become acute. Indeed, many physicians have commented that they could not imagine practicing medicine without PROMs. Similarly, many of the tools provide patients with educational materials and web-based interfaces to help them better understand and manage their conditions. Clinicians also reported a significantly higher response rate in cases where the ePROM was used in clinical care, as patients could directly recognize the value of it.

At the same time, ePROM tools can be used by registries, as self-contained registries, or by providers who wish to participate in registries. In this context, the data may or may not be used by physicians in their day-to-day practices. Rather, the primary intent is to aggregate data across multiple sites and organizations—sometimes across multiple countries—for clinical research. This type of research can be invaluable in identifying the most effective treatment approaches for a specific subgroup of patients, for example. When used for this purpose, efficiently administering the PROMs to a large volume of patients and pooling the data in a central location for analysis is of primary importance.

ePROM tools can serve as a valuable clinical aid… Indeed, many physicians have commented that they could not imagine practicing medicine without PROMs.

All of the solution-providers that participated in our landscape reported that their tools were generally suitable both for hospital and registry settings. Nevertheless, at least some of tools were clearly designed with one or the other purpose in mind. Additionally, while they all have the ability to submit data to a registry, not all of them can act as self-contained registries and be used to connect data from multiple hospitals.

Deciding on the right tool

Every situation is unique. Clinical needs, available resources, and the existence and importance of electronic medical records are just a few of the factors that will influence the choice of a tool. To help guide this decision-making process, we propose that clinical teams consider the following four questions.

1. **Who are the patients targeted?**
   The health and socioeconomic status of a patient, as well as the setting in which she will complete the surveys should be considered to ensure that the solution can easily be used by the target audience. An iPad or other tablet may be suitable for a waiting room, but it's unlikely that an elderly patient will have such a device for use at home.

2. **What are the IT constraints?**
   One must understand the IT context in which the tool will be used. Should the solution be linked to or integrated with the EMR? What are the data security and constraints of the institution. And, on the most practical level, is there Wi-Fi coverage in the waiting rooms where the tablets or touch screens will be used?

3. **What will be the impact on the workflow?**
   Our experience with organizations that have implemented outcomes measurement demonstrates that the support of staff is critical for success. To gain their support for the initiative, the burden of incorporating PROMs into their workflow should be minimal. Furthermore, if the tool provides valuable insights that inform the patient-provider meeting (e.g., by providing results of the patient's survey directly to the physician during consultation), adoption will likely increase. Understanding where in the care process and how data will be captured and used is of great importance.

4. **What are the costs?**
   Last but not least, acquisition and maintenance costs must be carefully considered. Our experience demonstrates that price points are highly variable and usually linked to functionality (tools that fully integrate with EMRs are typically more expensive).

As value comes to replace volume as the chief pursuit of health care systems around the world, measuring outcomes – the results that matter most to patients – has never been more important. PROMs give us key insights into outcomes – insights, indeed, that cannot otherwise be gleaned. Collecting PROMs can be difficult, to be sure, especially over time, but emerging technologies can help us in a variety of ways to overcome those challenges. Understanding the ePROM tools that exist and the unique needs of your organization will help ensure that your organization is at the forefront of outcomes measurement.

Learn more

This white paper is intended as a summary of our key findings. If you are interested in learning more, we invite you to join the ICHOM Implementation Network, an online resource repository and community of health care providers around the world who are using outcomes measurement to improve value for patients. The Implementation Network includes materials to support health care providers throughout the entire implementation journey, including how-to guides, case studies, databases, and more. Members of the ICHOM Implementation Network will also find additional details about each of the solution-providers included in our landscape, a detailed "decision framework" for selecting the right solution, and a list of ICHOM Certified Suppliers. These suppliers have already integrated one or more ICHOM Standard Sets into their solutions, providing a "ready-to-use" tool to facilitate implementation.

To learn more about the ICHOM Implementation Network, please visit: http://www.ichom.org/implementation-network/

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