

Evidence-Based, but Just How Accessible is it?

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How many times have you or someone you know ‘Googled’ your illness symptoms and attempted to self-diagnose based on information from resources such as Wikipedia and ‘whatsmydiagnosis.com’? In the midst of the information overload, have you ever been able to find robust, up-to-date, and comprehensible scientific evidence about the recent immunization controversy? Have you wanted to know more about the latest cancer research initiatives and discoveries, and how they are being funded? Medical research has made tremendous strides in the last few decades but we now question if enough is being done to effectively disseminate this knowledge to the users - the patients and the public.

Evidence-based medicine (EBM) has come a long way since the movement led by the late David Sackett in 1981.¹ His idea of EBM was centred on three core principles: the patient’s wishes, the physician’s clinical skills, and the best evidence available to physicians. He believed that these three ideas are paramount in patient care. It was this strong belief in the core components of EBM that changed the face of medicine to the way it is today.² Following the debut of EBM, a hierarchical framework of evidence was developed. This framework ensured adequate knowledge translation from the original research in the lab, to the synthesis of data via systematic reviews, to then establishing new standards of care, and to the implementation of new knowledge into everyday practice.³

Evidently, we can be proud of the scientific rigor and pragmatism that goes into shaping health policy and establishing quality of care standards. However, even with the many strides we have made to expand our body of evidence-based medical knowledge in healthcare, we have to ask ourselves the question ‘Are we doing enough to disseminate this knowledge to the general population?’ Or are we so distant in our ivory towers among fellow scientists that we have lost touch with the public? We maintain that the scientific community is not providing adequate guidance to the public searching for medical evidence, especially where disputes have reached the media. It is this disconnect between academics and the public that is leaving citizens without access to updated medical knowledge, and potentially leading them to seek biased or outdated sources of scientific information, such as online chat forums, television commercials, word of mouth, and, of course, Dr. Oz. As we recognize various financial and logistical barriers to effective dissemination of knowledge, we propose increased efforts to facilitate accessible information through various media outlets and a greater focus on patient engagement.

First, it is important to note the current state of inaccessibility that plagues our health research information system. Dr. Ian Graham *et al.* from the University of Ottawa conducted a study on Canadian health services and the degree of knowl-

edge translation from population health researchers to health practitioners, policy makers, and the public.⁴ In terms of dissemination strategies, the majority of researchers created a summary to policy makers (25%), while only 16% created summaries for patients. Moreover, educational sessions with practitioners was the most common implementation method (43%) for researchers, while only 23% used the media, 15% used educational sessions with patients, 15% involved consumers in knowledge translation, and 9% used knowledge brokers. When asked to compare the percentage of those who need to be aware of their findings with those who are aware of their findings, it was found that while there was only a 14% gap for researchers and academics, there was a 23% gap for the media and a striking 35% gap for the public.⁴ Thus, there is an undeniable imbalance: researchers seem to be engaging with the scientific community and policy makers, but there is insufficient sharing of research findings with the end-users of this information - the patients.

While the public could be left with unanswered health-related concerns, they could also come across unreliable information. A recent survey in the United States found that although citizens and scientists equally valued the contributions of science, there was a significant discrepancy between the public and the researchers on the perception of key scientific issues. These issues included evolution, genetically modified foods, climate change, and immunizations.⁵ It is clear that academics are overlooking the gap that still exists between scientists and the public in terms of communicating research findings and presenting information in an accessible, easy-to-understand form.

The question inevitably arises as to why it is so important to communicate research findings to the public. Graham *et al.* found that 80% of health researchers deemed their findings as quite/very important in creating new knowledge, and 46% said their findings had the potential to improve the health of Canadians. In addition, 49% of the researchers said their findings are important for the Canadian public to know. Therefore, the substantial amount of time and resources invested in health research will be going to waste if the findings are not effectively reaching the appropriate audiences.⁴ Moreover, the public is one of the largest stakeholders for government-funded research grants, as these grants are supported through the taxes they pay. In that sense, we are obliged, as researchers and scientists, to provide our investors with returns through more adequate dissemination of the new knowledge in layman’s terms.

Although it is the tax-paying public that is financially supporting the research, they are widely unaware of how the money is being used. In the last five years, the Canadian fed-

eral government has dismissed more than 2,000 scientists as a result of cutbacks to various research programs.⁶ Furthermore, specifically within healthcare research, the 30-year-old MD/PhD program, which produces a special breed of scientists who can transition easily from the lab bench to the hospital, has had major cuts in funding. This came as a shock following a CIHR report by Dr. Norman Rosenbaum indicating the need for a major increase in the number of health clinician scientists.⁷ Evidently, in times of financial hardship, the government has to make cuts in the budget, and this can be directed by public opinion, or in this case, the lack thereof.⁸ With the lack of accessibility to up-to-date information on current research projects and new discoveries that are funded by the taxpayer, will the public be so concerned if a few thousand scientists lose their jobs or if some research projects are abandoned due to insufficient funding?

Given the fluctuations of government-funded research grants, it would be wise to try to sway the public in our favour by keeping them more informed on the progress and findings of our research. Bridging the gap between researchers and taxpayers regarding transparency in research funding will not only benefit the general public with accessible EBM, but it may also encourage a new mode of research funding – crowdsourcing.

Crowdsourcing is the process of soliciting contributions from a large group of people to obtain needed services, ideas, or involvement.⁹ This potential new movement of health and research initiatives being facilitated via social networking would be a constructive step towards involving the general public in health-related research. In fact, there have already been several cases of crowdsourcing cohorts of patients through health social networks for conducting studies.¹⁰ Who is to say that crowdfunding will not begin to play a prominent role in financing new research proposals?

Before attempting to get the public's financial support, there is a need for more accessible and reliable medical information for the public. One option could be to provide open source articles and journals to engage the general public. However, the caveat is that these are often dense texts filled with scientific jargon that may make it difficult for the everyday reader to interpret. The other challenge is deciding just how much modern medical research needs to be shared in a digestible format with the public. Gaging the quality and quantity of research that is necessary to provide to the public has perhaps been preventing the creation of such open resources and the field of stem cell therapeutics research provides a good example. Therapies are typically tested in cell cultures, followed by animal models, and then in clinical trials for humans (if possible), before the therapy is approved for safety and effectiveness. If data from all these levels of testing are made transparent and available to the public, not only would this be an excessive amount of information, it is perhaps going beyond what is necessary to share. In an ideal situation, we would follow the same approach we have taken with health policy makers when disseminating information to the general public: following reproducible results in clinical trials affirmed by systematic reviews, the best summary knowledge

that is synthesized on a particular topic may be translated and disseminated to the public, as well as policy makers.

By doing so, the average individual would have access to a resource that provides lay summaries of the best available and most relevant evidence on a given topic. A database of this nature can provide the best focus on EBM in a language that is targeted for the general public. The McMaster Health Forum¹¹ has demonstrated the best possible representation of this idea through Health Systems Evidence (HSE).¹² HSE is a continuously updated, open access database providing evidence on how to strengthen health systems or make them more cost-effective. This repository provides an easy access point for health systems policy makers and stakeholders to rapidly identify research related to their work.¹² We propose implementing the concept of this database in the context of providing the general public with summaries, in layman's terms, of the best EBM research data available.

Moreover, social media is becoming a more prominent player in the dissemination of clinical practice guidelines.¹³ Its popularity, large platform, and wide audience may serve well in educating and informing the general public through outlets like Facebook and Twitter. The challenge would be ensuring that the public knows which social media accounts are relaying credible, reliable medical information, and which are simply individuals claiming to be "MD-verified". A potential solution to this barrier of online reliability could be to create one well-advertised, well-known, social media platform that would serve as a trustworthy source of medical information. A variety of resources could be created for the benefit of patients, all written by medical professionals.

Though utilization of the media to better communicate with the public is a key aspect of keeping them informed, a shift towards greater patient engagement in health research can also change our practice for the better. The James Lind Alliance in the United Kingdom and the Patient Centered Outcomes Research Institute in the United States have highlighted the need for the public and health researchers to work as partners in designing clinical trials to ultimately provide better patient care.¹⁴ This sort of partnership may provide synchrony between the answers that patients are looking for and the questions that health researchers are asking. Furthermore, the Choosing Wisely initiative in the United States is bringing patients and doctors together to identify and reduce the use of unwarranted and ineffective interventions.¹⁵ These movements targeted towards patient engagement in the research process are a logical next step in making EBM more accessible to the general public.

Ultimately, health research is conducted, refined, and published all for the benefit of the population at large. However, how useful are findings and guidelines that are not accessible? Keeping the public adequately informed about research endeavours and findings will not only benefit the population's health, but could also provide more support to the researchers. With the advancements thus far in EBM, it is imperative that we continue progressing towards understandable and accessible medical research for people of all backgrounds. Where there's a will to be informed, there should be a way to find the right answers.

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