Why members of the public self-test: an interview study

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Background. A wide range of self-tests are available where contact with a health professional is not necessary.

Objective. To investigate factors that influenced members of the public to use self-tests.

Methods. Questionnaires, sent to 2335 adults from two general practices in North Birmingham, asked whether recipients had used self-tests and sought consent for contacting them about taking part in an interview. Twenty-three people were interviewed, 20 of whom had used self-tests. The interviews were transcribed verbatim, and a thematic analysis was conducted.

Results. The findings were organized around two themes. ‘Motivations for self-testing’ describes the motivating factors surrounding participants’ choices to use self-tests. This appeared to be influenced by a number of factors that were organized into four sub-themes: ‘diagnosis or speculation’, ‘perceived benefits of self-testing’, ‘general attitudes to and experiences of health care’ and ‘general attitudes to health’. The second theme called ‘experience of self-testing’ describes participants’ access to, and use of self-tests, and is split into three sub-themes: ‘opportunistic awareness and access’, ‘use and application’ and ‘impact on life’.

Conclusions. Overall, self-testing encompasses a broad variety of beliefs and experiences. Some participants saw self-tests as a serious diagnostic tool, whereas others used them out of simple curiosity. Some were motivated by their generally positive attitude to health, but others may have been motivated by negative health care experiences. Some saw self-testing as an empowering process to be proud of, while others seemed to view it as an illegitimate activity that needed to be hidden from professionals.

Keywords. Diagnosis, routine diagnostic tests, self-care.

Introduction

Recently, the government has promoted self-care on the basis that the public favour more control over their health and that self-care improves outcomes and appropriate use of services. Concurrently, a wide range of diagnostic self-tests have become available. Results are available immediately or after sending a sample to a laboratory, but contact with a health professional is not necessary.

Members of the public might self-test not only because of perceived benefits of being tested outside a conventional medical setting, for example, privacy or convenience, but also because they assume that self-testing is a desirable self-care activity as promoted by the government. There are, however, potential harms from self-testing, for example, false reassurance arising from false negative results or the distress caused by false positive results. Self-tests also have the potential to reduce or reinforce inequity: the use of self-tests by people who can afford them and simply wish to check on their health could free up conventional services for others, but people who are unable to adequately communicate their needs to a health professional may end up buying expensive and perhaps undesirable self-tests. The use of self-tests could also result in demands on health services to investigate false positive results or clinically insignificant true positive results. Despite the potential impact, there is an absence of studies about why people use self-tests. The aim of this study was to use in-depth qualitative interviews to investigate factors that may have influenced members of the public to use self-tests that required them to take their own biological sample, such as urine or blood.

Because of the lack of evidence about self-tests, a systematic review conducted alongside this qualitative work focused on activities that may be
considered similar to self-testing because they relate to self-care and can be initiated without the involvement or recommendation of a conventional health professional. This found that users of complementary and alternative medicine (CAM) and over-the-counter (OTC) medicine in the UK are female, middle-aged, affluent and/or educated with some measure of poor health and that people who use the private sector in the UK are affluent and/or educated. Some studies also described reasons given for using CAM or OTC medicine, such as the influence of acquaintances or family members or orthodox medicine’s disadvantages, for example, rushed appointments and its limited effectiveness. Some studies also suggested a link with healthy lifestyles or being health conscious and knowledgeable about health. In line with the systematic review, a recent survey from the Netherlands found that self-testers generally reported lower health status than non-testers. It also reported that they had a higher body mass index but were more likely to engage in health-related behaviour, for example, use of dietary supplements and homeopathic medicine.

**Methods**

**Study population**

In June and July 2006, questionnaires and prepaid envelopes were sent to 2335 adults aged 18 years or older from two general practices in North Birmingham Primary Care Trust. The practices generated a random sample of 2500 adults but excluded 165 people who they felt that it would be inappropriate to approach. The questionnaire elicited age, sex, ethnic group, employment and health status. Self-tests were defined—‘Self-tests are bought from shops or over the Internet. They are used to test for conditions or diseases without involving a doctor, nurse or other health professional.’—and the questionnaire then asked whether the person had used named self-tests, identified by a systematic internet search or another self-test. The questionnaire then sought consent for contacting people about taking part in an interview about their views and experiences of self-tests. People were asked to return the blank questionnaire if they did not want to take part. One reminder was sent after 3–4 weeks.

Purposive sampling was used to select participants. It was felt that reasons for self-testing may vary depending upon the person’s sex and age and the type of test. Potential interviewees were, therefore, placed in groups based on sex, age (<50 and ≥50 years) and type of self-test (allergies, cancer, cholesterol, diabetes, fertility, kidney disorders, low blood count, sexually transmitted infections and urine infections). The plan was to invite people from as many groups as possible, randomly selecting from groups with more than one person. People who were selected were sent an information leaflet and reply slip with a prepaid envelope. People who were willing to be interviewed were contacted by telephone and given the option of being interviewed at home or at The University of Birmingham. Invites were sent out in two batches to facilitate analysis being conducted alongside interviews.

**Conduct of interviews**

Interviews are suitable for gaining an in-depth understanding of personal experience and perspectives. All interviews were conducted by AR. Informed consent was obtained before each interview and a topic guide, informed by the objectives of the study, was used (Fig. 1). The interviews always began with easy to answer questions about how interviewees found completing the initial questionnaire with the aim of easing them into the interview. Key areas for discussion were then signposted, for example, how the person found out about and decided to use the self-test, and follow-up questions were used if needed. The questions were designed to be open–ended, precise and clear, although the wording could be adapted to suit the interviewee. Respondent validation was sought by sending participants a summary of their interview and asking them to return a reply slip.

**Method of analysis**

A thematic analysis of the interview transcripts was conducted. This involved grouping the data into themes and examining all transcripts to ensure that all occurrences of each theme had been accounted for and compared. The analysis was undertaken in six phases, as described by Braun. The first phase involved familiarization with the data by transcribing the interviews and reading the transcripts. For the second phase, an initial list of codes was generated independently by AR and SG. During the third phase, the analysis focused on organizing the codes into themes and sub-themes, constantly comparing themes within and between different datasets. AR and SG then met before the next phase of data analysis to discuss and agree the codes, themes and sub-themes that had been identified. It was also agreed that no new relevant data were emerging in the later interviews and, therefore, that no more interviews were needed. The candidate themes and sub-themes were then reviewed, refined and finalized by AR and JI in the fourth, fifth and sixth phases of analysis, which involve reviewing themes, defining and labelling them and then producing the report of the research. Following Pope and Mays, an effort was made to go beyond a simple description of the data, with a view to explaining why people might choose to self-test and how broader social factors, which emerged from the data, might impact upon how this choice is made and the consequences of the choice.
Results

Study population

 Completed questionnaires were received from 1490 people (64%). Twenty-two had given a different sex and/or age (>2 years different) than the practice and were excluded as they did not appear to be the intended recipient, leaving 1468 eligible respondents. Excluding pregnancy tests as their use is now routine, 188 people (13%) reported using a self-test and 114 (60%) of them were willing to be contacted. One questionnaire was received after invitations to interview had been mailed and 10 people were excluded: three marked ‘other’ self-test but did not specify a test, three added free text that contraindicated their willingness to be contacted, three gave ages on the initial questionnaire that were (up to 2 years different) to the ages provided by the practice and one did not supply personal details. This left 103 people.

Potential interviewees were contacted in two mailings. In the first mailing, 23 people were invited for an interview, 15 replies were received, 9 people were willing to be interviewed and 7 interviews were conducted. It became apparent during early interviews that, rather than buying self-tests, people also borrowed devices or used them at work. As a result,
potential interviewees were asked how they had accessed tests before interviews were arranged. This was to allow purposive sampling based on how self-tests were accessed to ensure that sufficient people who had bought self-tests were interviewed. In the second batch, 53 people were mailed, 33 replies were received, 25 people were willing to be contacted, 17 appointments were made and 16 interviews were eventually conducted.

**Respondent validation**
Twenty-one of the 23 interviewees returned the reply slip and all agreed that the summary reflected what they had said.

**Characteristics of interviewees**
The 23 interviews involved at least one person from 18 of the 26 age-, sex- and test-specific groups that were populated. The interviewees comprised five men aged from 35–39 to 60–64 years and 18 women aged from 15–19 to 60–64 years. Twenty-two were white and one was Asian. Most (n = 17) were employed or self-employed and most (n = 17) described their health as good or fairly good.

Interviewees consistently stated that they had understood the definition of ‘self-testing’ on the questionnaire, but it became apparent during the interviews that three participants had only used self-tests with a clinician’s involvement. Interviewees accessed tests in a variety of ways (Table 1), but 12 had bought at least one of seven different types of tests for home use. The next most common way to access a test was to borrow a testing device, but this was only used for blood or urine glucose tests. Only four interviewees had undertaken tests at work, but each had accessed at least two different tests.

**Emerging themes**
The findings from the analysis of interviews can be organized around two main themes, which can themselves be split into four and three sub-themes, respectively. The first theme, ‘motivations for self-testing’, describes the motivating factors surrounding participants’ choice to self-test. This choice appeared to be influenced by a number of factors, which can be organized into four distinct sub-themes: ‘diagnosis or speculation’, the ‘perceived personal benefits of self-testing’, ‘general attitudes to and experiences of health care’ and ‘general attitudes to health’. The second theme, ‘experience of self-testing’ describes participants’ accounts of how they came to access the tests and is split into three sub-themes: ‘opportunistic awareness and access’, ‘use and application’ and ‘impact on life’.

The emerging themes, sub-themes and relationships are described below. Selected quotations have been used to illustrate the points being made. Given the small sample size, it is not appropriate, nor useful, to represent these findings numerically, although, where it is meaningful, indication has been given to whether the point under discussion was made by the majority or minority of participants.

**Motivations for self-testing**

**Diagnosis or speculation.** Some participants used self-testing because they were looking for a specific diagnostic outcome, whereas others used them speculatively, out of curiosity or for general reassurance about the state of their health. One participant, for example, made the decision to self-test for food allergies in an attempt to diagnose the problem behind her inability to maintain weight loss.

1698—Female aged 50–64 years: Well I’d always been fairly slim, all through my twenties and thirties and then I started to gain a lot in my forties. Didn’t feel I’d changed my diet in any way. Um I had thyroid tests. Still couldn’t, I could lose a couple of stone but it would go on again very quickly so I suppose that was an avenue to think was I allergic to something or to find out. Um so that’s why.

This ‘diagnostic’ test is interesting for two reasons. First, this participant is taking on for herself the role of ‘doctor’—identifying a symptom and undertaking tests to identify the cause. It suggests that the participant is willing to take responsibility for her own health and feels confident in talking on this role. Second, it is interesting because the test is diagnostically unsound. It is, medically speaking, highly unlikely that the results of a food allergy test would shed any light on the ‘symptom’ under investigation. This participant provides us with an example of the ‘empowering’ benefits of self-testing (described in more detail below) but also with an example of the danger of ‘lay ignorance’, leading her to undertake a test that was unlikely to provide the answer she was looking for.

Other participants undertook speculative testing, conducting a test out of curiosity or to monitor their general health in response to a perceived risk. One participant described himself as ‘fairly fit’ but acknowledged his job was stressful and, because of this, he carried out regular blood pressure and cholesterol tests.

673—Male aged 35–49 years: And yeah cholesterol really because I’m fairly fit, I play rugby every weekend, go training and try and keep fit in that sort of way, and it was just a case of seeing, you know, am I going to clog up in 20 years time or not. And whether that’s just a sole factor I don’t know, but I suppose you can just take it on in that way. My blood, I monitor my blood pressure just because I’m involved in work and, you
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know, you have a hectic day and you just make sure life is going along.

Another participant, knowing she had a family history of heart problems, decided to conduct a self-test to monitor the health of her heart.

**1004—Female aged 35–49 years**: And the heart one was cos my mum nearly died from a heart attack and she had, you know thank god she survived and everything, but she had a horrendous time, so I thought oh I’ll check that cos they say again that heart conditions can be hereditary.

Other kinds of speculative testing were undertaken by participants who simply talked about being curious and using a particular test just because it was available.

**673—Male aged 35–49 years**: Why cholesterol testing I don’t know to be honest. It was just an available product on the shelf.

**165—Female aged 35–49 years**: I hadn’t got a complaint that required that I needed to go and check it out, but it was available and I thought that’s something I’d really like to know.

The two motivations for testing described here, diagnosis based and speculative, describe two very different reasons for wanting to self-test. The former looks to confirm or explain the existence of a known or suspected problem and the latter seems to be practised for reassurance about the general state of a person’s health.

**Perceived benefits of self-testing.** Generally, participants tended to describe undertaking a (relatively superficial) cost/benefit analysis. Costs tended to be described in terms of monetary cost, with only minor consideration given to any practical or emotional burdens of carrying out or accessing the test. One participant, for example, described monetary cost as a significant barrier to self-testing, even when it was thought to be worthwhile.

**851—Female aged 35–49 years**: I mean it’s probably worth having it done if you’ve got a problem in that direction and you think it’s, you know I would, I would pay to have that done if I thought that was, you know, a good idea, but it is expensive and that’s the trouble with a lot of these tests, they do cost money.

On the other hand, a range of perceived benefits were described, which tended to be weighed against the monetary cost, predominantly the benefits of ‘anonymity’ and ‘avoiding a GP consultation’.

One key benefit described by some participants was the anonymity of self-tests, contrasted with the potentially distressing or embarrassing personal interaction necessary when seeing a doctor. Some participants felt that self-tests could be used to avoid seeing the doctor for ‘embarrassing’ complaints, such as those involving intimate body parts or bodily functions. As one participant put it:

**1697—Female aged 35–49 years**: There’s two elements involved because there’s the, if you like, the embarrassment factor of well, you know, that’s a part, I don’t mind talking to the doctor about my nose, but I’m not so keen to talk to him about what I do on the toilet.

A related benefit perceived by one participant was the potential for checking that there is actually a problem before going to the doctor with a potentially embarrassing complaint. This participant seemed to be suggesting that it would not be a problem seeing the doctor when she knew there was something wrong but wanted to avoid the embarrassment of disclosing intimate information if it was unnecessary.

**2292—Female aged 18–34 years**: In a way it’s a good thing because it might encourage more people to come forward, particularly I suppose, I presume your faecal occult is bowel cancer that you’re testing for, particularly maybe for bowel cancer because of the embarrassment factor that some people have with that.

This seems to be an example of another form of cost/benefit calculation where the cost of emotional distress/embarrassment is balanced against the benefit of treatment. If a benefit is relatively certain (it is likely there is a problem that needs addressing), this may shift the balance of the calculation and override the ‘embarrassment factor’, prompting a visit to the GP.

While one reason for wanting to avoid a consultation may be the ‘embarrassment factor’ described above, other reasons were described. Some participants, for example, felt that a GP’s time was valuable and felt that they could avoid ‘wasting’ the GP’s time by self-testing.

**365—Female aged 50–64 years**: And I’m just thinking of freeing the doctor up really. So I suppose in a way these self-tests are a good thing because if you go and you think ooh I’ve got this and it comes up that you haven’t then you’ve not wasted the doctor’s time but you, that time could have been valuable for somebody else.

**1260—Female aged 50–64 years**: I do think really, just get the general impression GPs are busy and so I just wouldn’t bother them with something that
I wanted to do routinely. I would do that myself sort of thing.

Some participants also felt that self-tests could save them time and avoid some of the logistical difficulties involved in going to see the GP. One participant, for example, described how she felt self-testing could help reduce the amount of time spent waiting for appointments and test results.

1697—Female aged 35–49 years: It might be hard to fit that in around the times that are available and the times that you’re available so that’s a delay. There’s then the time involved in actually getting something tested and whether that’s something the doctor does and sends off or whether you go down a hospital and do it, and it’s not huge delays but if you can compare that to a pregnancy test is a good example, you know you can just go and buy it and do it there and then and five minutes later you’ve got your answer.

Another participant had similar feelings but described the logistical benefits in terms of avoiding the need to find a parking space. She felt that it was not always easy to just ‘bring a sample in’ and it would be much easier to do the test yourself at home and phone in the results.

2280—Female aged 35–49 years: Well yes because then, cos usually they’d say oh well we want to do a test, bring a sample in tomorrow so that we can test it. Well it’d save you a journey then if you’ve done it already. You know, you can do it at home and say well this is what the results were. So that would be a good way. Because it’s always parking as well at doctors, you can never get parked, so that’s another good reason.

These perceived benefits tended to be discussed in the context of a general belief that self-testing is quick, easy and convenient. One participant likened medical care to banking: self-tests, like cashpoint machines, are just more convenient than going to the bank.

673—Male aged 35–49 years: No, but the thing is I can do the cholesterol five minutes at home. Yeah, going to the doctor, I’m going to sit there for 40 minutes or so. Yeah, I’m going to have to take time out at some stage. And it’s just inconvenience really. It’s like going to a bank. I don’t go to a bank anymore, I go to a cashpoint or I do it on the internet or I do it over the phone, you know.

Although it was not clearly expressed by the participants themselves, there also seemed to be a tacit assumption that self-tests are effective and reliable and are an appropriate substitute for professionally administered tests.

General attitudes to, and experiences of, health care. While many of the perceived benefits described above are likely to be significant positive motivating factors to self-test, some participants described negative motivations, based on their experience of visits to the GP in the past, including GPs being uninterested or dismissive.

1697—Female aged 35–49 years: I can think back to a time when I was having problems with, after I’d had my child, having problems with really bad PMT and having the doctor sit there telling me that that was all in my head as well, you know, and thinking OK well I’ll just sort myself out, shall I?

1698—Female aged 50–64 years: I think I felt the doctors would say, you know, just eat less there’s nothing wrong with you. I didn’t, I think unless you’ve got really severe symptoms from food intolerance, you know I, problems with your bowel and that sort of thing, I wouldn’t have thought they were that interested really.

Related to this was the feeling expressed by one participant that GPs are so busy, and can therefore be so dismissive of problems, that she needed to use a self-test as ‘ammunition’ to justify her decision to make an appointment. In the same way that patients may use self-testing to justify the visit to themselves, they may also use self-tests to present the GP with evidence that the consultation is justified and they are not time wasters.

2121—Female aged 50–64 years: So it’s almost like getting ammunition to go the doctor because they’re very busy.

One male participant offered no other reason for wanting to avoid a consultation than the fact that he did not like seeing doctors.

673—Male aged 35–49 years: I mean I know the doctors like to see their patients, but to be honest patients don’t like to see doctors, or I don’t.

Another negative aspect of a GP consultation that motivated one participant to self-test was the use of medical jargon within the consultation.

1956—Female aged 50–64 years: Sometimes the doctors talk to you in it’s a way above your head, you know, and you ask them a question about something and they answer it, but it’s in doctor’s terms that they’re using so sometimes
you might be as well to go out and get a test and do it yourself.

General attitudes to health. For many participants, the decision to self-test was located within a broader narrative concerning the amount of control they felt they had over their own health and the amount of control they wanted to have. Some participants described self-testing as an empowering process, by which an individual can take back control of, and responsibility for, their own health.

1260—Female aged 50–64 years: I think it puts you more in control because you're thinking well I'm making this decision to go and buy this and I'm looking at this and testing for myself and I think that I'm then in control rather than sort of abdicating it over to your doctor again, you know.

1868—Female aged 35–49 years: I think it does perhaps put the onus, make people realise that yes they can do things themselves, they don't have to go running to a doctor for everything.

Others described the way in which self-testing can empower people by enhancing their ability to make informed autonomous choices about their own health and implied that people would benefit from this.

2121—Female aged 50–64 years: The more that people take responsibility for their own health, and the more knowledge that they get, the better they're going to be able to look after themselves in the future, and then it's their own choice then.

2338—Female aged 18–34 years: It's about knowing your own physical state really and then being able to make choices around that, whether to buy any supplements and all the rest of it.

Summary—positive versus negative motivating factors. Broadly speaking, we can see both positive and negative motivators for self-testing. Interviewees generally spoke about a mix of positive and negative factors, although more extreme profiles were noticeable. At one extreme, participants tended to have a positive attitude towards their health. They liked to be in control of their health and self-testing enabled them to carry out a routine check on the state of their health, for example, on their cholesterol level. They tended to have more positive experiences of health care, and self-tests were simply preferable to visiting the doctor because they were convenient or did not take up their doctor's valuable time.

At the other end of the spectrum, participants self-tested to diagnose a specific problem, and they tended to want to avoid conventional services because they had been dismissed repeatedly in the past or they felt that doctors would dismiss what, to the medical profession, might be considered to be a minor problem. Figure 2 gives examples of these two extreme journeys.

Experience of self-testing

Opportunistic awareness and access. Despite the majority of participants being able to identify multiple perceived benefits of self-testing, many did not seek out tests based on an a priori notion of those benefits, nor for a specific purpose, but rather accessed tests opportunistically. Some, for example, simply came across the tests while out shopping and brought them on impulse, while some brought them in response to advertising.

673—Male aged 35—49 years: Just walking round Boots to be honest, yeah so I was walking round Boots, don't know what I'm looking for, just saw it and said oh that's a good idea.

Additionally, some found out about tests that were used by friends and family and tried them out of curiosity.

365—Female aged 50–64 years: Well, we'd seen him, we knew of it anyway, so we knew he was testing it, himself with it. So I don't think we went into a lot of conversation about it really. He just happened to get the equipment out and we were just talking about it then.

Similarly, another participant talked about how she became aware of, and decided to access, a food allergy test after listening to a friend describe a positive experience. One participant, however, described how even opportunistic purchasing of self-tests was probably motivated by some pre-existing health concern.

1004—Female aged 35–49 years: She'd put on weight, and she had this food test and she said she couldn't get over how much better she felt. She said I feel so well and everything. I thought blooming hell I'm going to try that and see if I can lose some weight.

1697—Female aged 35–49 years: Sitting in the chemist waiting to, for your prescription to turn up, you know you read everything's that's available cos it's, you're a bit bored. And saw it there originally and probably had, it had been kind of latently in the back of my mind for some time.

What is interesting here is that although some participants clearly did self-test with a specific purpose in mind (see ‘diagnosis or speculation’ above), others clearly accessed self-tests opportunistically in response...
to having seen a test used or advertised, which may resonate with a pre-existing concern. The pre-existing concern might not be sufficient to warrant a visit to the doctor or to go out with the intention of buying/accessing a self-test, but it may be sufficient to motivate a person to use a self-test when they happen upon one. This kind of opportunistic access suggests that the use of the test, and the possible consequences, are not always thought through in advance.

Use and application. Most participants who had used self-tests described the process and experience as unproblematic, having found instructions easy to follow and the tests easy to use. One participant did highlight a concern about the test she had used, leading to worries about whether or not she had performed it correctly.

165—Female aged 35-49 years; You know, you’ve got to have a little piece of paper and you’re just looking and you can’t really see it and you think hmmm. And you always doubt cos it’s the thing with cholesterol tests it has to be quite quick, and you think have I looked at it quick enough or at the right time. You leave it so many minutes before you read it. You’re always sort of slightly doubting.

Some participants suggested that they would have difficulty with self-tests, even simple tests, which involved taking blood. While some had no problem with the idea of this, others felt that they would always need help.

314—Female aged 18-34 years: I didn’t mind it. It was just a tiny prick, bit of blood on the thing, stick it into the little monitor. I don’t mind it.

365—Female aged 50-64 years: I let him do it cos I couldn’t, I couldn’t do that because I know some tests, well that test I know you’ve got to, you know, and I was going, and he said well come here and he did it. So I suppose going on from that some tests I probably would think oh no I don’t think I can do that if it means that you’ve got to.

The language used by participant 365 is particularly interesting. Not only is she saying that she could not perform a self-test that involved a needle but also she can’t bring herself to actually describe the test—and makes her point with a quick ‘you know’. This ‘squeamishness’
speaks to an obvious limitation of self-testing and a potential barrier to certain kinds of test being routinely used or properly administered.

Impact on life. Some participants spoke of the positive impact on their lives of having used self-tests. One woman described the experience as ‘revolutionary’.

1697—Female aged 35–49 years: Some kind of nut I think might have been one of them that was sort of slightly sensitive, but the one that really stood out was milk, and, I mean depressing though it was, that was kind of pretty revolutionary because cutting milk out my diet has made a huge difference.

Another spoke about the positive reaction she had from her doctor when she revealed to her that she had undertaken a self-test for blood sugar levels.

2280—Female aged 35–49 years: I just said oh by the way I’ve done this test for my sugar with one of the sticks, and she said oh good, what result did you get, and she was very helpful.

This reaction from the doctor reinforces the idea, discussed above, that self-testing can be empowering. Performing this test, and getting a positive reaction from the doctor, seemed to enable this participant to view herself as a partner in her own health care and being able to contribute something significant. Simply being able to respond to the doctor’s question of ‘what result did you get’ represents a shift in the traditional doctor–patient power dynamic, where the patient is able to provide ‘medical’ information to the ‘medical expert’.

Not all participants experienced this benefit, however, with some saying that they would not mention they had performed a self-test to their GP. Reasons offered for this reluctance included embarrassment over the cost and the belief that the GP would be sceptical about the value of some tests.

1004—Female aged 35–49 years: With this, I went on the internet and spent nearly three hundred pound and it was just, I suppose I just feel a bit embarrassed I just dived in and like that and done it because I was thinking oh, and you start thinking oh god, you know, perhaps I should get that done, I’ve never heard of that before and that’s better than cholesterol, and I thought oh I’ll do it.

1697—Female aged 35–49 years: It’s not so much that they might feel, that they might think badly of me having gone off and found this out myself as they might treat it with an element of scepticism, and I think that’s different to say going in with a pregnancy test result or going in with a chlamydia test result, you know, cos they are what they are.

The accounts from these participants suggest that the experience of self-testing may sometimes be accompanied by concerns about being perceived negatively by their doctor or even feelings of guilt over having spent money on something that had not been recommended by the ‘expert’ and exceeding their boundaries as non-experts.

Other participants described their hopes for a positive change being unfulfilled because of an inability to access the necessary aftercare. One woman described her disappointment at this and decided that the self-test was a ‘bad thing’ because it did not lead to any tangible benefit.

1004—Female aged 35–49 years: And I think as well if I had have spoken to the consultant I might have carried on with the food allergy thing, but I didn’t understand it and they weren’t, they haven’t contacted me back or anything, so I just knocked it on the head as a bad thing.

It appears from these accounts that alongside the potential for empowerment is the potential for disempowerment, with users of self-tests feeling that they have to hide their actions from sceptical, disapproving or uncooperative professionals.

Discussion

The data presented here suggest that the decision to self-test is complex and influenced by a number of factors, ranging from a desire to take control over one’s own health to a desire to avoid a GP consultation. This is generally consistent with recognized patterns of health and illness behaviour, which point to the ‘heterogeneous assembly of factors that are known to influence decisions about medical consultation’, or ‘mechanic has listed 10 variables that are known to influence consulting behaviour’. It is likely that some of these factors apply to these interviewees, such as frequency of appearance of signs and symptoms, the extent to which they disrupt activities and the tolerance threshold of the person concerned. These data suggest, however, that there may be important differences between pathways leading to conventional care and self-care without clinical involvement. There may be different thresholds if symptoms are present, and unlike instances of self-medication, self-testing can occur in the absence of symptoms, for example, using a self-test for cholesterol as a routine check or out of curiosity.

We can understand the decision to self-test as broadly taking place within what Kleinman describes as the ‘popular’ health care sector, which operates outside of professional medicine, in which the emphasis is on self-care and self-treatment. The ‘popular sector’ is traditionally associated with lay health beliefs, traditional remedies, old wives tales.
and behavioural and dietary solutions. The use of self-testing introduces to the popular sector the kind of technology and associated scientific legitimacy that is normally associated with the ‘professional sector’, representing something of blurring of the boundaries. This seems particularly so where participants use self-tests as diagnostic ‘ammunition’ to take to the GP or as a means of empowerment. In this way, through the use of self-tests, some participants may see themselves as becoming ‘quasi-professional’, drawing on the scientific legitimacy of ‘medical technology’ to allow them to negotiate, on an equal footing, with health care professionals. The value of this ‘professionalizing’ effect may be debated. For some of the participants in this study, self-testing was a very positive thing, but not all participants had universally positive experiences. Some participants who used self-tests as a response to a perceived lack of GP care thought GPs would be sceptical about the results and would think badly of them and consequently would not tell their GP about their use of the test, which may to a large extent negate the potential benefits of diagnosis. This resonates to some extent with the findings of Stevenson et al., who reported that patients are reluctant to report use of OTC medicine to doctors and that doctors are reluctant to ask about their use.

Limitations
It had been originally anticipated that interviewees would have bought self-tests, but they had actually accessed tests in a variety of ways, for example, borrowing a testing device or using tests at work. It seems feasible that people who accessed tests in different ways and who used different types of tests may have different motivations for using them. Although there is the suggestion in these narratives that this is the case, particularly for different types of tests, as illustrated by the different motivations of the cholesterol and allergy self-test users in Figure 2, it would be inappropriate to draw firm conclusions about this using a limited sample.

While generalizability is not an appropriate paradigm through which to assess qualitative research, it is generally accepted that qualitative findings may be ‘transferable’ to sufficiently similar groups and contexts. For this to be possible, it is necessary to consider the demographic make-up of the participants and reflect on the potential for transferability. Most interviewees were white, and the findings may not apply to people from other backgrounds with, for example, other cultural influences about when it is appropriate to visit a doctor. Most people interviewed were also women: there were fewer males available to select because women were more likely to reply to the questionnaire and report self-test use. This may represent a true difference, that females are more likely to self-test, but the hypotheses generated from these findings may not extend to males. Both general practices involved in the study were in the middle of the ranking of areas in England based on the Index of Multiple Deprivation 2004, and the findings may also only relate to people from similar areas. Recruiting participants through general practices may also mean that they are less likely to report dissatisfaction with their doctors or health care generally.

Conclusions
Overall, self-testing seems to encompass a broad variety of beliefs and experiences. For example, some participants saw self-tests as a serious diagnostic tool, whereas others used them out of simple curiosity, and some may have been motivated by their generally positive attitude to health, whereas others may have been motivated by negative health care experiences. Some see self-testing as an empowering process to be proud of, while others seem to view it as an illegitimate activity, which needs to be hidden from the professionals. The potential ambiguity of the self-testing experience itself, for good and for ill, was summed up well by one participant, who warns ‘you’ve got to be careful, haven’t you?’

365—Female aged 50–64 years: So long as you don’t start reading into everything and turn you into a hypochondriac because that’s what can happen, isn’t it really? I mean like I know people who’ve got medical books and the slightest thing and they’re in the book, and I mean a lot of symptoms are very similar, you know. So I think, you know, I think I’ve agreed that I would do some self-testing, so long as you’re, you’ve got to be careful, haven’t you?

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References