

Communicating laboratory test results for rheumatoid factor: what do patients and physicians want?

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Objective: This study aimed to explore patient and physician perspectives on current laboratory test reporting practices and to elicit ideas for improvement.

Methods: Two independent studies were conducted. The first solicited members of an online physician community for opinions on current laboratory test reporting practices and possible improvements. The second addressed the same topic, but solicited patient feedback, and included an evaluation of a mock laboratory test report for the rheumatoid factor blood test.

Results: Both physicians and patients expressed a desire for patient-friendly information on laboratory reports. Physicians expressed a need for education for patients around false-positive and false-negative results within laboratory reports, while patients sought context around the meaning of results, relevance to other tests, and follow-up steps.

Conclusion: Physicians and patients see value in enhancing laboratory test reports to improve communication. While reports should include the context that patients value, they should also contain cautionary interpretation emphasized by physicians. Patient consultation on improving laboratory reports may help improve such patient-focused communication and promote greater patient understanding of health information, thereby increasing patient participation in their own health care and improving outcomes.

Practice implications: Laboratory reports are typically designed by experts. Including patients in laboratory report design may facilitate communication and improve outcomes through better patient engagement.

Keywords: laboratory test reports, doctor–patient communication, patient-centered, medical records, health records

Introduction

In recent years, direct patient access to laboratory test reports has increased significantly. An amendment passed in 2014 to the Patient Protection and Affordable Care Act of 2010 requires that patients must be allowed to access their laboratory test reports directly,¹ bypassing the ordering and treating physician. As a consequence, patients in the United States are now able to access much of the same information as their health care providers. Similar efforts are being made in Europe, such as are described under the Digital Agenda for Europe.² In a recent EU-commissioned study of the country-level policies on interoperability and sharing of electronic health records among health care providers and patients, it was found that each EU member state has policy or policies to provide patients with access to their electronic health records, with around half of EU countries granting patients full access to their health data, without exemptions and/or restrictions.³

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There is inconsistency in whether and how communications about laboratory test results take place. In the United States, between 6.8% and 62% of laboratory test reports are not followed up by physicians in ambulatory care settings, with potentially negative consequences for patients, including missed diagnoses.⁴ While most physicians are comfortable with direct reporting (ie, patients' receipt of laboratory reports without initial physician screening) of normal results to patients, many physicians are less comfortable with direct reporting of abnormal results and are concerned that providing patients with direct access to laboratory test reports introduces the risk of misinterpretation and may cause some patients undue worry and confusion, or cause them to seek unreliable health information.⁵⁻⁷

Patients want immediate access to their medical reports, whether results are normal or not, and find information written in lay language to be helpful.⁸⁻¹² Direct access to medical records enhances patient empowerment and involvement in medical care, which is associated with better outcomes,^{13,14} better adherence to treatment recommendations, and greater satisfaction with the health care system.^{15,16} Unfortunately, patients find laboratory test reports to be among the most difficult parts of their health record to understand, as these reports use professional medical terminology and may lack explanation of complex concepts such as reference ranges.¹⁷

In the United States, as in Europe, there is no regulatory requirement to provide reports in a patient-friendly format, nor are there standards for how to construct reports to enhance patient comprehension.¹⁸ Many efforts have been targeted at bringing health materials to a level that more closely matches patients' health literacy and numeracy based on observations of patient barriers to comprehension,¹⁹⁻²⁵ while others have focused on the design and display of medical records.²⁶ Patients value the content of reports (ie, interpretation of results, clinician advice, and purpose of testing) more than pictorial displays of results.²⁷ However, few studies have gathered direct patient insight on ways to make laboratory test reports clearer and more understandable.

The need for patient-centered laboratory reports may be most acute with tests that require clinical interpretation and patient education, eg, rheumatoid factor (RF). The RF blood test uses a diagnostic blood biomarker found to be elevated in patients with certain autoimmune and other diseases, especially rheumatoid arthritis.²⁸ Interpretation of this test necessitates consideration of multiple clinical factors in addition to requiring a high degree of physician-patient communication. An examination of patient and physician attitudes of the challenges of RF test reporting may illuminate

key considerations in communicating other laboratory test results.

To explore ways in which laboratory test results can be communicated in a patient-friendly manner, we conducted two independent surveys to explore physician and patient perspectives regarding: 1) the current content of RF blood test reports; 2) the adequacy of physician-patient communication about laboratory reports in general; 3) the adequacy of physician-patient communication about RF laboratory reports; and 4) potential areas for improvement in the presentation of laboratory test results to patients. We included perspectives from the United States and from physicians in three European countries (the United Kingdom, Germany, and Switzerland). The research sample was drawn from these four countries due to the similarity of each of the countries in health care policy and practice regarding patient access to health records and to the ease of availability of data from a sample of physicians within each country and a sample of patients within the United States.

Methods

Two independent studies are described in this paper: the physician study was conducted as a survey among physicians within the United States, United Kingdom, Germany, and Switzerland; the patient study was conducted as a survey among US patients.

Physician study

Participants

Eligible physicians were 1) members of the Sermo physician social networking platform; 2) practicing in one of the following specialties: rheumatology, immunology, general medicine, or family medicine; 3) previously opted into receiving surveys through Sermo; and 4) located in the United States, Germany, Switzerland, or the United Kingdom. Sermo is a large medical social network for exclusive use by physicians in the United States (in which over 300,000 US physicians are registered as users) and in other countries, including those in Europe; physicians primarily use Sermo to connect anonymously with each other to discuss medical cases and professional issues, but can also participate in research through the platform.²⁹ Physicians received a nominal fee for completing the survey. IRB/EC approval was not required for this survey, which contained exclusively a physician sample.

Procedure

A convenience sample of physicians who met eligibility criteria was recruited through Sermo. The data were collected through a cross-sectional online survey, which was posted on

the Sermo website, and for which a link was sent to Sermo member physicians who had opted into receiving surveys.

Measures and materials

Laboratory test report survey

The survey instrument applied within this research was developed by 1) identifying a set of research domains that were appropriate based on the primary research questions; 2) developing a draft survey instrument to assess the domains; 3) evaluating the draft instrument for content and construct validity through review with four practicing clinicians and survey instrument experts; 4) revising the draft instrument based on the pilot testing; and 5) preparing the instrument with complete user instructions and formatting appropriate for online implementation. The survey instrument consisted of nine questions. These included two questions about the current state of information contained in laboratory test reports (eg, How much general information about the laboratory tests is currently provided on the laboratory test reports your patients receive?); three Likert scale items on physicians' perspectives on doctor–patient communication for general laboratory test reports and three Likert scale items for RF reports (eg, I sometimes find it challenging to communicate with my patients about lab results); and an open-ended item that asked about areas of potential improvement for laboratory test reports. The complete survey is provided in Supplementary material A.

Analysis

Quantitative analysis

Data collected from the physician survey were analyzed through descriptive methods with mean values and standard deviation presented for numerical data and frequencies for categorical data. χ^2 , *t*-test, or analysis of variance analyses were conducted as applicable to compare between groups.

Qualitative analysis

A conventional approach to content analysis was used to analyze the qualitative responses that were provided by survey respondents to the open-text question.³⁰ This approach involved the following steps: all comments were collected within a Microsoft Word document; two researchers (AK and NA) independently reviewed the qualitative data as a set and identified a small set of primary themes into which the data could be organized; the researchers then met to discuss the thematic groupings of the data and resolved discrepancies through collaborative discussion, resulting in a final list of codes; two researchers (NA and AK) coded the qualitative data set within Microsoft Excel and developed a summary

of the findings identified among the final set of themes and associated qualitative comments; a final summary description of findings associated with the qualitative data was developed through collaborative review by all researchers.

Patient study

Participants

For the patient study, eligible participants were 1,954 patients who met the criteria of 1) having registered on the Patient-sLikeMe (PLM) website; 2) having reported a diagnosis of systemic lupus erythematosus (SLE) or rheumatoid arthritis as a health condition on the PLM profile (patients with these two conditions were targeted for the survey because they are likely to have received a blood test for RF in the past); 3) being located in the United States; 4) having had at least one login into the PLM website in the last 90 days; and 5) being aged ≥ 18 years. PLM is an online platform comprised of many disease communities, which allows patients with life-changing, typically chronic, medical conditions to find other patients like themselves, to share information about their outcomes, and to learn more about their condition. At the present time, there are over 7,600 and 8,300 patients with diagnoses of rheumatoid arthritis and SLE, respectively, registered on PLM.

Procedure

A convenience sample of patient members of PLM who met eligibility criteria were invited to complete an online survey, hosted on the PLM website. Participation in the survey was voluntary; the nature and potential risks of the study were explained. Informed consent was obtained electronically from participants before they were able to access and complete the survey. Of the eligible population, 270 (13%) opened the survey, and, of those, 211 completed the survey (78%). According to CHERRIES guidelines for online survey report, this represents a satisfactory recruitment rate and completion rate.³¹ Participants were not remunerated for their participation. The research study was approved by the New England Institutional Review Board on November 18, 2014.

Measures and materials

Patients laboratory report survey

The patient survey (presented in Supplementary material B) consisted of open-ended and Likert-type questions on overall clarity of the laboratory reports, patients' preferences, and satisfaction and was divided into the following parts: 1) eight demographic/clinical questions on age, sex, race, ethnicity, education, health insurance, last time the laboratory test report was received, and if they ever had a blood test for RF; 2) 19 items about past laboratory test report

experiences in general; 3) 3 items regarding experience of receiving results on the RF blood test and presented only to those who reported they had the test in the past; 4) ten questions on doctor–patient communication with regard to laboratory test reports; and 5) 13 questions related to a mock laboratory test report for RF.

Mock laboratory test report

To elicit feedback on a laboratory report containing additional information written for patients, a mock report was developed and included within the patient survey as the final section encountered by patients when completing the survey online. The mock laboratory test report used in the patient survey was based on a typical US commercial laboratory report that physicians and patients receive. However, this typical report was revised based on the findings from the physician study within this research and based on recommendations for patient-facing health care information, as discussed in patient engagement literature.^{14,24} The resulting mock laboratory report included explanatory information about the laboratory test and patient resources based on information from quality patient educational websites written by health care professionals.^{27,32} In addition to information about the patient, provider, laboratory, test results, and reference range, the mock report also included sections defining RF, the units used and reference range, an explanation for what an elevated score means, and links to trusted websites where patients could find more information. Language was simplified to reflect a Flesch–Kincaid grade level of 9.9 in Microsoft Word; however, this level may be elevated due to the inclusion of medical terminology.

Analysis

The analysis for quantitative and qualitative data followed a similar approach as that of Study 1. The themes identified for the coding of the qualitative survey responses, using a conventional analysis approach, were discussed among several researchers until consensus was reached (EC, KS, AK, and CR).

Results

Physician study

Physician sample

A total of 348 physicians practicing in four countries (the United States, United Kingdom, Germany, and Switzerland) across four specializations completed the physician survey in the Sermo platform. Table 1 lists the distribution of physician responses across the four countries and specializations. A summary of responses from US physicians and (separately) all other physicians is available upon request.

Table 1 Physician demographic characteristics (N=348)

Characteristic	Statistics
Age, mean (SD) ^a	48 (9.61)
Sex, n (%)	
Male	220 (63)
Female	61 (18)
Unreported	67 (19)
Country, n (%)	
United States	102 (29)
United Kingdom	99 (28)
Germany	97 (28)
Switzerland	50 (14)
Specialty, n (%)	
United States	
General/family practice	26 (26)
Internal medicine	26 (26)
Rheumatology	25 (24)
Allergy and immunology	25 (24)
United Kingdom	
General/family practice	32 (32)
Internal medicine	32 (32)
Rheumatology	25 (25)
Allergy and immunology	10 (10)
Germany	
General/family practice	27 (28)
Internal medicine	25 (26)
Allergy and immunology	25 (26)
Rheumatology	20 (20)
Switzerland	
General/family practice	33 (66)
Internal medicine	15 (30)
Allergy and immunology	1 (2)
Rheumatology	1 (2)

Note: ^aN=216 for this characteristic due to nonresponses on the optional survey item.

Current state of laboratory test reporting

When asked about the current availability of laboratory test reports for their patients, only one in five (19%) physicians reported that their patients always receive a copy of their laboratory results. Half (50%) of physicians reported their patients “sometimes” receive laboratory results, depending on the kinds of tests ordered or other factors; about a third (31%) reported their patients do not receive a report of laboratory results at all. Comparing US to non-US countries, a greater proportion of those outside the United States reported that patients do not receive laboratory test reports at all (16% in the United States vs 37% outside the United States, $\chi^2 = 107.38$, $P < 0.01$). This is mostly driven by responses by physicians in the United Kingdom; the majority of UK physicians in our sample (68%) reported that patients never receive their laboratory reports, whereas in Germany and the United States under 20% of physicians report the same; Switzerland falls in-between at 27%.

Of the 69% (240 physicians) who reported that their patients receive laboratory test reports all or some of the time, over half (58%) said the laboratory test reports their

patients receive contain a small amount of general information about the laboratory tests. The aggregate responses from the physician survey are listed in Table 2.

Doctor–patient communication

All physician participants were asked whether they find it challenging to communicate with their patients about laboratory results. On average, physicians tend to agree that they find communication with patients about laboratory test reports challenging ($M=2.89$ [1.21]) on a scale from 1: completely disagree to 5: completely agree). No difference between country or specialty was found. The same statement was posed to the physicians regarding RF tests. In this case, physicians disagreed, on average, with the statement that communication was sometimes challenging ($M=1.92$ [0.64]).

Areas for improvement

Physicians were asked their opinion about the helpfulness of providing more general information about laboratory test results on their patients' laboratory reports. On average,

most physicians felt that more information on laboratory test reports would be helpful for patients ($M=3.21$ [1.14]). Furthermore, physicians also tend to agree with the statement that adding general information could improve their relationship with their patients ($M=3.05$ [1.16]). Physicians were then asked about these same statements in relation to RF tests. Unlike laboratory test reports in general, on average, physicians disagreed that providing this information about RF tests could help their patients ($M=2.66$ [0.66]) and disagreed that adding this information could improve their relationship with their patients ($M=2.49$ [0.64]).

Qualitative results

Table 3 lists the key areas of improvement as suggested by physicians. Most respondents did not believe anything should be changed about the current reporting of laboratory results. Suggestions for improvement focused on interpretation of the numeric result. For example, physicians would like patients to be cautioned that a test result alone is not a diagnosis, but needs to be assessed together with

Table 2 Physician survey responses (N=348)

	n (%)				
1. When you order laboratory tests for your patients, do they receive a report of their laboratory results (paper or electronic)?					
• Yes, patients always receive a report of their lab results	66 (19)				
• Patients sometimes receive a report of their lab results, depending on the kinds of tests ordered	77 (22)				
• Patients sometimes receive a report of their lab results, depending on other factors	97 (28)				
• No, patients do not receive a report of their lab results	108 (31)				
2. How much general information about the lab tests is currently provided on the lab reports your patients receive? ^a					
• There is no general information about the lab tests provided	130 (37)				
• There is a small amount of general information about the lab tests provided	181 (52)				
• There is a large amount of general information about the lab test provided	37 (11)				
	1 strongly disagree	2 n (%)	3 n (%)	4 n (%)	5 strongly agree n (%)
3. Given the abundant information that patients receive today on the Internet and other sources, how much do you agree with the following statements about lab results/reports for your patients?^a					
I sometimes find it challenging to communicate with my patients about lab results	55 (16)	76 (22)	103 (30)	77 (22)	33 (10)
It could help my patients if more general information about the tests were provided on their reports	32 (9)	66 (19)	88 (26)	117 (34)	40 (12)
It could improve my relationship with my patients if more information were provided on their reports	38 (11)	74 (22)	107 (31)	83 (24)	40 (12)
	1 strongly disagree	2 n (%)	3 not applicable	4 n (%)	5 strongly agree n (%)
4. How much do you agree with these same statements specifically regarding RF tests?^a					
I sometimes find it challenging to communicate with my patients about RF test results	41 (12)	88 (25)	82 (24)	109 (32)	26 (7)
It could help my patients if more general information about RF tests were provided on their reports	28 (8)	76 (22)	86 (25)	117 (34)	40 (11)
It could improve my relationship with my patients if more RF information were provided on their reports	36 (11)	84 (24)	105 (30)	91 (26)	1 (9)

Notes: ^aData were missing for this question, resulting in total number of responses provided <348; percentages presented reflect the relative percentage of responses for this item.

Abbreviation: RF, rheumatoid factor.

Table 3 Physician suggestions for additional information to be included in laboratory test reports

Theme	% of participants with comment within this theme	Theme description	Quote
Meaning of results	27	Physicians would want to see a description of the meaning of test results	“What the result may mean and its implications” “General information regarding the significance of high or low values”
False-positives or false-negatives	9	Physicians would want to see a description of false-positives and false-negatives	“Detailing in addition to normal values examples of false negatives and positives and the differential”
Prompt to contact provider with questions	7	Physicians would want to see some prompting language to patients regarding follow-up to questions from the test results	“Info: ask your doctor” “That test result is NOT a diagnosis usually. Ask your doctor to interpret.”
Results are not a diagnosis	5	Physicians would want to see some language on the context of interpretation of test results	“The disclaimer that above or below normal is not necessarily diagnostic or abnormal” “Explanation that low titer positivity does not make a diagnosis”

other clinical considerations, that there is a possibility of false-negative and -positive results, and the importance of a follow-up discussion with their physician. Most opinions did not vary significantly between the four countries surveyed. Some physicians, mostly in Germany, stated that no additional information is needed on laboratory test reports, citing that providing this information is the responsibility of the physician. However, caution should be used in drawing conclusions about regional differences as the sample sizes in individual countries were limited, and the survey was provided in English, which could have skewed the results in countries where other languages are prevalent.

Patient study

Patient sample

Eligible participants who completed the survey (n=211) were included in the final analyses sample. About half (49%) reported they had rheumatoid arthritis, 46% reported they had SLE, and 5% reported they had both SLE and rheumatoid arthritis. Demographic characteristics are listed in Table 4.

Current state of laboratory test reports

Most (73%) of the 211 survey respondents reported they received a laboratory test report the last 3 months, and 99% received one within the last year. Patients’ overall evaluation for the clarity of typical laboratory test reports was 3.16 (SD 1.12, Cronbach’s $\alpha=0.87$), on a scale from 1 to 5. More than 30% strongly disagreed that their most recent report had easy-to-understand explanations of the results or about future steps. No results showed any correlation with age or sex.

Patients were also asked the extent to which they felt they understood their RF test report. A total of 19% reported they did not understand what the results of their RF test meant (ie, they

selected somewhat disagree or strongly disagree with the statement “after receiving the results, I understood what the results of my RF test meant”). Self-reported understandability of the results was not correlated with age or sex.

Almost half of the 172 patients who have had an RF test (47%) said that their most current reports did not provide general

Table 4 Patient demographic characteristics (N=211)

Sex (female), n (%)	189 (90)
Age, mean (SD)	52.7 (10.0)
Race, n (%)	
• White	188 (89)
• African-American	9 (4)
• Other	13 (6)
• Preferred not to answer	1 (0.5)
Ethnicity (non-Hispanic), n (%)	198 (94)
Residence (United States), n (%)	203 (96)
Education, n (%)	
• Below high school	1 (0.5)
• High school	21 (10)
• Some college	100 (47)
• Undergraduate degree	45 (21)
• Advanced degree	42 (20)
• Preferred not to answer	2 (1)
Insurance, n (%)	
• Private	91 (43)
• Medicare	68 (32)
• Medicaid	23 (11)
• Military	8 (4)
• None	7 (3)
• Other (VA, national, other)	12 (6)
• No answer	2 (1)
Diagnosis, n (%)	
• Rheumatoid arthritis	103 (49)
• SLE	97 (46)
• Both	11 (5)
Had laboratory test within last 3 months, n (%)	154 (73)

Abbreviations: SLE, systemic lupus erythematosus; VA, Veteran’s Administration.

information about the laboratory results; about half (47%) did not find it easy to understand RF reports they had received.

Doctor–patient communication: general laboratory test reports

Most (76%) of 210 patients have reported that doctors always or most of the time tell them the reasons why the tests are being done. According to patients, their doctors also frequently explain to them how and when they may expect the results, what the abnormal results are, and what the results measure. However, patients have reported that doctors are less likely to tell how and where a patient can get more information about the test, explain how to read the laboratory test report, or arrange an office call to ask if a patient has any questions. Figure 1 provides more details.

Doctor–patient communication: RF laboratory test report

Most of the 170 patients within the sample who have had an RF test and chose to answer the questions feel comfortable talking to their doctors about their results (79% strongly or somewhat agree) and most agree that they could understand the doctor's explanations (69% strongly or somewhat agree). Most patients would find the opportunity to talk to their doctor or doctor's office about their laboratory results helpful (52% strongly or somewhat agree) (Figure 2).

Areas for improvement

We asked patients about what they find helpful to have included in the RF report on 1–5 Likert scale, where 1 was strongly disagree and 5 was strongly agree. Figure 3 shows the extent to which patients would like to have specific information in their laboratory test reports.

There was high agreement with all statements, with the highest agreement for what is the “normal” range of results (93% either strongly agree or somewhat agree) to the least agreement for how often the test might be done (62% strongly or somewhat agree).

In addition, more than half (57%) of 168 respondents believed they would benefit from including more general information about the RF test in RF laboratory test reports; 50% of 167 respondents strongly or somewhat agreed it would be helpful to have specific instructions on what to do next in the RF report (Figure 4).

Additional information seeking

Almost half of 211 patients (47%) usually do not look for more information when they receive their laboratory results. Among those who do look for more information, most prefer

to go to the Internet (78%), while a sizable minority talk to their physician (36%) or to other patients (25%).

Mock RF laboratory test report

Overall, participants had highly positive responses to the mock laboratory test report. The highest agreement was with the statement “I would want to see this much information in all of my laboratory test reports” (95% somewhat or strongly agree). The lowest agreement was for “I would be likely to go to the suggested websites to learn more” (86% somewhat or strongly agree).

Four most frequent themes were revealed in analysis of open text responses to questions about shortcomings of the mock laboratory test report (Table 5). The most common area of improvement was inclusion of more explanations and recommendations about the next steps. The less common suggestions (<3%) were design recommendations, request to list comorbidities, and to include more online resources.

Discussion

We assessed patient and physician perspectives about current laboratory test reporting practices and tested a prototype RF test report with patients. In a context where patients receive laboratory reports written for use by physicians, the primary goal of this research was to understand what would aid communication of such test results to patients. While both physicians and patients agreed that providing additional, patient-oriented information about the test results in the report would be of help to patients and would enhance communication, patients wanted a more extensive explanation of the meaning of the results, while physicians would like to see cautionary text to mitigate errors in interpretation of the results by patients.

Patients find laboratory test reports to be lacking in the kinds of information they find most helpful, that is, what the results mean for them. Patients want more than an in-depth explanation of the purpose of laboratory tests, the result, and reference range. Rather, our findings suggest that what matters to patients is what the results mean, in simple language, including how they fit in the patient's overall medical history and the next steps to take with their care.^{1,12,13,19,20} Additionally, patients reported that physicians skip high-touch follow-up of laboratory reports. To address this unmet informational need, patients report they supplement the laboratory test report information with online resources, a reflection of broader trends in Internet use for health-related purposes.^{33–37} By asking patients for their input, laboratory test reports can be redesigned to include information they

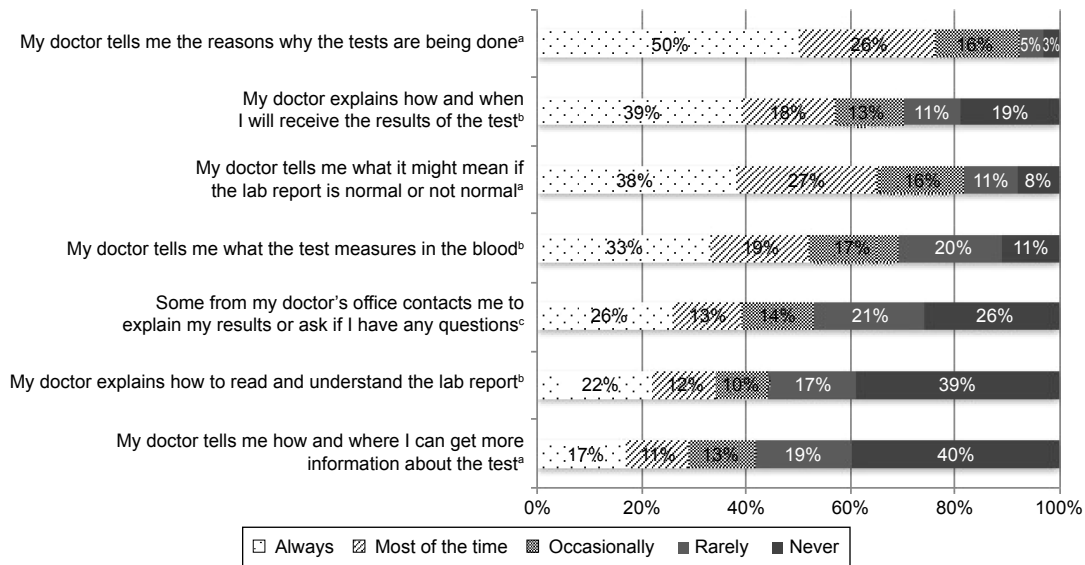


Figure 1 Doctor–patient communication regarding general laboratory test reports. **Notes:** ^aMissing one case, ^bmissing two cases, ^cmissing three cases.

find helpful or guide them to resources where they can find such information.

Physicians, however, had a more cautionary approach to laboratory test reports. While they felt that providing more information to patients would enhance communication and aid patient understanding, they emphasized that this information must be provided with explanations about potential false-positives and false-negatives, reassurance

that positive results do not by themselves confirm diagnosis, and a prompt for patients to contact their physician if they have further questions. This is consistent with previous findings that physicians are concerned that patient access to medical records might increase worry and confusion.^{6,38} Yet overall, both groups agree that providing more information on laboratory test reports has the potential to improve care.

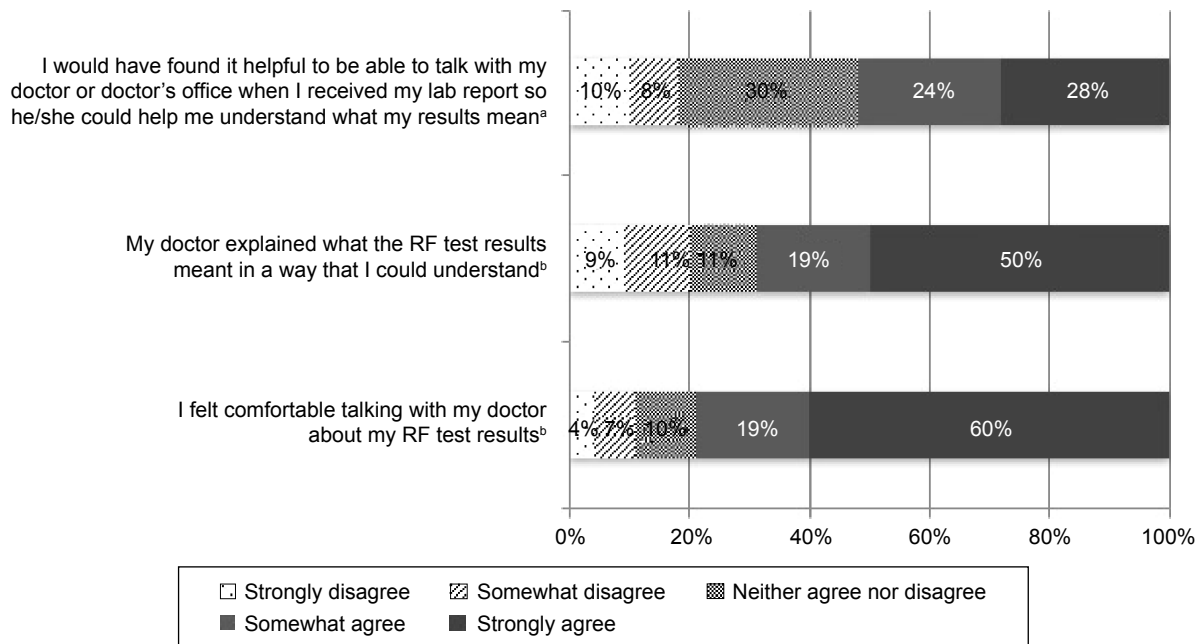


Figure 2 Doctor–patient communication regarding the RF laboratory test report. **Notes:** ^aMissing six cases, ^bMissing one case. **Abbreviation:** RF, rheumatoid factor.

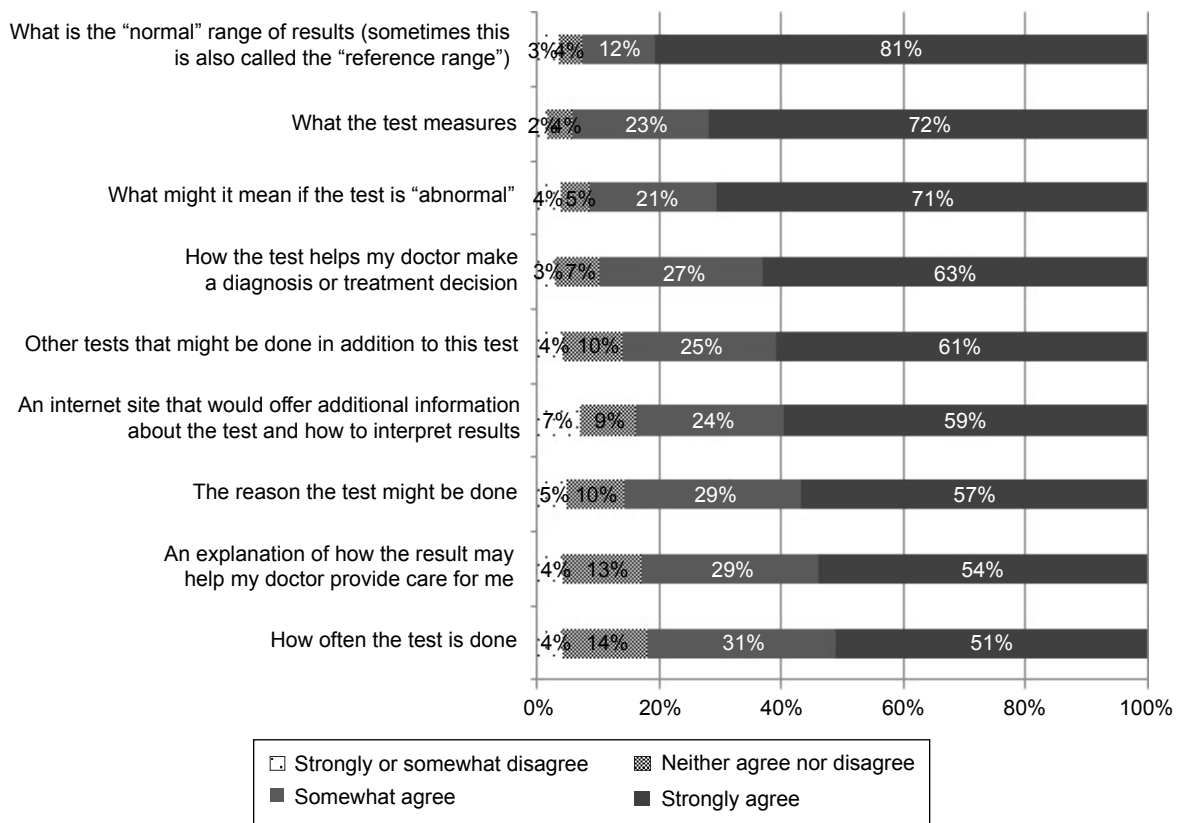


Figure 3 What kinds of information would you like to be added to the laboratory reports you receive to help you better understand the test results and what the results mean to you and your health? (N=209).

Note: N=209; Missing data for two patients.

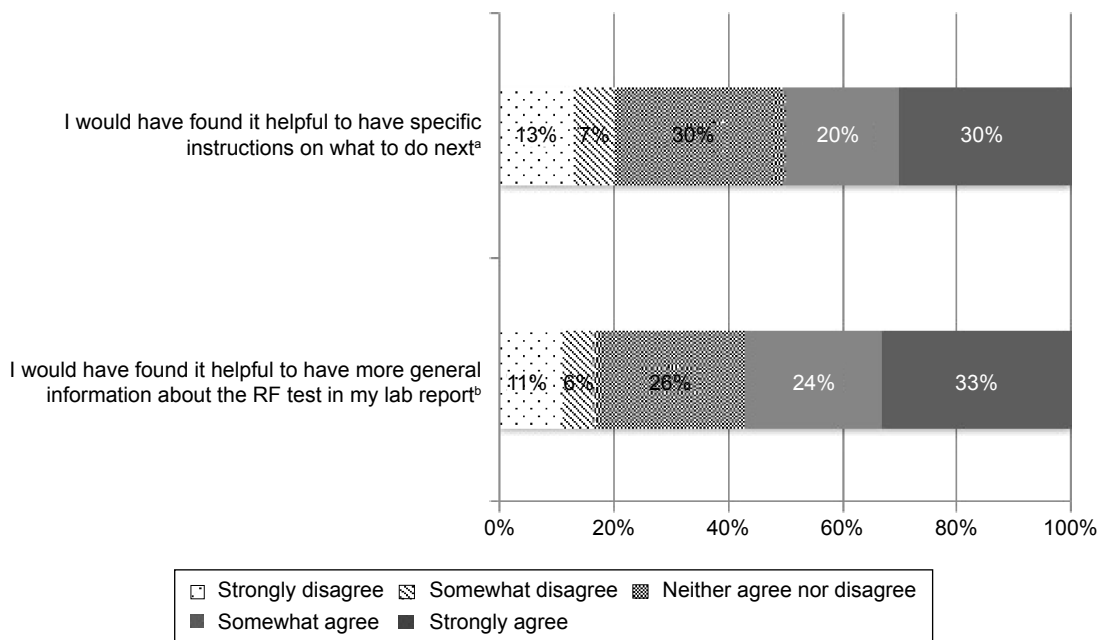


Figure 4 Patients' attitudes regarding desired information in the RF report (N=168).

Notes: ^aMissing four cases, ^bMissing five cases.

Abbreviation: RF, rheumatoid factor.

Table 5 Most frequent themes in suggestions for improvement to information contained in mock laboratory test report

Theme	% of participants with comment within this theme ^a	Theme description	Quote
None/nothing	41	Patients request no additional information	"I think this report should be an industry standard"
Meaning of the results	16	Patients would like to know why the test was ordered and what could affect the results	"Maybe a more thorough explanation of possible meds or other things that might affect the results"
Recommended next steps	15	Patients ask for providing information about the next steps	"What are the next steps and how often does the test need to be repeated?"
History of results	5	Patients request providing past test results	"Recap of past tests if applicable"
Procedural details	4	Patients request to know details about who will see the report and when and how it will be reviewed	"The time between the lab testing and when the doctor actually sees or reviews the lab results"

Note: ^aOut of 211 patients, 126 chose to skip this open-response question.

On the basis of these results, we identified four elements that could improve laboratory test reports for RF. First, include an explanation of the blood test and meaning of the results to the extent possible and practical. Second, flag results that need careful interpretation and physician follow-up discussions due to the potential for false-positives and false-negatives to mitigate the risk of undue worry or misinterpretation. Third, provide information on what actions to take next so that patients understand their options and as a safeguard against missed follow-ups.⁴ Finally, RF test reports could contain trusted resources for more information, including physician contact and balanced and accurate education or information resources. Based on this research, it appears that patients tend to want to receive sufficient information to understand not just what their laboratory test results are, but what the result means and what their next steps should or could be; physicians appear to generally agree that patients need enough helpful information to guide them to understand the meaning of their test results within the context of practical, patient-centered, and evidence-based medical care.

Limitations

There are several limitations to this study. First, participants in both studies consisted of a convenience sample of patients and providers who are members of online communities and may be somewhat different from the general patient and physician populations. For example, patient demographics in this study generally reflect the sex distribution seen in patients with lupus and rheumatoid arthritis, but an increased proportion of Hispanic and African-American patients might be expected based on the epidemiology of lupus in the United States.³⁹ Patients who are active in a health-tracking website may be particularly interested in health information and may have different perceptions about laboratory test reports from

the general public. Likewise, physicians who are members of an online physician community may have perceptions about laboratory test reports and communication with patients that differ from those who are not members.

Second, the surveys used to collect physician and patient data were constructed with similar, but not identical, questions and response options, thereby limiting comparisons between the two groups. Third, the results of the feedback on the mock laboratory test report may not be generalizable to other types of laboratory tests or diagnostic tests, for example, biopsy, imaging results, or genetic tests. Furthermore, there were some inconsistencies in variability across items with some evidence of acquiescence bias. Patients may be seeking as much information on laboratory test reports as possible, and may have a tendency to report high levels of agreement across a broad range of items.

Conclusion

Overall, these results suggest that laboratory test reports present an opportunity for improving communication between physicians and patients. Involving both patients and physicians in the design of reports is an important step to ensure patients can understand and act upon the information contained in their laboratory test reports.

This paper also highlights the limits of patient-centered approaches for specificity. There are a range of laboratory reports requiring different levels of comprehension and need for professional guidance. Simply providing patients with access to their reports without understanding these differences may be premature. There is a need to develop laboratory report standards that are patient centered and patient friendly. Future research is needed to determine the types of information patients do not understand, the types of reports that are particularly challenging, and communications needed for different types of reports. A study of regional and

international differences, which may be sensitive to cultural and policy variations, and with different types of laboratory test reports, would provide more generalizable results in terms of the impact of health conditions and demographic factors on preferences for laboratory test reports. Finally, the effect of using such patient-centered laboratory reports on patient outcomes warrants further investigation.

Practice implications

The widespread availability of direct patient access to laboratory test reports underscores the need for reporting of results in a way that patients understand and that enhance doctor–patient communication. Our study suggests that patients and physicians have unique perspectives on laboratory reporting. Including both patients and physicians when designing laboratory test reports may lead to better patient engagement, doctor–patient communication, and potentially improved outcomes.

Acknowledgments

We acknowledge the contribution of patients and physicians who participated in the study questionnaires. Chris Curran supported the preparation and submission of the manuscript.

Disclosure

EC, JB, EC, and KS are employees of PatientsLikeMe and hold stock options in the company; the PatientsLikeMe Research department has received funding from Genentech. AK, CR, and NA are employees of Genentech. The authors declare no other conflicts of interest in this work.

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Supplementary materials

A: survey instrument for the physician sample

1. When you order laboratory tests for your patients, do they receive a report of their laboratory results (paper or electronic)?
 - Yes, patients always receive a report of their laboratory results.
 - Patients sometimes receive a report of their laboratory results, depending on the kinds of tests ordered.
 - Patients sometimes receive a report of their laboratory results, depending on other factors.
 - No, patients do not receive a report of their laboratory results.
2. How much general information about the laboratory tests is currently provided on the laboratory reports your patients receive?
 - There is no general information about the laboratory tests provided.
 - There is a small amount of general information about the laboratory tests provided.
 - There is a large amount of general information about the laboratory tests provided.
3. Given the abundant information that patients receive today on the internet and other sources, how much do you agree with the following statements about laboratory results/reports for your patients?

1	2	3	4	5
Strongly disagree				Strongly agree

 - I sometimes find it challenging to communicate with my patients about laboratory results.
 - It could help my patients if more general information about the tests were provided on their reports.
 - It could improve my relationship with my patients if more information were provided on their reports.
4. How much do you agree with these same statements specifically regarding RF tests? (Mark “3/not applicable” if you do not order these tests.)

1	2	3	4	5
Strongly disagree		Not applicable		Strongly agree

 - I sometimes find it challenging to communicate with my patients about RF test results.
 - It could help my patients if more general information about RF tests were provided on their reports.
 - It could improve my relationship with my patients if more RF information were on their reports.
5. What kind of information would you add to patients’ laboratory reports to be most helpful to them and/or your relationship with them? (Free text response.)

B: survey instrument for the patient sample

A "laboratory report" or "lab report" are results from blood tests that you receive from your doctor or from the laboratory that performs the test. A lab report usually includes the name of the blood test(s) performed by the doctor or lab; the result, or "numbers" from the test(s); and the range of results that are considered "normal." Sometimes this report also includes other information, such as information on what to do if your results indicate that you need to see the doctor again or see another doctor.

Demographic Questions

1. Age
2. Sex
3. Race
4. Ethnicity
5. Education
6. Health Insurance

In the following questions, "doctor" refers to any of your doctor(s).

- 1) The last time my doctor ordered blood tests and I received a laboratory report was: (Please select one)
 - a. Within the last month
 - b. 1–3 months ago
 - c. 3–6 months ago
 - d. 6–12 months ago
 - e. More than a year ago
 - f. I do not remember ever receiving a lab report following blood tests

2) Please select the best response below for each item. [note: answer options should be: always, most of the time, occasionally, rarely, never.]

When my doctor orders laboratory tests to be done for me,

[then list each sentence completer as a separate option, with the scale available for each option, in a grid]

- a. my doctor tells me the reasons why the tests are being done
- b. my doctor tells me what it might mean if the lab report is normal or not normal
- c. my doctor tells me what the test measures in the blood
- d. my doctor tells me how and where I can get more information about the test
- e. my doctor explains how and when I will receive the results of the test
- f. my doctor explains how to read and understand the lab report
- g. someone from my doctor's office contacts me to explain my results or ask if I have any questions

3) Think about the last lab report you received. Please select the best response below for each item. [note: answer options should be: strongly disagree, somewhat disagree, neither agree or disagree, somewhat agree, strongly agree]

The last lab report that I received:

[list each sentence as a separate option, with the scale available for each option, in a grid]

- a. Included general information about the lab tests
- b. Had easy-to-understand explanations of the lab tests
- c. Had easy-to-understand explanations of how to read the test results
- d. Was confusing to understand
- e. Included a clear explanation of what I needed to do next (such as call the doctor, make an appointment, etc)

4) Think about the ways that you get information about your health, such as from you doctor, the internet, other patients, and other sources.] Please select the best response below for each item. [note: answer options should be: strongly disagree, somewhat disagree, neither agree or disagree, somewhat agree, strongly agree]

[list each sentence as a separate option, with the scale available for each option, in a grid]

- a. If I do not understand why a blood test was ordered or what my report means, I go to the internet for more information.
- b. When I receive my lab report, I usually contact my doctor's office to ask questions so I can better understand what my report means to me.
- c. I will typically talk about my test results with other patients with my condition to help me understand how my results compare to others
- d. I usually do not seek more information when I receive my test results because I generally understand my lab report.

5) Have you ever had a blood test for Rheumatoid Factor (RF)?

- a. Yes
- b. No (skip to 7)
- c. Not sure (skip to 7)

6) The following statements refer specifically to the blood test for Rheumatoid Factor (RF). Please select the best response below for each item. [note: answer options should be: strongly disagree, somewhat disagree, neither agree or disagree, somewhat agree, strongly agree]

[list each sentence as a separate option, with the scale available for each option, in a grid]

When the RF blood test was performed on me,

- a. I felt comfortable talking with my doctor about my RF test results.
- b. After receiving the result, I understood what the results of my RF test mean
- c. I would have found it helpful to have more general information about the RF test in my lab report.
- d. I would have found it helpful to have specific instructions on what to do next, when I receive my lab report.
- e. I would have found it helpful to be able to talk with my doctor or doctor's office when I received my lab report so he/she could help me understand what my results mean
- f. My doctor explained what the RF test result meant in a way that I could understand

7) What kinds of information would you like to be added to the lab reports you receive in order to help you better understand the test results and what the results mean to you and your health? [note: answer options should be: strongly disagree, somewhat disagree, neither agree or disagree, somewhat agree, strongly agree]

To be better able to understand my test results in my lab report, my lab report needs to include

[list each sentence completer as a separate option, with the scale available for each option, in a grid]

- a. The reason the test might be done
- b. What the test measures
- c. What is the "normal" range of results (sometimes also called the "reference range")
- d. What might it mean if the test is "abnormal"
- e. Other tests that might be done in addition to this test
- f. An internet site that would offer additional information about the test and how to interpret results
- g. An explanation of how the result may help my doctor provide care for me
- h. How often the test is done
- i. How the test helps my doctor make a diagnosis or treatment decision

Below is a sample lab report. This is an example of the type of report that a patient might receive following a lab test being performed. We would like to learn what you, as a patient, want to see in lab reports you might receive. We would value your feedback to a small number of questions that you will see below this sample lab report.

University Medical Center

Patient: Jane Doe
Gender – DOB: F 3/23/1962

Page 1 of 1
Location: UMC
Ordering Physician: J. Smith, MD.

REFERENCE LAB TESTS

RHEUMATOID FACTOR

Specimen: BLOOD
05/21/2014
12:15

Test Performed By:
Diagnostics Institute
T. Jones, MD. Laboratory Director
123 University Ave
Smalltown CA 94212-6724

WHAT IS RHEUMATOID FACTOR?

Rheumatoid factor is an antibody that is measurable in the blood and that can bind to other antibodies. Antibodies are normal proteins in the blood that are important parts of the immune system.

WHAT DID YOUR TEST SHOW?

Your result is **3023 IU/mL**, which is higher than the reference range of **<20 IU/mL**.

	Result	Units	Reference
Rheumatoid Factor	30H	IU/mL	< 20

H: indicates it is higher than the reference range.

IU/mL: stands for "international units per milliliter." It is a measurement used in the laboratory that performs the test on a patient's blood sample.

Reference Range: range seen in most normal, healthy people who do not have rheumatoid arthritis or other related disorders.

IF YOUR LAB RESULT WAS ELEVATED (H):

An elevated rheumatoid factor is often called a "positive rheumatoid factor". Rheumatoid factor is sometimes elevated, or is higher than the reference level, in normal, healthy people. It is often, but not always, elevated in adults with rheumatoid arthritis. It can also be elevated in people who have other disorders such as other kinds of arthritis or autoimmune disorders or infections, and other disorders.

An elevated rheumatoid factor by itself is not enough to make a diagnosis of rheumatoid arthritis or any other disorder. Your doctor may use this blood test, along with your history, physical exam, and results of other tests, such as blood tests or X-rays, to help make a diagnosis and to help decide on a treatment plan with you.

FOR MORE INFORMATION:

For additional information and to help understand your test results, please contact your doctor.

Here are two sources that your doctor trusts:

MAYO CLINIC: <http://www.mayoclinic.org/tests-procedures/rheumatoid-factor/basics/definition/prc-20013484>

LAB TEST ONLINE:

http://labtestsonline.org/home/SearchForm?Search=rheumatoid+factor&action_ProcessSphinxSearchForm=Go

This document contains fictitious information and is for the sole purpose of creating a mock lab result.
It is not to be distributed to unauthorized individuals. If this is received in error please discard immediately.

8) Please select one answer for each of the following questions related to this example lab report. [Answer Options: strongly disagree, somewhat disagree, neither agree or disagree, somewhat agree, strongly agree]
<ul style="list-style-type: none"> a. This lab report clearly describes what the lab test measures. b. The description of the blood test and what it measures helps me understand my lab report. c. This lab report clearly describes my test results. d. The description of what the test results may indicate helps me understand my lab report. e. I would want to see this much information in all of my lab reports. f. Overall, the lab report answers my most important questions about the test results. g. I would likely go to the suggested websites to learn more.
9) Is there a section of the sample lab report you do not find helpful?
<ul style="list-style-type: none"> a. Yes b. No (skip to 11)
10) Please describe [open text]
11) What additional information (if any) should be included in your lab report? [open text]
12) Would you like to see any additional resources listed in the lab report, such as resources other than internet sites?
<ul style="list-style-type: none"> a. Yes b. No (Skip to 14)
13) Please describe [open text]
14) What makes this report more or less useful than other reports you have received from your doctor? [open text]
15) Please also describe any other information you would find helpful to be included in your lab report and why it would be helpful. [open text]

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