Opinion Paper

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Communicating laboratory results to patients and families

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Abstract: People are increasingly able to access their laboratory results via patient portals. The potential benefits provided by such access, such as reductions in patient burden and improvements in patient satisfaction, disease management, and medical decision making, also come with potentially valid concerns about such results causing confusion or anxiety among patients. However, it is possible to clearly convey the meaning of results and, when needed, indicate required action by designing systems to present laboratory results adapted to the people who will use them. Systems should support people in converting the potentially meaningless data of results into meaningful information and actionable knowledge. We offer 10 recommendations toward this goal: (1) whenever possible, provide a clear takeaway message for each result. (2) Signal whether differences are meaningful or not. (3) When feasible, provide thresholds for concern and action. (4) Individualize the frame of reference by allowing custom reference ranges. (5) Ensure the system is accessible. (6) Provide conversion tools along with results. (7) Design in collaboration with users. (8) Design for both new and experienced users. (9) Make it easy for people use the

data as they wish. (10) Collaborate with experts from relevant fields. Using these 10 methods and strategies renders access to laboratory results into meaningful and actionable communication. In this way, laboratories and medical systems can support patients and families in understanding and using their laboratory results to manage their health.

Keywords: clinical laboratory information systems; computer graphics; decision making; education of patients; electronic health record; humans; patient access to records; user-computer interface.

Introduction

Nearly 50 years ago, an article published in the *British Medical Journal*, now known as the *BMJ*, sounded the alarm about the introduction of a new home pregnancy test. Women could not fully understand the results of such tests or act on them in meaningful ways, the article argued. They needed a health professional to explain the results and help them plan follow-up actions. Therefore, women should only use these tests and access test results through a doctor's surgery [1].

Such views seem anachronistic now. People clearly want – and should be empowered to have – access to their own laboratory results [2, 3] if, for no other reason, to get the good or bad news sooner rather than later and avoid the stress of waiting [4]. Yet, as health systems move towards providing each person with full access to their own health-related data via patient portals to electronic health records, modern versions of such views are echoed in concerns that patients cannot understand their own laboratory test results [5].

It is true that interpreting laboratory results, often presented as numbers in tables, can be challenging for people. Some people have lower health literacy, numeracy, or graphical literacy, meaning less ability or confidence to understand, evaluate, and use health information [6], numbers [7, 8], and graphs [9], respectively. Past research demonstrated that people with lower numeracy struggle to interpret basic laboratory test results tables [10].

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However, the core issue is not that certain people struggle to interpret laboratory test results but that many current ways of presenting results inhibit comprehension [11]. As famously articulated by Bret Victor, one of the first user interface designers for the iPad, “Back in the days of Roman numerals, basic multiplication was considered this incredibly technical concept that only official mathematicians could handle. But then once Arabic numerals came around, you could actually do arithmetic on paper, and we found that 7-year-olds can understand multiplication. It’s not that multiplication itself was difficult. It was just that the representation of numbers – the interface – was wrong [12].”

We propose that the key challenge when communicating laboratory results to patients and families via patient portals is optimizing the design of the interface, meaning the way results are offered or presented.

Our central premise is this: When presenting laboratory results, it is critical to recognize that the numbers, values, terms, and units do not necessarily have meaning for the person receiving them and to design systems accordingly. Laboratory results are data. Data are distinct from information and knowledge [13–15]. Data are symbols, information is symbols with meaning, and knowledge is information placed in the context of other, existing knowledge such that it becomes actionable [16]. Providing data alone is inappropriate if people lack a base of prior knowledge built through experience. The system must help the person using it to convert data into information, and information into knowledge.

It is therefore imperative to ensure not only that people can obtain their results but also that they can easily understand and use them. To that end, in this paper, we outline ten recommendations to help ensure that, as patient portals and electronic health records finally become the norm, laboratory test results are communicated in ways that support understanding and informed health decisions for everyone who accesses them.

Ten recommendations for presenting laboratory results to patients and families via portals

Whenever possible, provide a clear takeaway message for each result

Patients who are viewing their laboratory results may not actually care about the number itself. Instead, they

often have a primary underlying question: “Is this good or bad?” or, more personally, “Am I OK?” or “Do I need to do anything?” [17, 18] Whenever possible, providing clear, plain language indications of why the test was done [17] and whether or not a result is worrisome can help answer this question. Although takeaway messages can be stated in text form, carefully designed graphics may help convey a clear takeaway message [19]. Explaining what actions, if any, might be indicated may also help [11]. In more complex situations, such as when extracting meaning from results requires combining different results together, determining a takeaway message may require expert interpretation or more complex algorithms. Although focusing on a single takeaway message may prove challenging, devoting the effort to achieve such clarity is essential to improving usefulness.

Signal whether differences are meaningful or not

It may not be obvious to people whether differences between values are meaningful. This applies to differences between a result and the reference range and also to differences between a new result and a previous result. For example, a 1 percentage point change in hemoglobin A_{1c} (HbA_{1c}) expressed in g/g means something quite different than a 1 percentage point change in hematocrit. Providing the range of commonly observed values, informed by thorough, standardized reports of biological variation [20], can help to identify how meaningful each unit of variation is, especially when the distribution in a patient population may be highly skewed. A number line graphic, for example, implicitly defines the range of potential values through the length of the line (in test result units). Similarly, a line graph showing results over time implies the relevant range of variation through its scaling of the y-axis. Moreover, stating directly what level of variation is considered clinically significant may be particularly helpful.

When feasible, provide thresholds for concern and action

There is a difference between knowing that one’s alanine aminotransferase value is elevated and knowing that the value is beyond a threshold that is clinically worrisome. Providing an explicit signal such as, “Many doctors are not concerned until here,” can reassure people whose results do not exceed that threshold and spur action among people whose results are worrisome [21]. Such

action thresholds are commonly used in communications of environmental contaminants such as lead or radon, and they offer similar value in this context. Although establishing such thresholds may raise medicolegal concerns, this could be accomplished in a similar way to establishing clinical guidelines. Failing to provide such thresholds simply means that people will decide what to do based on less information and may seek advice from less reliable sources. It also creates disparities between those recipients with access to additional knowledge and expertise and those who lack such access.

Individualize the frame of reference by allowing custom reference ranges

It is always preferable to provide a frame of reference to aid in interpretation. A typical frame of reference for laboratory results is a standard range, or the range of values observed among a large proportion of healthy people. However, standard ranges are not particularly applicable to individual patients in certain situations, for example, those with a known acute or chronic health condition. In such contexts, it is useful to personalize the frame of reference to specify what might be standard or desired for them. We note, however, that comprehension increases when the focal frame of reference is tailored versus simply adding a second frame of reference because of the potential for confusion [22]. Given that the frame of reference may depend on other factors that may or may not be known (for example, age) within current systems, this may be most appropriately done by a member of the patient's health care team.

Ensure the system is accessible

All people must be able to use information systems, including disabled people. This may be especially important for health-related systems because frequent users of such systems may be more likely to have disabilities and thus face potential barriers to access. The four core principles of accessibility stipulate that content in a system must be presented in such a way that all users can perceive, interact with, and understand it, and it must be widely interpretable, including by assistive technologies such as screen readers for people who are blind or vision impaired [23]. Adhering to guidelines for accessibility (for example, Web Content Accessibility Guidelines [23]) can help to ensure that laboratory results systems meet these requirements.

In addition to reducing barriers for people with recognized disabilities, laboratory results can be made more accessible for people with lower health literacy by explaining concepts in plain language [24] and for people with lower numeracy and graph literacy by presenting numbers and graphs using best practices for presenting quantitative data to patients [25].

We note here that accessibility is sometimes conceptualized as access to the Internet. This paper is about designing interfaces for presentation of test results. Addressing the barrier of the digital divide and computer literacy is therefore outside of scope. However, we highlight that this is a critical issue that must be solved to avoid exacerbating health disparities because the people who are more likely to have difficulty accessing or using an online system are also more likely to experience more social disparities and have worse health [26, 27].

Provide conversion tools along with results

Displays of test results should offer the option of converting values to other units. Such a conversion tool offers two primary benefits for users. First, some people may wish to use their results as input into other tools to extend their understanding of what their laboratory results mean for their health. This may require converting results from one unit to another. For example, a patient who has received her HDL cholesterol results in milligrams per deciliter may wish to use one of many online risk calculators providing individualized cardiovascular risk estimates [28], but the risk calculator may require input of one's HDL in millimolar. Second, unit conversion tools would support patient-centered care for people moving internationally. People with a chronic illness who are used to reviewing their laboratory results and who move between countries may receive laboratory results using different measurement systems than those with which they are familiar.

Design in collaboration with users

It is critical to adapt systems to people rather than expecting people to adapt to systems. To achieve this, systems must be designed with the involvement of the people who will use them. Despite the best intentions of the people developing the system, it is inefficient and clumsy to attempt to predict how people will use a system in the absence of data. Methods of user-centered design [29–35], on the other hand, allow designers to gather representative samples of potential users, observe the problems

they encounter when interacting with prototypes, and iteratively refine the design accordingly. When users are even more deeply involved in the design and development process such that they share responsibility for design decisions, this may be considered codesign.

Design for both new and experienced users

Laboratory results may be familiar to some people and wholly new to others. For example, a HbA_{1c} result is a familiar and understandable number for people who have lived with type 1 or type 2 diabetes for years, but it may be a new concept for someone who has only recently been diagnosed with diabetes. People have limits on the amount of data and information they are able to absorb at one time [36] and may therefore benefit from methods of presenting data and information one element at a time [37].

For those who are new to a result, it may be helpful to step them through the process of understanding their result for the first time. However, for people who are familiar with a given laboratory test and who understand the meaning of its results, the support provided to newer users is unnecessary and may be annoying and inappropriate.

These conflicting needs can be reconciled by offering an onboarding process for new users, layering information such that people who wish to have more information can access it, and building flexible systems that allow the user to customize their settings. For example, data relevant to the accuracy and precision of a given test could be layered such that people who wish to learn about such metrics could click to see them. People could specify in the settings of their account whether they wish to see details about uncertainty all the time or not.

Make it easy for people use the data as they wish

People should be supported in using their own data as they wish. Beware of being overly cautious when specifying how people may access and use their results. When data are made available, users will come up with ways of using them that were not originally anticipated [38, 39]. Such user innovation should be supported, not feared.

Although a patient portal may include carefully designed and tested displays for presenting laboratory results, people may prefer to view their results differently, combine them with other data, or simply log the data outside the portal [40]. To support user goals such as

these, systems should provide easy ways to download data in standard file formats such as comma-separated values (.csv), tab-separated values (.tsv), and plain text (.txt).

Collaborate with experts from relevant fields

The technical development of a portal for communicating laboratory results is only part of the challenge of making laboratory results available to patients and families. Experts in health communication, psychology, design of patient materials, and a range of related fields such as human factors, human-computer interaction, user interface design, user experience design, information design, and graphic design all have valuable expertise. Such experts bring perspectives, principles, and methods that can be combined with the expertise of users and those in laboratory medicine to create optimal designs. For example, Gestalt principles of perception for visual displays [41] and methods of optimizing user experience, such as user-centered design described above, can help create systems that are medically accurate for, usable by, and useful to patients and families.

Conclusions

Patients and families deserve to have full access to their health records, including laboratory results. However, full access, by itself, is insufficient to achieve the full benefits of such data and information. By using best practices to present laboratory results in ways that help people understand and use them, we can support people in making informed health decisions and managing their health.

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