Patient perspectives on test result communication in primary care: a qualitative study

INTRODUCTION

The frequency of test ordering in primary care continues to increase and, whether for screening, diagnostic, or monitoring purposes, the timely and appropriate communication of results remains key to ensuring patients receive the necessary care. The failure to communicate results appropriately has implications for both patient satisfaction and patient safety, and can lead to medicolegal concerns for practices.1–3

The management of the testing and result communication process, which includes phlebotomy, sample analysis, and communicating results, is a complex one that requires multiple stakeholders — often with differing objectives and motivations — to communicate effectively. As a consequence, there is significant potential for mistakes throughout the process, from ordering and implementing tests, to relaying results to clinicians and notifying patients.4 Over the past decade, research undertaken predominantly in the US has recognised growing concerns among physicians in general practice about testing and result management, including the lack of defined administrative procedures and the frequency of delays in the process.5,6

Recommendations have begun to emerge, outlining areas where the process can be improved and standardised. These include defining key terms, developing protocols, and outlining responsibilities of care providers, and specifying the time period between ordering and reporting.6,7 In particular, the importance of the patient’s role in the process, along with the necessity of accounting for patient requirements and preferences, has been recognised.8,9

Existing evidence in the UK suggests that patients are comfortable receiving results using a variety of methods, provided preferences for privacy, responsive and interactive feedback, and timeliness are taken into account.10,11 What is less well known is what patients perceive to be the strengths and weaknesses of the overall system and, specifically, those of the current methods that are employed for communicating results.

To better understand patient perspectives on both the organisational and technological aspects of current and prospective systems, and to gauge not only preferred methods of communication but also the factors that influence them, a series of patient focus groups was conducted to explore attitudes to existing systems and to gather suggestions for improvement.

METHOD

This study was drawn from a group of 10 general practices in Birmingham, UK, that had previously collaborated with the University of Birmingham on a prospective study of abnormal liver function tests.12

Within these 10 practices, purposive
How this fits in

The number of blood tests ordered in primary care continues to increase. Failure to communicate results appropriately, without taking into account patient preferences, has implications for patient satisfaction and patient safety, and could lead to medicolegal concerns for practices. Patients in this study expressed frustration at what appeared restricted access to phlebotomy and were concerned with reception staff handling sensitive, confidential, and clinically relevant information. Currently the responsibilities of patients within the process of test result communication are indistinct and it would appear beneficial to all parties if they were more clearly defined.

Box 1. Patient focus group schedule

1. Can you briefly tell me what the procedure is for communicating test results to patients?
   **Prompts:** Do you know if it varies for different kinds of tests?

2. How did you get the result of your test?
   **Prompts:** Who told you and how?
   If referred elsewhere (for example, hospital) did you know how you would receive results?
   Did you receive results in the way you expected?

3. What were the strengths and weaknesses of the system?
   **Prompts:** Did you encounter any delay?
   Did you understand the implication of results?

4. What are you preferred methods for communicating results?
   **Prompts:** Via telephone (clinical/non-clinical staff)
   Face-to-face (clinical/non-clinical staff)
   Written word (for example, text, e-mail, letter)

5. Which factors are important in deciding on your preferred method?
   **Prompts:** Is the test for a new or ongoing condition?
   How familiar you are with the practice?
   Potential impact of the result?
   Accessibility of staff?

RESULTS

Table 1 gives a description of each practice, including the number of patients registered, number of whole-time equivalent GPs, and index of multiple deprivation ranking. Table 2 outlines the age and sex of focus group participants. The practices ranged in size from having 3.0 to 12.3 full-time equivalent GPs; patient numbers ranged from just under 6000 to nearly 27 500.

The majority of patients who attended focus groups were aged >64 years; the recruitment of patients at Practices 3000 and 4000 was lower than intended.

The first theme describes patient perceptions and attitudes and was reflected in the topic guide, the second theme relates to the patient role, and the third theme concerns improving the current system. All three themes are discussed.

Patient perception of, and attitudes toward, existing systems of result communication

Patients described their understanding of current systems and their perceptions of strengths and weaknesses. These included the timeliness of result notification, preference for a particular communication pathway, and the costs incurred when retrieving results.
Patients reported that, typically, they were instructed to telephone for results, usually after a given period of time, although results were not always provided, causing anxiety. Practices would sometimes initiate contact, causing confusion for patients, who were unaware that this could happen:

‘Nine times out of 10 the receptionist will tell you what your results are, but when they say “you’ve got to speak to the doctor” then I think it worries you even more.’ (Patient [P]1022, focus group [FG] 1, female)

‘They usually say “We will have your results in a couple of weeks” but I have also been called by the surgery and I thought, “Why are they calling me?”.’ (P2012, FG2, female)

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‘Timeliness. Timeliness was clearly important and patients described how delays in communication of their test results could lead to increased anxiety:

‘I get very anxious when I don’t hear about the results actually.’ (P2019, FG2b, female)

Despite affecting the patient’s prognosis, there remained several points in the process where delay could arise. One notable source of frustration concerned the wait for phlebotomy tests following the decision to test:

‘If you wait until you have an abnormal result to make an appointment then you start panicking, trying to get a booking.’ (P4009, FG6, male)

‘It’s a bit frustrating at times when you ring [for results] and staff say, “… but you can’t see the GP for 3 weeks.”’ (P1017, FG1, female)

Concerns over the communication of results by non-clinical staff. Typically patients would call receptionists for results. This prompted patients’ concerns over the suitability of reception staff for communicating clinical information, other than, perhaps, those relating to the most routine, low-impact tests. Patients questioned these staff members’ lack of clinical knowledge, which led to reduced reassurance about ‘normal’ results communicated by receptionists who were unable to provide any further information:

‘I would never accept results off the receptionist unless it’s [for] cholesterol.’ (P1023, FG1, female)

‘If you actually need a straightforward “There is no problem whatsoever”, that’s OK to get that from the receptionist, but that might not be particularly helpful to you if you’re not feeling so well… Did they do the right test?’ (P2013, FG2a, male)

Receiving results from reception staff, typically situated at the front desk, also prompted concerns over confidentiality:

‘They did withdraw it, so that the telephone was in the back office and patients waiting in the waiting room could not hear the conversation and now, of course, it’s gone back!’ (P1017, FG1, female)
Patients also felt it was important for those communicating results to understand the potential impact that the result might have on a concerned patient:

'It’s not so much about being given the results over the phone as the person giving the results understanding the impact of what they are saying to the person on the end of that phone.' (P2012, FG2, female)

Patient time and resources spent retrieving results. Patients spoke of the impact on their time and money if they were required to return to the surgery, either for phlebotomy appointments or to receive results from clinicians:

'Well, there isn’t a bus; I usually get a taxi now. I used to walk but since I’ve been ill ...' P3009, FG3, female

The common instruction was to call the practice for results. However, with practice telephone lines often busy, patients reported frustration at the amount of time spent trying to reach a member of staff:

'If you are hanging on the end of the phone because there is a big queue, it is a bit of a pain.' (P4008, FG4, male)

Patient role
The patient’s knowledge of, and attitudes toward, the system the practice employs influences the part that patients play in the result communication process. Some patients were proactive in seeking to influence the practice to provide results according to their preferred method; others were more passive, trusting the practice to initiate contact as required.

Proactive behaviour. Some patients reported methods they employed to overcome anticipated delays between having a test done and securing an appointment with their GP to get the results. They would book an appointment after the initial consultation, when the decision to order was made:

'You can’t get an appointment with the doctor for at least 2–3 weeks, so I normally book in an appointment at the same time [I have my blood taken].' P4009, FG4, male

If needs be, these patients would cancel the appointment if their test results were normal.

Passive behaviour. Patient confidence in the process varied, with some believing that GP practices would assume responsibility for communicating results whenever a test required further action:

'I presume that they’re going to get the results back and if there’s something dire they will contact me ... I’ve got enough faith in the GP to think that.' (P3011, FG3, male)

Some patients felt that practices should assume more responsibility for communicating all results:

'It should be that they are proactive with these results ... it shouldn’t be that we have to collect ... if we’ve had a test done we should have the result sent to us.' (P3011, FG3, male)

Others, however, believed the responsibility lay with the individual patient:

'Very much, it’s up to the patient to pursue things. People who work on the assumption that no news is good news ... It’s a bit naive.' (P1017, FG1, female)

Improving the current system
A number of suggestions for improvements emerged from the focus groups as patient preferences were discussed. These suggestions centred predominantly on the most common default system of calling the practice for results and included:

• better management of patient calls;
• improved training for relevant reception staff;
• increased accessibility to GPs; and
• a more clearly defined protocol governing testing and result communication.

Managing patient calls. Patients suggested introducing a queuing system to manage calls in busy periods to enable patients to decide whether they wanted to wait for an answer or call back if the line was too busy:

'I must say it [a queuing system] would help ‘cause I found it a little annoying that I didn’t know where I was in the queue waiting for a response on the phone.' (P4008, FG4, male)

Staff training. To overcome concerns about non-clinical staff relaying clinical information, targeted training in the communication of sensitive information was proposed:

'There should be one member of staff who
is specifically trained in how to hold those conversations over the phone.’ [P2012, FG2a, female]

Accessibility to GPs. Patients also felt that a number of appointment slots should be retained in the GP’s schedule for those requiring a consultation to receive and discuss their results:

‘If your doctor phones to say “I would like to see you”, you are going to worry. Therefore, he should be able to see you fairly quickly. He should not see you 10 days later. If he has got that sort of message he should see you within a day or two.’ [P1019, FG1, male]

Communication protocol. Patients suggested practices should clarify the current system for communicating results, and present it to patients:

‘Patients aren’t — and even I’m not really — aware of how tests are communicated. You know, there is no poster on the wall. There is no information in the waiting room. So maybe that would be helpful to patients?’ [P2015, FG2b, female]

They felt that, if results require further action, this protocol should include information on the typical procedure to help reduce anxiety:

‘... a bit of reassurance, explanation about what will happen if it shouldn’t be normal, just so you know what to expect.’ [P1017, FG1, female]

Alternative methods that could help facilitate the proactive communication of results by practices were discussed; patients acknowledged that their preferences were influenced by the likely impact of the result:

‘I think text messaging is a good idea for a routine test.’ [P2020, FG2, female]

If a more serious test was undertaken or condition was suspected, then it was felt the process should be flexible enough to reflect this:

‘It all depends on what it’s for. I mean if you’ve been sent for something where you think you might have a tumour or something then, I think, that’s got to be dealt with totally differently.’ [P1023, FG1, female]

In considering the various options potentially available, one patient felt that, ultimately, the decision ought to be made by the patients:

‘Ideally you would be given a choice ... I mean, that’s what the NHS is supposed to be about these days isn’t it — patient choice?’ [P1017, FG1, female]

DISCUSSION

Summary

The default process for testing and the delivery of results was described and, generally, required patients calling the practice. Repeated delays in the process were a common and persistent source of dissatisfaction; specifically these delays were caused by the wait for phlebotomy, the difficulty in reaching receptionists on busy telephone lines, when results required a follow-up consultation, and GPs’ lack of availability.

Patients expressed disquiet at receptionists imparting clinically relevant information, querying their awareness of the confidentiality of medical data, and their ability to communicate sensitive information to patients who were concerned.

The differing approaches of patients who were proactive and passive towards taking responsibility for results suggests that the likelihood of patients receiving their results in a timely manner may be dictated by the patient’s own attitude rather than by clinical significance.

A number of constructive suggestions to improve current systems emerged from the focus groups. These included: introducing a telephone queuing system; giving reception staff some, or better, training in data handling and communication; and the practice routinely communicating with patients to tell them about results that require no further follow-up. Finally, patients suggested that a clearly defined, widely available protocol for test result communication should be produced.

Strengths and limitations

Focus groups consisted of patients with recent experience of the testing and result communication process. Where possible, groups that were mixed by age and sex were created; however, this was not always achieved as younger patients that had committed to participate failed to attend focus groups and the desired ethnic mix was not achieved. As the time available for recruitment was finite, this led to a preponderance of participants aged >64 years. However, this does reflect the reality of the practice environment in
England, in which the majority of primary care patients are older adults. Nevertheless, the lack of representation of patients aged <30 years meant that it was not possible to gain the perspectives of younger patients, who were more likely to be working full-time and, as a result, have different needs and expectations. This does preclude the extrapolation of this study’s findings to all groups.

The use of alternative technologies that are not yet freely available in the NHS to communicate results directly from laboratories to patients was not explored in depth; neither was the potential impact on result communication of an increase in point-of-care testing. However, this may be worth exploring further in future research.

Although the number of focus groups was limited to four, this is within the range used successfully in previous studies,15 with no new themes emerging by having a greater number of focus groups.16 Although the researchers of this study cannot claim that the perspectives of patients at the study practices are internationally representative, previous studies in the US have also found that the process for communicating test results is haphazard and that dissatisfaction with current practice is pervasive.9,11

Comparison with existing literature

Timeliness. Although the service a patient ultimately receives from a clinician may be courteous, efficient, and complete, the length of time it takes to receive that service can adversely impact their overall satisfaction with care.17 In a recent survey, 57% of physicians in the UK reported that their patients experienced long waits for diagnostic test results, and although they use different models of healthcare delivery, this is higher than in Germany, the Netherlands, and the US where 9% reported the same.18

Telephoning the practice. Patients felt their phone calls could be managed better by the practice and suggested a telephone queuing system be employed to keep them better informed about the length of the wait for their call to be answered by an operator. Practice staff from the same practices also acknowledged they were finding it difficult to deal with the number of calls, but none had made changes to the way calls were managed.19

Receptionists communicating results. There is a dearth of literature describing the specific role of receptionists communicating results in primary care. Currently there are few requirements for receptionist staff to be trained and none that apply directly to either handling sensitive and confidential information or employing appropriate discourse styles for communicating that information.20–22 Evidence suggests that, without an objective explanation of results, patients remain worried about undetected medical problems if symptoms recur.23 This uncertainty surrounding the meaning or accuracy of normal results may lead to additional costly, unnecessary medical visits and diagnostic procedures. The need for reassurance may be a contributing factor to patients who book a GP appointment, regardless of the instruction they have been given for retrieving results. Evidence indicates that, if information is delivered to patients by their own GP, those patients benefit from improved continuity of care, patient understanding, and reassurance.24

GP appointments. That patients were unhappy with the availability of appointments with GPs is not new; several initiatives have attempted to free up GP time by either adopting business process models or by introducing auxiliary members of staff, such as associate physicians, to alleviate the pressure;24,25 although the results are promising further work is required.

Patients’ attitudes. Patients can adopt either a proactive ‘consumerist’ approach, or a more passive, reactive stance.26 This was reflected in this study sample, in which some patients felt it was the responsibility of the practice to communicate results while others said that getting test results was the patient’s responsibility. As a result, the quantity and quality of information provided may be dictated by the approach of the patient and not the clinician.27 More consistent information delivered by staff with appropriate training may help address the potential imbalance between patients who are proactive and passive; an important consideration in attempting to empower and engage all patients in their own care.28,29

Implications for practice

Test result communication is a core activity in primary care. Creating a system that ensures that patients get the correct test information at the right time, and from the most appropriate person, is a prerequisite for the delivery of compassionate and effective health care. Considerable effort has gone into developing and evaluating diagnostic tests, yet a chasm has opened up
between ordering the test and ensuring a patient both receives the result in a timely fashion and understands it.

There are several aspects of the current system in which primary care providers can improve efficiency and patient satisfaction, not least in reducing the wait for results, which can often be weeks.

Although not directly affecting the method of communication, improving access to phlebotomy can reduce the wait for results, no matter which method of communication is ultimately chosen. This more timely provision of phlebotomy appointments does not necessarily involve greater expense and the service may benefit from greater alignment to patient needs. ‘Lean management’ techniques that place emphasis on value for patients and more efficient utilisation of existing resources have already benefited phlebotomy services in secondary care and may do the same for primary care.30,31

In the future, the increase in affordability and accuracy of point-of-care testing, along with access to patient records via the internet, may have a positive impact on many of the issues highlighted here, including helping to reduce delay.32

The number of calls to a practice may be reduced considerably by automated, proactive communication of normal results, such as text messages; there is some, albeit limited, evidence that communicating normal results in this way can reduce anxiety in some patients.33,34 In addition, initiatives such as the UK Department of Health’s Power of Information strategy aim to increase electronic access to results and may also reduce the demand on staff time.35

When patients make no attempt to retrieve results, modern communication technologies may help. The proactive communication of normal results by practices would be welcomed by many patients who participated in this study; it also has the potential to reduce demand on practice staff. In addition, it seems that improved training of non-clinical staff involved in communicating results may improve the patient experience, as would a clearly defined and accessible protocol.

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