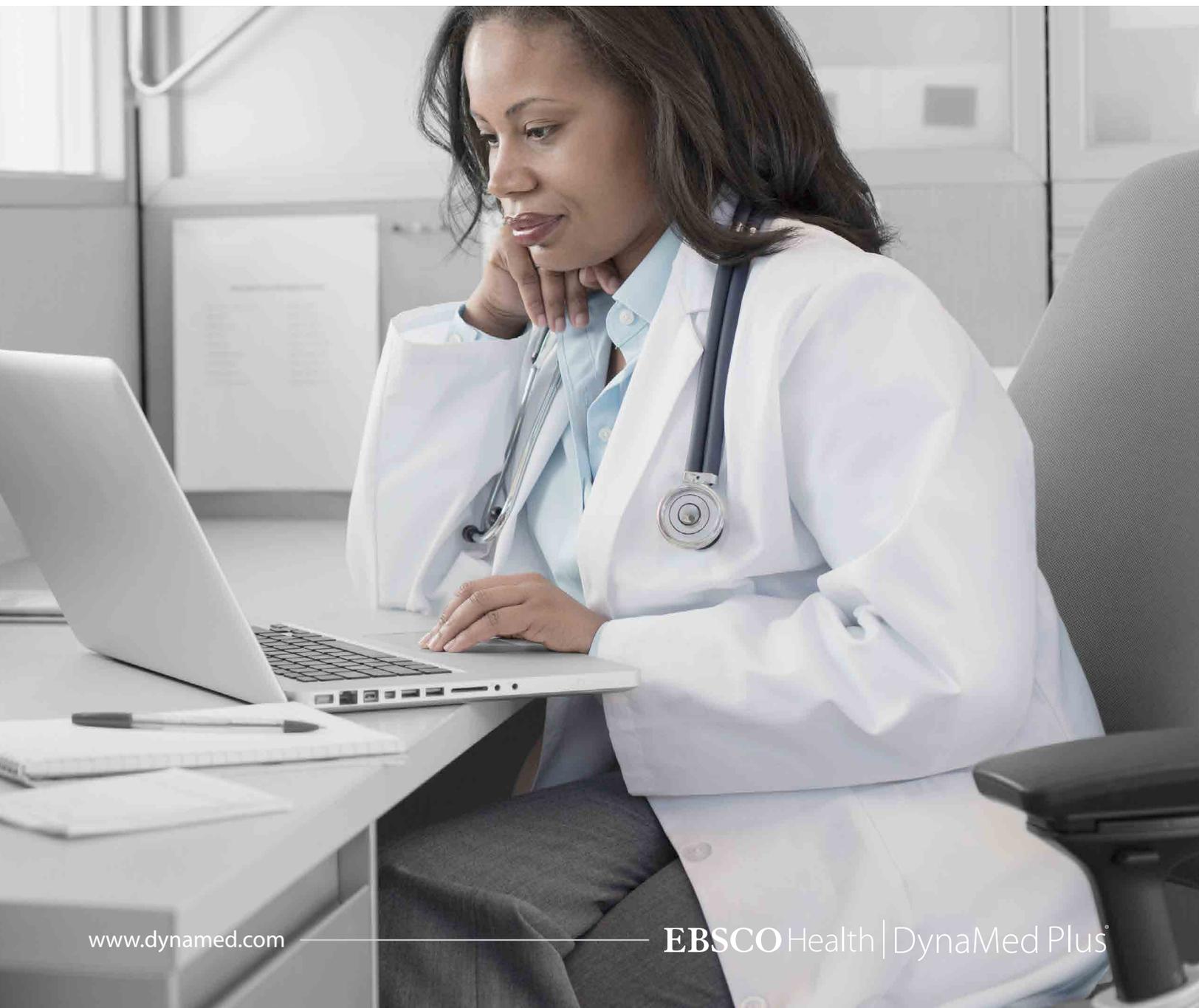


TRANSPARENCY IN HEALTHCARE

Achieving clarity in healthcare through transparent reporting of clinical data



THE KNOWLEDGE NETWORK: The Haven for the Select Few

In the past, physicians were the keepers of secret knowledge they gained through extensive training. Years of medical school and residency combined with real-world clinical experience resulted in unquestioned authority. Physicians shared knowledge with a select few, namely younger physicians early in their careers and trusted colleagues. There was a firmly-held belief among healthcare consumers, clinical leaders, and practicing physicians that a lifetime of training invariably led to expertise.



To bridge the secret knowledge divide, physicians need a thorough understanding of clinical evidence and the facts about the risks and harms associated with treatment alternatives.

In the last 20 years, there has been substantial research that suggests a major flaw in this approach. Physicians who rely solely on personal experience or the collective wisdom of peers can often duplicate flawed approaches. To bridge the secret knowledge divide, physicians need a thorough understanding of clinical evidence and the facts about the risks and harms associated with treatment alternatives.

LET THE LIGHT IN: Providing Transparency

Transparency is defined as “lack of hidden agendas and conditions, accompanied by the availability of full information required for collaboration, cooperation, and collective decision making.” Basically, transparency lets the light in. There has been a loud and clear call for greater transparency in medicine, requiring an openness and willingness to share information upon which clinical decisions are based.

Transparency is critical across the healthcare spectrum. It touches everything from how physicians practice medicine, to how information is shared with patients, to how hospitals gather and report outcomes. Transparency provides clarity to physicians, promotes trust among patients and leads to long-term improvements in outcomes.

Evolution of Evidence-Based Medicine

Much of what we believed to be true 20 or 30 years ago has been shown to be incorrect or in need of modification as new clinical research studies provided deep insights and new evidence. Although the foundation for clinical practice is based on clinical training and experience, clinical practice guidelines and a continual review of newly published articles in the medical literature form the basis upon which many physicians modify or improve their clinical practice. Physicians rely on the recommendations made by clinical practice guidelines, with the assumption that they are based on the best evidence that is available for the effective diagnosis and management of a specific condition. The goal of clinical practice guidelines is to reduce unwarranted variation in care, thereby leading to consistent, efficient, and high-quality care.

At times, national or international clinical practice guidelines supported by professional organizations have issued conflicting recommendations for clinical care; this may be due to inconsistencies in the guideline development process. These inconsistencies can include the methods whereby relevant evidence is identified, appraised for quality and relevance, and interpreted. Differences may also occur in the translation of the evidence into practical recommendations for the target audience. A long-standing challenge for clinicians seeking high-quality evidence-based clinical practice guidelines is unwanted inconsistency in the quality and rigor of evidence supporting the recommendations.

Developing a clinical practice guideline is a vast and time-consuming undertaking, often relying on experts in the field to volunteer their time as part of the guideline panel. The constitution of a guideline panel may influence the strength and focus of a recommendation, where potential financial or intellectual conflicts of interest may exist and influence the guideline development process.



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Making Science Transparent

In 2011, the Institute of Medicine, now called the National Academy of Medicine, developed standards for creating trustworthy clinical practice guidelines in response to concerns about understanding and implementing practice recommendations (Graham R, 2011). The goal of the Institute of Medicine standards was to develop criteria for unbiased, scientifically valid, and trustworthy evidence summaries and clinical practice guidelines. The Institute of Medicine developed eight standards for creating scientifically valid and trustworthy clinical practice guidelines that included: 1) establishing transparency; 2) managing conflict of interests; 3) following guideline development group composition guidelines; 4) using high-quality systematic reviews; 5) establishing evidence foundations for and rating strength of recommendations; 6) clearly articulating recommendations; 7) using external review; and 8) periodic updating.



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A variety of tools and methodological approaches have been developed to promote consistency in the quality and approach to clinical practice guideline development. The Appraisal of Guidelines Research and Evaluation (AGREE II) tool can be used to assess the quality of existing guidelines (Brouwers M, 2010). The ADAPTE collaboration provides a structured approach of adapting or

adopting pre-existing clinical practice guidelines as an alternative of creating new clinical practice guidelines. (Adapte.org, 2012). The Assessment of Multiple Systematic Reviews (AMSTAR) tool is used to evaluate the methodological quality of systematic reviews (Shea BJ, 2007). Grading of Recommendations Assessment, Development, and Evaluation (GRADE) is a methodological approach for making recommendations that includes a stepwise approach of evaluating the quality of evidence and implementing an evidence-to-decision framework that can be used to develop and grade the strength of recommendations (Brozek JL, 2009). The GRADE working group was initially formed in 2000 to attempt to address the shortcomings of previous grading systems, and GRADE has subsequently become the standard for CPG development (GRADE: <http://www.gradeworkinggroup.org/>; accessed June 12, 2017).

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TRANSPARENCY IN ACTION: The GRADE Approach to Making Recommendations

Clinical practice guidelines make recommendations based on the balance between the desirable and undesirable consequences of a particular diagnostic or therapeutic intervention. A recommendation to perform or implement an intervention implies a greater net benefit compared to not performing or implementing the intervention; a recommendation against an intervention indicates a greater net harm. The strength of each recommendation is determined by the level of confidence that the desirable effects outweigh the undesirable effects.

Using a systematic approach such as GRADE can minimize bias and inconsistencies in determining net benefit/harm and level of confidence, and aid in the interpretation of the evidence used to support a recommendation. The GRADE approach has several advantages over other recommendation grading systems, some of which include: 1) a clear separation between evidence and strength of the recommendation; 2) clear criteria for downgrading or upgrading the quality of evidence; 3) explicit evaluation of the relative importance of various outcomes; 4) acknowledgement of patients' values and preferences; 5) a transparent way of moving from the evaluation of evidence to making a recommendation; 6) clear recommendation even when there is very little available evidence; and 7) clear interpretation of "strong" and "weak" recommendations (Brozek JL, 2009).



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The Currency Challenge

It can be challenging for physicians to remain current as new clinical studies are published and the recommendations of clinical practice guidelines are updated. In addition to reviewing peer-reviewed journals relevant to their specialty, clinicians often rely on point-of-care tools or online medical textbooks, newsletters, or alerts that summarize the most recent advances in their field. All sources of information feeding the fountain of knowledge are best when they evaluate the quality of new clinical studies, determine if they are practice-changing, and anticipate the likelihood of changes in recommendations by clinical practice guidelines. A significant concern about online textbooks and newsletters that summarize recent advances in medicine is that there may not always be a clear separation between the evidence and the opinion or personal experience of the author, who is often a specialist in the field. Providing transparency in point-of-care tools, online textbooks and newsletters allows the reader to more easily discern the results of new clinical studies from an interpretation by one or more authors.

Although providing expert opinion about the meaning of clinical studies is useful, it may be subject to biases from personal experience or potential financial or intellectual conflicts of interest. Ideally, any point-of-care tool would strive to adhere to the same standards set by the Institute of Medicine for clinical practice guideline development.

Do Patients Really Want the Detail?

It could be argued that no member of the healthcare community wants transparency more than patients. Of course, some patients are reluctant to question the advice provided by physicians, no matter what information is available. But there is a movement underway by healthcare consumers to become part of the decision-making process. To do that, patients need complete transparency. This is especially important when complex decisions are involved. For example when a patient with atrial fibrillation is evaluated for treatment to prevent a stroke, the patient risk of stroke and bleeding must be taken into account while comparing up to eight treatment options.

One of the major barriers to transparency is access. Patients need access to their healthcare providers and they need access to information. The amount of time allotted for a specific patient-provider interaction is limited. Short appointment windows and busy schedules are not conducive to complex or in-depth discussions about a test result or treatment plan for either the provider or the patient. Patient access to information, either from their own medical record or for educational purposes, is also a limitation to greater transparency. Overcoming these barriers require open access to patient-specific medical information, additional time spent with other healthcare personnel such as nurses, nurse practitioners, and physician assistants as well as access to patient-specific information including patient handouts and decision-aids.



One of the major barriers to transparency is access – access to time from healthcare providers and access to information.

There is a growing trend toward providing patients with full access to their medical records including test results and provider notes through patient portals. Although some physicians remain reluctant to adopt these systems, the success of patient portals has been documented at a number of very large health systems in the United States, and financial incentives to institute them are supported through the continuation of Meaningful Use programs (CMS, 2013).

Patients seek out information about their medical conditions through multiple sources and have an interest in seeing their test results, provider notes, and hospitalization records. This allows patients to become more informed about their medical condition and, when they do see their own healthcare provider, to ask more focused questions.

Most patient portals restrict the information to selected components. In a 2010 study, in which patients were made aware that progress notes related to their care were available online, 90% read their notes (Delbanco T, 2012). The majority of doctors have not reported any negative impact from sharing the notes with patients and the practice has led to high patient satisfaction in a study from the U.S. Veterans Administration hospitals (Woods SS, 2013). Patient involvement can also provide important feedback on how healthcare providers and healthcare systems can make improvements in documentation and presentation of this information.

Given that patient appointments average about 12 minutes, it's impossible to share the full range of information available. To overcome this limitation, one approach is to connect patients with nurses, physician assistants, and nurse practitioners to promote education and in-depth discussions about care. These discussions can lead to a much better understanding of the conditions for which patients are being treated, the different treatment options and their associated risks and benefits, and the potential complications that may be avoided through better control of their condition. A well-informed patient is more likely to ask focused questions that might make a short visit with a physician more productive.



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For complex patient care decisions, where multiple treatment options exist, each with their own associated risks and benefits, shared decision-making tools are especially valuable. These tools can allow a patient to comprehensively review the pros and cons of competing treatment options, taking into account his or her individual values and preferences. Access to this information before or even during a visit with a healthcare provider can greatly reduce the anxiety associated with making a complex health-related decision. Patients who are fully informed are more likely to trust their physician and have confidence in the decisions they make regarding the possible treatment option, independent of the subsequent outcomes.

Healthcare Systems Embracing Transparency

Transparency in healthcare systems leads to better patient experiences and improvements in the care delivered. Greater transparency on the performance of providers in terms of outcomes and patient satisfaction would go a long way. How are reviews of healthcare providers by individual patients reported? How do the outcomes differ among different providers who perform the same procedures? Most patients would like to know the answers to these questions and would prefer to make an informed decision when choosing a provider. However, there is limited data available comparing physicians for a given specialty.

Transparency can also be improved at the hospital level. How is safety of a hospital measured and reported? What are the overall complication rates of common procedures for a given hospital, and how do their results compare with other healthcare institutions? Open reporting of a variety of common measures such as outcomes after surgical procedures, infections rates, and lengths of stay for different types of hospitalization can provide patients with transparent ways of evaluating where to get their care. These measures can also provide institutions with ways of identifying important differences that may ultimately lead to improvements in care if the reasons can be identified and where correctable measures can be instituted.

Conclusion

Transparency in medicine promotes better quality and consistency of care at multiple levels in the healthcare system. It can also greatly improve the trust and overall relationships patients have with providers and ultimately promote better outcomes and satisfaction.

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