

Can patients use test results effectively if they have direct access?

Maurice O’Kane and **Danielle Freedman** say that patients welcome direct access to test results and that they improve clinic visits, but **Brian J Zikmund-Fisher** worries that the data are currently presented in ways that make them meaningless to most patients



TEK IMAGE / SPL

A PATIENT'S VIEW

In the real world, test results are not just delivered by supportive clinicians, with occasional lapses from that norm; direct access aside, the standard delivery of test results is much more varied than that. I have had results given to me by a general practice receptionist as part of the surgery's normal practice; this included the receptionist's interpretation of what the numbers meant. I have tried to get the results of blood test monitoring and been told by a nurse that these are not given out until the next appointment, with standard waiting time 12 months, by which time the information offered by the test would no longer be useful for self management.

Some clinics send test results by post. I have had devastating diagnostic test results sent in a letter, with context and interpretation so alarmist it made me nearly vomit with fear. One clinic, after doing tests, sends me an appointment card for my next screening. No useful information is offered about what the last set of tests found, but I have come to realise that if my next appointment is in a year's time rather than scheduled more urgently, the results were probably okay.

Rosamund Snow patient editor, *The BMJ*
rsnow@bmj.com

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YES Patients increasingly have direct access to medical records and test results. This increased patient engagement may contribute to better decision making and care. Evidence indicates that patients value access to test results, particularly those with chronic disease. Having direct access may improve the doctor-patient relationship and increase satisfaction with care. Traditionally, patients access test results through the requesting clinician, who provides an interpretation and puts the results in the context of the patient's overall health condition. This model presents problems, however, in particular delays in communicating results to patients. Evidence from several studies has highlighted failure to inform patients of abnormal results in a substantial proportion of cases and also clinicians overlooking results that should have been acted on.^{1 2}

In February 2014 the US Department of Health and Human Services, partly in response to concerns that patients were not receiving test results (and some high profile cases in which cancer diagnosis reports were overlooked by the clinical team), mandated patients' direct access to reports of their laboratory tests. NHS England has also stated that patients should have direct access to medical records held by general practitioners, including test results.

Patients welcome access to test results and think that it provides better preparation for clinic visits and more efficient consultations.^{1 3 4} Although access to results occurs within the wider context of empowering patients through direct access to medical records, concern has been raised that an unwelcome result or misinterpretation of the findings could cause patients anxiety. This in turn might increase clinicians' workload by raising demand for consultations to discuss the findings.

NO Although providing patients with direct access to laboratory test results could provide important benefits, such as better self management of disease and engagement with medical decision making, most patients cannot yet effectively use these data. Effective use requires patients to translate raw test results into actionable knowledge. Unfortunately, there are individual level and system level barriers to this process that at present make these data literally meaningless to most patients.

To start, international surveys show that patients vary widely in their numeracy—that is, their ability to understand and derive meaning from health related numerical data.⁹⁻¹¹ Less numerate patients are (by their own preference) less likely to seek out health numbers, less able to translate from one numerical format to another, and less able to manage number rich tasks such as calculating drug doses.¹² Less numerate patients start their interactions with test

Simply providing test values and standard ranges is not enough. We must increase the usability of the results

results at a disadvantage,¹³ much as though they were trying to follow a complex play presented in an unfamiliar language.

Furthermore, most test results are currently presented to patients in essentially the same tabular form as provided to clinicians. Patients receive test values, a standard or reference range, and that's about it. Some displays mark high or low values, but others omit interpretive markers from the patient facing displays.

Patients need more than numbers

Recently, several colleagues and I conducted a large experimental vignette study to examine people's ability to identify which results were outside the reference range when provided with information in the standard tabular format.¹⁴ This task is the precursor to all other,

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Little evidence supports these concerns, however. In a US survey of all members of a Kaiser Permanente healthcare plan who had accessed test results directly in the previous year, the majority of the 1546 respondents expressed positive emotions such as “satisfied” or “appreciative,” with less than 7% reporting negative emotions such as “worry” and “confusion.”

Online support

Typically, patients discussed results with family and friends or sought further information from a healthcare website rather than contacting their clinician: only one in 20 patients sought an appointment with their doctor to discuss the meaning of the results.⁴ A key finding was the extent to which previous conversations with the doctor about what to

expect from the test results altered patients’ responses and actions. Patients who had been prepared by their doctor were more satisfied and less likely to seek advice from family and friends or the internet.⁴

LabTests Online UK (www.labtestsonline.org.uk) is an example of an internet based, patient centred resource. It is a peer reviewed non-commercial website created by practising laboratory clinicians and scientists that provides readily accessible information on many tests, with information grouped by test and disease. The website receives about 150 000 hits a month. A 2014 web based survey of its users found that almost 90% of 659 respondents would like to be able to access their test results at the same time as their clinician sees them, although this facility was available to only 20% of respondents (unpublished data).

Direct access to test results may have particular value in chronic conditions. The NHS website Patient View (www.patientview.org) allows patients with chronic

kidney disease to access their results and to receive information and advice on their condition. Over 17 000 patients are registered from over 50 units, and the portal is accessed more than 1000 times a week. Users report satisfaction, greater engagement with their care, and more preparedness for hospital visits. Furthermore, good evidence indicates that for some chronic conditions, such as type 2 diabetes, and in warfarin treatment, suitably prepared patients can use test results to improve management and outcomes.^{5 6}

Shift in doctor-patient relationship

Direct access to test results will undoubtedly change the interaction between patients and clinicians.⁷ Doctors will need to provide more information to patients about what tests are being performed and why, what the result might mean, and how this might affect clinical management. Providing patients with direct access does not remove the primary responsibility of the clinician to act on abnormal results

but may provide an additional safety net whereby patients can raise concerns about abnormal results. Clinicians will need to ensure that there are mechanisms in place to allow discussion of test results by email, telephone, or face to face consultation, as appropriate. This is perhaps the most important element of patient direct access: it repositions the doctor-patient relationship and fosters greater interaction and engagement.⁷

As yet evidence is limited on how health outcomes are affected by direct patient access to medical records, let alone specific access to test results.⁸ The value of direct access is greater than simply viewing results: it is an opportunity for redrawing the doctor-patient relationship, and one which health professionals must embrace.

Maurice O’Kane consultant chemical pathologist, Altnagelvin Hospital, Western Health and Social Care Trust, Londonderry
Maurice.OKane@westerntrust.hscni.net
Danielle Freedman director of pathology, Luton and Dunstable University Hospital NHS Foundation Trust, Luton

more nuanced, uses of test data to guide self monitoring, calibrate risk perceptions, or inform decision making. Yet our study showed not only that overall accuracy was disturbingly low (only 51% could identify a raised haemoglobin A_{1c} value as out of range) but also that this ability was tightly correlated with numeracy and health literacy. Less numerate and less literate participants were less than half as likely to identify accurately the result as being out of range as highly numerate and literate participants.

Even when patients can identify results as out of range, they often cannot fully interpret their meaning. Although medical professionals have experience and training to draw on when trying to translate a test result into meaningful information, patients do not. Clinicians recognise that a 1% change in haemoglobin A_{1c} is highly meaningful but that a 1% change in packed cell volume is less so. Without help, patients do not know

the difference. Clinicians know that a platelet count of $110 \times 10^9/L$, although below normal, does not signal a clinically important risk of short term bleeding. Without guidance, patients may reasonably assume it does. Clinicians mentally interpret test values in terms of categories of risk and thresholds for action that are unfamiliar to or even hidden from most patients. This contextual information provides a rich, colourful palette of meaning to clinicians, but most patients can see their results only in black and white terms—that is, as a good or a bad result.

The decision making literature refers to variations in meaningfulness as variations in “information evaluability.”^{15 16} Numbers presented in isolation, without context, are much harder to evaluate than the same data presented side by side with relevant reference standards. Multiple experimental studies find that hard to evaluate data are comparatively ignored in decision making.^{17 18}

People make decisions as if the information were not even there.

Meaningful information

Our society has invested much time, energy, and money to enable patients to have direct access to laboratory test results, but access and exposure are insufficient to create actionable patient knowledge. If we burden patients with the task of figuring out what test results mean and with the responsibility to act (or not act) based on that information, then we have the parallel responsibility to make these data as meaningful as possible.

We could improve patient interactions with test results in many ways—for example, visual displays (such as number line graphs) can use spacing, colours, labels, and other cues to clarify whether a change of one unit or 10 units should be seen as clinically important. More importantly, we could frame test results with multiple richly meaningful reference

points designed to help patients not just answer the basic question of “is my result abnormal?” but more practical questions like “does this mean I am at immediate risk?” and “has my value changed enough to make a difference?” Applying well established human factors design principles to this problem should open the door to meaningful use of test results by patients in the future.

Meanwhile, however, we must accept that most patients cannot use test results effectively, even if they have direct access, because simply providing test values and standard ranges is not enough. We must increase the usability of the results to reap the benefits of our investment. The potential is there for effective patient use. But data that are not understood will always remain data unused.

Brian J Zikmund-Fisher associate professor, Department of Health Behavior and Health Education, University of Michigan, Ann Arbor
bzikmund@umich.edu

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