

Patient and Primary Care Physician Perceptions of Penicillin Allergy Testing and Subsequent Use of Penicillin-Containing Antibiotics: A Qualitative Study



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What is already known about this topic? Up to 15% of primary care patients carry an unsubstantiated label of penicillin allergy. Penicillin allergy testing offers an opportunity to confirm or exclude allergy, but despite recommendations, clinicians rarely use allergy services.

What does this article add to our knowledge? This article fills an important gap by highlighting barriers and facilitators to using allergy services and subsequent consumption of penicillin from the perspective of both patients and primary care physicians.

How does this study impact current management guidelines? Both patients and clinicians need to be supported to use penicillin allergy services, and be provided with the skills and information to prescribe and consume penicillins appropriately following a negative test result.

BACKGROUND: Removal of an inaccurate penicillin allergy record following testing allows patients to access first-line treatment for infections, and reduce the use of broad-spectrum antibiotics, which contribute to antibiotic resistance. However, it is seldom undertaken.

OBJECTIVES: To identify clinicians' working in primary care and patients' views on barriers and enablers for penicillin allergy testing and subsequent antibiotic use.

METHODS: Fifty interviews with patients and clinicians, including 31 patients with a record of penicillin allergy, 16 with

experience of testing, and 19 clinicians. Interviews were analyzed thematically.

RESULTS: Patients were often unaware of the benefits of penicillin allergy testing and only those patients who had experienced negative consequences of having a penicillin allergy label were motivated to get tested. Clinicians were reluctant to change patient records on the basis of their clinical judgment alone but had limited experience of referring patients with suspected penicillin allergy and were often uncertain about referral criteria and what the testing involved. Clinicians felt that

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This study summarizes independent research funded by the National Institute for Health Research (NIHR) under its Grants for Applied Research Programme (grant reference no. RP-PG-1214-20007). S.T.C. received additional funding from the NIHR Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance at the University of Oxford in partnership with Public Health England (PHE) (grant no. HPRU-2012-10041). The research is supported by the NIHR infrastructure at Leeds. The views expressed are those of the author(s) and not necessarily those of the National Health Service, the NIHR, the

Department of Health and Social Care, or PHE. The funder had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript, or in the decision to publish.

Conflicts of interest: M. Wanat, C. C. Butler, J. A. T. Sandoe, S. H. Pavitt, and S. Tonkin-Crine have received funding from the National Institute for Health Research. S. Tonkin-Crine also received funding from the National Institute for Health Research Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance at the University of Oxford in partnership with Public Health England. The rest of the authors declare that they have no relevant conflicts of interest.

Received for publication January 16, 2019; revised February 8, 2019; accepted for publication February 21, 2019.

Available online March 12, 2019.

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2213-2198

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<https://doi.org/10.1016/j.jaip.2019.02.036>

allergy testing could be beneficial and patients who had attended testing reported benefits of the test. Clinicians expressed uncertainty related to whose responsibility it was to make sure that the patient understood allergy test results.

CONCLUSIONS: Clinicians would benefit from information about penicillin allergy testing to be able to use these services appropriately, and to discuss referral with patients. Patients might be more motivated to seek testing if they were more informed regarding its benefits. Good communication between primary and secondary care would facilitate the updating of medical records, and promote better patient education. © 2019 American Academy of Allergy, Asthma & Immunology (J Allergy Clin Immunol Pract 2019;7:1888-93)

Key words: Penicillin allergy; Antibiotic stewardship; Prescribing; Antibiotic resistance; Qualitative

INTRODUCTION

It is estimated that up to 10% of patients registered with a UK general practitioner and up to 15% of primary care patients in the United States carry an unsubstantiated label of penicillin allergy. Fewer than 10% of these patients are found to be allergic when formally tested.¹⁻³ Therefore, a significant proportion of the population may, unnecessarily, be denied access to first-line antibiotic therapy.

The consequences of incorrect penicillin allergy records are significant. They include longer hospital stays,⁴ increased surgical-site infections,⁵ and increased infections with Methicillin-resistant *Staphylococcus aureus* and *Clostridium difficile* through the use of nonpenicillin antibiotics.⁵⁻⁸ Patients are also more likely to be prescribed broad-spectrum antibiotics such as quinolones, clindamycin, tetracycline, and sulphonamide macrolides,^{6,7} which are often more expensive and are associated with increased treatment failure.⁹ This research has recently informed the UK National Institute for Health and Care Excellence (NICE) advice to clinicians to “double check patients with penicillin allergy to avoid increased MRSA risk.”¹⁰ The Choosing Wisely initiative of the American Board of Internal Medicine Foundation recommends “don’t over-use non-beta-lactam antibiotics in patients with a history of penicillin allergy, without an appropriate allergy evaluation.”¹¹

Patients are frequently given a label of penicillin allergy due to common side effects of the drug such as nausea, or rash caused by concomitant viral illness. Often, there is incomplete or inconsistent documentation of allergy in medical records; or patients received the allergy diagnosis in childhood and have no recollection of the index event.^{2,12,13}

Penicillin allergy testing offers an opportunity to confirm or exclude penicillin allergy; patients who test negative can be “de-labeled” and advised that their risk of allergy is the same as for the general population. Testing with a combination of skin testing and oral challenge offers 99% negative predictive value for penicillin allergy.¹⁴ Despite recommendations from key organizations such as the American Academy of Allergy, Asthma & Immunology and UK NICE to test patients with a penicillin allergy record,^{1,14,15} clinicians rarely use these services,^{16,17} so it is vital to identify the barriers and enablers to uptake of testing among both physicians and patients. A recent rapid review assessing patient and clinician views on testing and subsequent antibiotic use found limited relevant literature, and no qualitative studies exploring these issues.¹⁸ We aimed to address this important gap by identifying clinician and patient views and experiences of referring to

or attending for penicillin allergy testing, and the use of penicillins following negative allergy testing.

METHODS

Participants and procedure

Design. This was a qualitative study using semistructured interviews with patients with a penicillin allergy record and clinicians in UK primary care.

Recruitment

Patients. Patients were identified using 2 methods. Patients with experience of penicillin allergy testing were identified from a general adult hospital allergy clinic in the North of England. An audit of clinic records identified patients who had attended for testing between April 2015 and April 2017. In addition, patients who did not undergo testing were identified from general practices in the geographical area that the allergy clinic served. Each general practice identified 50 to 100 patients with a record of penicillin allergy. All potential participants were sent a recruitment pack and asked to contact the research team if they were interested in participating in an interview.

Primary care clinicians. Clinicians were identified using 3 methods. First, clinicians working in practices with patients who had undergone penicillin allergy testing in the hospital allergy clinic were identified and invited; second, clinicians working in general practices in the geographical areas served by the hospital were invited; third, clinicians who contacted the local microbiology services with queries during the study period were invited. All potential participants were sent a recruitment pack and asked to contact the research team if they were interested in participating.

Interviews

Two semistructured interview guides were developed on the basis of primary research questions and informed by the existing literature on penicillin allergy.¹⁸ Interview guides were added to as necessary, when initial interviewees discussed additional relevant topics (see this article’s Online Repository at www.jaci-inpractice.org). Patients were asked about their personal experience or hypothetical views on penicillin allergy testing and subsequent use of penicillin. Clinicians were asked about their views of penicillin allergy testing and prescription of penicillins to patients who had a negative test result. After obtaining consent, interviews were conducted over the telephone by an experienced qualitative researcher (PhD qualified with substantial experience of conducting qualitative research), audio recorded, and transcribed verbatim. Interviews continued until data indicated saturation in each participant group.

Analysis

Data collection and analysis took place concurrently. Data from all interviews were analyzed. Transcripts were read and reread by M.W. both during and after data collection. To enhance the credibility of our analysis, researcher triangulation was performed; this meant that one-third of transcripts were read and analyzed by the wider multidisciplinary team to ensure that data were accurately represented. An inductive thematic analysis approach was used to analyze data.¹⁹ One author (M.W.) independently coded initial transcripts, which were then discussed with the wider team who met to review and agree on preliminary codes. Following coding of further transcript, M.W. developed a draft coding framework that was discussed and agreed by the team. The remaining interviews

TABLE I. Summary of patient and PCP characteristics

Characteristic	Patients	Clinicians
Mean age (y)	56	42
Age range (y)	19-72	34-60
Sex (%)	25 women (80%)	16 women (84%)
Experience of penicillin allergy testing/referring patients for penicillin allergy testing	16 (51%); (4 reported testing positive; 11 reported testing negative, and 1 reported an inconclusive result)*	9 (47%)

*Patient reports of the test outcome have not been independently verified; rather, these numbers reflect patient understanding of the test result.

were then analyzed using this framework, with changes made if needed. To enhance the trustworthiness of data, analysis was conducted and discussed by a multidisciplinary team consisting of psychologists, a sociologist, a primary care clinician, and colleagues from hospital-based immunology with expertise in penicillin allergy and microbiology services.

RESULTS

Participants

A total of 50 participants completed an interview. Of these, 31 were patients and 19 were primary care clinicians. Table I provides a summary of participant characteristics. Interviews were conducted between December 2017 and August 2018 and lasted 20 to 60 minutes (average 46 minutes).

Three themes captured the variation in patient views and experiences of attending for penicillin allergy testing; 3 themes captured the clinician experience of using penicillin allergy services.

Patient views

Personal relevance and benefits of the test. Patients both with and without experience of penicillin allergy testing reflected on the extent to which penicillin allergy created a problem for them. Most participants who were motivated to get tested had already experienced negative consequences of having a penicillin allergy label, such as not being able to have a planned operation, being denied first-line treatment, and having limited antibiotic choice because of other allergies or having the impression that other antibiotics were not working for them. Importantly, they had not been aware of these consequences of penicillin allergy labeling before they experienced problems.

I said well look, I'd like [a penicillin allergy] test. I've been asking for years for a test [...] because I've had infections where it has been bad—I said my body's just used to erythromycin. My body's just used to it [...]. It's like taking sweets. Doesn't do anything at all for me. (P1, female, 69, negative allergy test result)

In contrast, participants whose penicillin allergy status did not affect their day-to-day lives did not see an allergy test as personally relevant. This was often because they had not needed to take antibiotics and therefore had not experienced any negative impact of a penicillin allergy label. They also were not informed about benefits of having access to penicillin.

I suppose the only benefit would be it would be an alternative option to prescribe, I don't know whether that would be a benefit. As I say, I've not had a really negative impact, I've never had a condition where an antibiotic hasn't been

prescribed to me that hasn't seemed to do the trick. (P22, female, 51, no allergy test)

Finally, a small number of patients without experience of testing but who had sought additional information and were aware that penicillin is a first-line treatment for many infections felt that having access to a wider range of antibiotics could be beneficial to them in the future.

If the test showed that I was not allergic, I would be pleased; it would be a relief to know I wasn't. (P17, female, 68, no allergy test)

Importance of safety and perceived risks of test. Patients often considered risks involved in undergoing a penicillin allergy test. The first common concern was related to the possibility of having an allergic reaction. This was particularly true when patients had been told by their primary care clinician for many years to avoid penicillin.

The doctors were telling me I was allergic to them, then you worry that if you're going to do [a test] we'll get a bad reaction. (P7, female, 65, negative allergy test result)

Severity of the index reaction played a role in how patients perceived the risk of a further reaction; patients with previous severe reactions were more apprehensive about having the test. Patients with perceived severe comorbidity worried that if they were to have a reaction this could worsen their overall state of health.

The second concern of patients was around the degree of invasiveness of the test. Skin testing was generally perceived to be less frightening than an oral challenge test.

Because it's on the skin, it's not going in your mouth is it? You're swallowing a tablet, or two or three tablets, that's going in your system and you don't know what the reaction is going to be. I think that's the fear bit, really. (P18, female, 68, no allergy test)

Patients were concerned about how they would be monitored during a test. Assurance of access to trained medical staff at the time of the test seemed to counterbalance patient worries about reactions. Taking penicillin at home following allergy testing in the clinic to check for delayed reactions was particularly worrying for some.

Participants who had previously undergone penicillin allergy testing described the importance of feeling safe while undertaking the test. They commented that feeling "properly monitored" was important but did not want the procedure to be overly medicalized (eg, not having to lay in a bed). Participants felt reassured when testing took place on hospital premises.

Finally, participants also described the importance of the provision of information before testing, presented in lay terms. This allowed participants to know what to expect and addressed their concerns.

The [allergy] doctor I saw was very, very good. I mean he explained everything. He went through everything with me and you know, even made a joke about certain things that I was frightened of you know so it was — I was quite at ease in a way. (P1, female, 69, negative allergy test result)

Confidence in test result. Patients reported benefits and reassurance from having undertaken allergy assessment but also some uncertainties. Those who had had an allergy test often felt that the test result provided a definitive answer about their allergy status and was perceived as a proof.

You always have that bit of doubt in your mind of am I or aren't I [allergic]? My husband thought it was [psychological], because I was reading what can happen, but even when I didn't read what could happen, it still happened, so [the test result] put my mind at complete rest that it's not just in my mind, it is actually an allergy that I've got. (P4, female, 47, positive allergy test result)

Participants reported having confidence in the test when they felt they had undergone a thorough testing procedure. Other participants felt confident in the result after they had taken penicillin without a reaction following the test.

I think if I hadn't had all the thorough testing, I would have been quite nervous to take penicillin. Because obviously with what had happened before, when I was younger. But now, I'm fine. It doesn't bother me, I can take it and it won't scare me. (P3, female, 19, negative allergy test result)

Of note, some participants reported that their clinician had doubts about a negative test result and continued to prescribe alternative antibiotics; other clinicians reversed changes to medical records to reapply the allergy label if participants experienced any side effects from penicillin. Relabeling might have been appropriate in some cases; however, it was not possible to assess on the basis of patients' reports.

Most participants felt anxious about taking penicillin after a negative test result. This was often related to the fact that the allergy label had been in place for a long time; occasionally they (incorrectly) believed that they had only received small doses of penicillin during the test and were worried about having a full dose of penicillin for the first time without supervision.

Cause I've lived with that fear, if anybody gives me penicillin I'm gonna die sort of thing, for years you know, from being a baby so of course you can't just terminate a fear like that. It's still there in the back of your mind all the time. (P1, female, 69, negative allergy test result)

Similarly, some patients with no experience of testing doubted whether they would ever believe a result that indicated they were not allergic to penicillin, because they believed they had had very severe reactions in the past.

Clinician views

Doubts about removing penicillin allergy labels.

Clinicians often reflected on whether allergies recorded in medical records were likely to be accurate and often doubted whether allergy labels were correct. However, for most their clinical judgment alone was not enough to change the medical records and they were worried about being responsible for causing someone to have an allergic reaction.

In general practice quite often once something is coded, yes of course you can change the codes but quite often when something is coded it's kind of set in stone. (Clinician 11)

On occasions, this was due to the clinician's perceived lack of knowledge, for example, being unsure whether allergy is hereditary and therefore avoiding penicillin in the children of patients who are allergic to penicillin.

Some clinicians perceived patients taking penicillin without problems as convincing evidence that a patient was not allergic and felt confident in changing medical records in this situation.

Yes, if it's been demonstrated that they're actually okay with the antibiotic after that original documentation then I have removed it. For example, if it said allergy to amoxicillin and they've subsequently had amoxicillin and been fine with it then I'd remove the allergy warning. (Clinician 13)

However, even after repeated penicillin prescriptions, some clinicians were still reluctant to amend the records and for most, only penicillin allergy testing was perceived as definite proof of tolerance.

If I was 100% sure I had specialist advice that the patients did not have an allergy to penicillin I would remove it from the records. (Clinician 4)

Knowledge of the allergy service and referral process.

Although clinicians saw value in the allergy service, they had very limited experience of it and thus poor understanding of what the service could offer. Even clinicians with experience of referral had limited information on the actual test procedure and accuracy of the results. Although some were familiar with skin testing, few were aware of the oral challenge test component. Clinicians described the importance of guidelines in learning about the allergy service as well as deciding which patients should be referred. Many felt that because they lacked information about tests, including benefits and risks, they were unable to advise or encourage patients to be tested.

Maybe some advice on what we can tell the patient about what it would mean for them, as in if they weren't penicillin-allergic, what actual benefit we'd be able to provide to them if we could give them penicillin [...] because they might say, "Actually, I've never had penicillin, I'm not bothered, just don't give me it, I don't want to go and have any testing." (Clinician 2)

Clinicians had a range of experiences in referring patients for penicillin allergy testing, but none routinely referred. Clinicians with experience of referring patients mostly referred those reporting numerous allergies or who had developed an antibiotic-resistant

infection. They also referred patients who had suffered a severe reaction. Clinicians were particularly concerned about the appropriate referral criteria and whether they would overburden the allergy service; in many cases, this resulted in never referring patients.

Clinicians with experience of referring had positive views on the service and the referral process and thought it helped them improve their management of patients. However, some could not recall seeing patients' test results, indicating a possible lack of follow-up.

Process of updating medical records. Most clinicians reported that it is easy to change a patient's allergy status on their electronic medical record if required, provided a reason is given. Others highlighted that allergy alerts might still be active if the system did not differentiate between intolerance and allergy; this might prevent penicillin prescriptions despite negative test results.

Clinicians described their views on who should be responsible for the process of updating the records and how and whether the results should be communicated to patients. Some felt this was the responsibility of the allergy clinic; others believed it was their role to ensure the patient understood the results because they were responsible for ongoing care. Some felt it was important to discuss negative test results to address patients' potential concerns about taking penicillin.

You would have to discuss [the test results] with the patient, because some patients might say, "I still don't want it." [...] I think patients have their own opinion, so if information came back to me that it was safe to prescribe, I would have to speak to the patient, because they might just say, "Oh, I don't care about that result, I don't want it anyway." (Clinician 8)

DISCUSSION

This study is the first to provide an in-depth understanding of patients' and primary care clinicians' views of the consequences of a penicillin allergy record and penicillin allergy testing. It highlights key barriers and facilitators to effectively using penicillin allergy testing services and prescribing/using penicillins appropriately after a negative test result.

Although most patients talked freely about their perception of risk, many were unaware of the negative consequences of a penicillin allergy label; those who were had gained this understanding through direct experience. Most patients who had undergone testing felt confident to take penicillin after a negative test result; however, some patients remained anxious about safety.

Clinicians were aware that penicillin allergy records were often incorrect but felt reluctant to change them on the basis of their clinical judgment. They had positive views toward penicillin allergy services but reported numerous barriers to their use. They were uncertain about whose responsibility it was to make sure that the patient understood the allergy test results.

Only 2 questionnaire studies have previously explored patients' views on, and satisfaction with, penicillin allergy testing.^{17,20} These studies demonstrated that patients had positive views toward getting tested for penicillin allergy and those who had undergone testing felt that it provided them with useful medical information.^{17,20} Our study highlights that patients weigh the possible benefits of testing against the perceived risks. Not knowing the potential negative consequences of a penicillin allergy label meant that patients had

reduced motivation to attend for testing. The results highlight that patients appeared to judge the risk of the test on the basis of a number of factors; perception of likelihood and severity of a reaction; degree of invasiveness of the test; and the degree to which they felt they would be monitored.

In line with previous research^{18,21} we found that clinicians had limited experience of referring patients for penicillin allergy testing and were often unaware of the existence of allergy services. Even clinicians with experience of referral were sometimes unaware of the specific nature of the testing. Clinicians approved of the penicillin allergy service; however, they would benefit from more information about the harms of a penicillin allergy label and the process of testing to help them confidently refer and to be able to discuss referral with their patients. Patients' concerns about potential benefits and risks of testing need to be addressed by both clinicians and allergists to increase their motivation to attend for testing. Appropriate evaluation of patients with a penicillin allergy label is rapidly becoming a focus point for public health and antibiotic stewardship initiatives.^{10,12,22}

We identified the potential barriers and facilitators to penicillin prescription and use following negative testing. This is an area not well defined in the literature; studies have highlighted patient anxiety around having a reaction,²³⁻²⁶ lack of confidence in the safety of penicillin administration,²³⁻²⁶ or uncertainty about which class of antibiotics could be safely received.^{27,28} Patients were reassured by having undergone a "thorough" testing process and having a need for a penicillin following a negative test result motivated consumption of penicillin; a barrier to consumption was the presence of an allergy label for many years.

Clinicians expressed uncertainty about who is responsible for ensuring patients understand the results and for updating the medical record. This highlights the need for a clear and consistent approach to delabeling with support from colleagues in secondary care. Documentation of side effects during future courses of penicillin needs to be clear and precise to prevent relabeling of the patient.¹³

Strengths and limitations

This is the first qualitative interview study to provide in-depth understanding of patient and clinician views and experiences of penicillin allergy testing and of subsequent penicillin use. It highlights key barriers and facilitators to clinicians referring patients, and to patients then attending for testing. Because previous studies used mainly survey designs and often focused on clinicians' views, this study fills an important gap by providing a patient-centered perspective. This is a qualitative study with a purposeful sample that recruited from one region in England; the results should be interpreted cautiously in terms of their transferability to other settings. The next step could include conducting a survey with a representative sample of patients, designed on the basis of results from this study.

CONCLUSIONS

Both patients and clinicians need to be supported to use penicillin allergy services, and be provided with the skills and information to prescribe and use penicillins appropriately after a negative test result.

Acknowledgment

We acknowledge the support of the National Institute for Health Research Clinical Research Network.

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ONLINE REPOSITORY

TOPIC GUIDE—CLINICIANS

1. Can you tell me about how you usually identify patients who have a penicillin allergy?

Prompts: How is penicillin allergy recorded in patient notes? How easy it is to obtain this information? How often do patients report a penicillin allergy themselves?

2. Can you tell me about a time where you have queried whether a patient is actually allergic to penicillin?

Prompts: In what sort of situation do you doubt that a patient has a genuine allergy to penicillin? What makes you query a penicillin allergy record? How has this influenced your prescribing decision?

3. What do you think are the consequences of patients having an incorrect penicillin allergy label?

Prompts: What disadvantages are there for patients? What disadvantages are there for your practice? Any other disadvantages?

4. What action do you take if you think a penicillin allergy record is incorrect?

Prompts: When would you choose to refer someone to an allergy service? Are there any barriers to changing a penicillin record?

5. Can you tell me about the allergy services that are available for patients in your area?

Prompts: Where is your nearest allergy service? What do these services provide? What do you think of these services?

6. Can you tell me about a time you have referred a patient for penicillin allergy testing?

Prompts: What made you decide to refer the patient? How did you refer the patient? To whom did you refer the patient? Were there any barriers to referring to the service?

7. Can you tell me what happens when a patient is referred to an allergy service in your area?

Prompts: How quickly are patients seen by the service? Who are patients seen by?

8. Can you tell me what you know about penicillin allergy testing?

Prompts: How does testing work? What are patients required to do? How long does it take to get the result? What do you think about the process of being tested?

9. Can you tell me what happens to the results of the test?

Prompts: How confident are you in the results? How would you interpret the results of the test? What do you do if the test result comes back negative? Would you/How do you discuss the results with the patients?

10. What do you think are the advantages of correct penicillin allergy label?

Prompts: What advantages are there for patients? What advantages are there for your practice? Any other advantages?

Topic Guide—Patients

Part A—for patients who have undergone penicillin allergy testing in secondary care

1. Can you tell me about how you first got referred for the test?

Prompts: Who referred you? What did they say when they referred you? Why did they choose to refer you? What had happened for you to be referred?

2. How did you feel about going for the test when you were originally referred?

Prompts: What did you think the test was going to involve? What concerns did you have about the test? How important do you think it was to have the test?

3. Can you tell me what happened when you went for the test in the allergy clinic?

Prompts: What did you have to do? Who carried out the test? What did the test involve? How long did the test take?

4. How did you feel about having the test?

Prompts: Was the test different from what you expected? Were there any problems when carrying out the test? Was it easier than you expected? Would you do it again?

5. What would you say to other people with a suspected penicillin allergy about the test?

Prompts: Would you recommend other people to have the test?

6. What was the result of the test?

Prompts: What happened after the test? What changed as a result of the test? Did you speak to your GP about the result of the test? Did you take any different types of antibiotics as a result of the test? What did you think of the result of the test? How do you feel about taking penicillin now?

Part B—for patients who have not undergone penicillin allergy testing

1. Can you tell me what you think about the penicillin allergy test?

Prompts: Have you heard about this test before? Does anything surprise you about the test? Does anything concern you about the test?

2. How would you feel about being referred for this test yourself?

Prompts: Do you think you would attend for the test if it was offered to you? Why/why not? How easy do you think it would be to have the test?

3. What benefits do you think there are of people having penicillin allergy testing?**4. What disadvantages do you think there are of people having penicillin allergy testing?****5. How would you feel about the result of the test if you attended?**

Prompts: If it was positive and confirmed your penicillin allergy? If it was negative and confirmed that you weren't allergic to penicillin? Would you feel confident in test results? What would you do with the results?

For all participants

15. Is there anything else you would like to mention that we haven't talked about?

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