



Patient views on visual field testing for glaucoma monitoring

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Title: Patient views on visual field testing for glaucoma monitoring

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Competing Interest Statement

None of the authors have any competing interests in relation to this work.

Contributions of authors

FCG: Conducted data analysis, and wrote and edited the manuscript (joint first author).

HB: Conducted focus groups and data analysis, and wrote the manuscript (joint first author).

DPC: Conceived and designed study, and reviewed and edited the manuscript.

Abstract

Objectives: To investigate the views and experiences of patients regarding their glaucoma follow-up, particularly the type and frequency of visual field (VF) testing.

Design: A qualitative investigation using focus groups. The group discussion used broad open questions around the topics in a prompt guide relating to experiences of glaucoma follow-up, and in particular, VF monitoring. All groups were taped, transcribed and coded using manual and computer aided methods.

Setting: Three NHS hospitals in England; two focus groups took place at each hospital.

Participants: Twenty-eight patients (mean [SD] age: 74 [9] years; 54% female) diagnosed with glaucoma for at least 2 years. Each focus group consisted of 3-6 patients.

Primary and Secondary Outcomes:

- 1) Gather information regarding patient views about their glaucoma follow-up care, with a particular focus on VF monitoring.
- 2) Identify areas of importance from the patient's perspective for successful follow-up.

Results: Whilst patients expressed a general dislike for the VF test, they recognised the importance of regular monitoring for preserving their vision. Patients would be open to more frequent VF testing if the clinician felt it would enhance their care. Nevertheless, a number of themes recurred throughout the focus groups representing perceived barriers to follow-up care. The testing environment, patient-doctor communication, waiting times, efficiency of

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3 appointment booking and travel to the clinic were all perceived to influence the general
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5 clinical experience and the quality of assessment data.
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10 **Conclusions:** Patients trust the clinician to make the best decisions for their glaucoma follow-
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12 up. However, patients highlighted a number of issues that could compromise the effectiveness
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14 of research-supported guidelines for frequency of VF testing. Addressing patient-perceived
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16 barriers could be an important step for devising optimal strategies for follow-up care.
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20 21 22 Article Summary

23 24 25 **Article Focus**

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- Glaucoma is a chronic and progressive eye disease and all diagnosed patients will require lifetime monitoring of their vision.
 - Visual field (VF) testing is one of the most widely used assessments for glaucoma and places a large burden on NHS resources; research is needed to devise the most effective strategies for glaucoma VF monitoring.
 - This study used focus groups to investigate patient views about VF testing in their follow-up care. Effective VF testing will require the confidence and cooperation of the patient.

47 48 49 **Key Messages**

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- Although patients disliked VF testing, they accepted it as an important part of their vision assessment and disease management.
 - Patients discussed a number of areas of perceived importance for VF monitoring, raising particular concerns about distracting testing environments, the quality of test

instructions, how results were explained to them and excessive pre-testing waiting times.

Strengths and Limitations of this study

- This is the first study to examine patient views of visual field monitoring using focus groups.
- Focus groups only took place at three selected hospitals - it is assumed that the views expressed represent the experiences of patients in a wider UK population.

Introduction

Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively, could lead to visual impairment or blindness. Currently, the only modifiable risk factor for disease worsening (progression) in glaucoma is reduction of intraocular pressure (IOP). A variety of different approaches to IOP lowering are available, meaning surveillance of the patient is important in selecting the correct intensity of treatment. Nearly half a million people are thought to have the condition in England alone, receiving over a million outpatient visits annually[1]. Since the prevalence of glaucoma increases exponentially with age, these figures can be expected to increase dramatically with an ageing population. Glaucoma monitoring therefore represents a major workload for eye services in the National Health Service (NHS).

Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a sophisticated automated instrument. The test is carried out in a darkened room and takes about 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a large semi-circular bowl covering their entire field of view. The instrument presents a series of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the VF while the patient fixates on a central point. The patient responds by clicking a button when a stimulus is detected. This process yields a map of the seeing parts of the patient's field of view; this map is subjected to statistical analysis comparing a patient's results to normative values for people with healthy vision. Speed of VF loss varies considerably between treated individuals, so it is vital that the VF is monitored accurately and at appropriate intervals in order to preserve visual function[2]. The National Institute of Clinical Excellence (NICE) reported gaps in evidence regarding how best to monitor patients with glaucoma over time[1]. Guidelines proposed by the European Glaucoma Society (EGS) recommend that the

frequency of VF tests should be increased for newly diagnosed patients in order to better determine speed of VF progression. This notion is supported by research evidence which has indicated that three VF tests per year would be useful for identifying patients that are deteriorating at fast rates in the first 2 years of follow-up[3-5]. However, a recent audit of glaucoma clinics in England indicated that most patients only have about one VF test a year[6]. Furthermore, VF monitoring intervals assigned by clinicians (for hypothetical patient scenarios) are variable[7]. Many glaucoma specialists concede that better tracking of the VF would be helpful in managing patients but view it as impractical in the current health setting[7]. This finding suggests that personal attitudes regarding the frequency of testing could play an important role in translating research to practice.

The clinician ultimately drives decision-making based on their own estimates of the likelihood and speed of disease progression, but establishing effective monitoring strategies may also require the input of the patients themselves. Care plans that place burdens on patients may result in a reduced willingness to return for follow-up and compromise the quality of the data obtained that is subsequently relied on during management[8]. Anecdotal evidence suggests that patients dislike doing the VF test, and one study showed that patients rate the VF test least favourably of all the vision assessments[9]. However, no study has asked patients with glaucoma in detail about their perceptions of the VF test and their follow-up care.

When considering the patient's perspective of their health condition, many studies opt to use questionnaires to quickly gather information about the perceptions of service users. However, this method can be impersonal and restrictive, and patients may misinterpret the meaning of the question or simply not be given an appropriate opportunity to contribute their full opinion.

Qualitative techniques, such as focus groups, offer an alternative method of gathering information about not only what a patient thinks, but also how they think or why they may hold a particular view. Group interaction encourages participants to explore and clarify individual and shared perspectives and supports the participation of people who may be reluctant to contribute their views in a more formal one-to-one scenario[10].

For the first time, the current study aims to explore patient views and experiences of glaucoma monitoring via focus groups. One objective was to establish patients' views about VF testing.

Method

Participants and methods

Focus groups took place between May 2012 and January 2013 in the following locations: The Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation Trust in London. The study was multi-centred to reduce the bias that might come from one geographical area and to encompass healthcare trusts in both urban and rural locations. The sites were chosen because they were involved in a wider programme work, of which the current study was a component. There were two focus groups at each site, with participants randomly allocated to one of the two groups at the corresponding hospital.

The study used purposeful sampling whereby a consultant ophthalmologist at each participating eye hospital selected participants that were suitable for the study. To take part, the participant was required to be aged 60 years and over and to be an established glaucoma

1 patient who had been under review for at least two years. These criteria were chosen to ensure
2 that participants had had sufficient experience of VFs as part of their glaucoma follow-up.
3 One of the authors (HB) then telephoned patients who had given their permission to be
4 contacted to invite them to take part in the study. Interested participants were subsequently
5 sent further information by post.
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14 A total of 28 participants (mean age [standard deviation] 74 [9] years; 54% female) took part
15 across the six focus groups. Each group consisted of three to six patients and included
16 participants of both genders.
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25 Procedure
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27 A topic guide was devised prior to beginning the study outlining question areas regarding
28 general glaucoma care, leading on to more specific questions about experiences of the VF test
29 and opinions about VF test frequency. Study topics were informed by an initial pilot exercise
30 involving a discussion with two patients with glaucoma, who also provided additional verbal
31 and written information about their experiences. Questions were broad, open and “non-
32 leading”. Prompts were used to introduce topic areas and encourage respondents to elaborate;
33 however the onus was on the participants to supply the overall content of the discussion. If
34 discussion went substantially off-topic, or one participant was dominating the conversation,
35 the interviewer would reflect back to a previous topic and encourage other participants to
36 contribute their views.
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54 Prior to the study, participants were informed that they would be involved in “an open
55 discussion about glaucoma care”, but were unaware of the emphasis on VF testing frequency.
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All focus groups were conducted by one of the authors (HB), a post-doctoral researcher who had prior experience of qualitative research involving patients with glaucoma[11, 12]. The interviewer and participants had no prior knowledge of each other in a clinical or personal context, so each focus group began with general introductions. Field notes were taken during the sessions to aid later interpretation of the data, although note-taking was purposely minimal so that the interviewer could be fully attentive to the discussion. The focus groups lasted between 60 and 75 minutes.

The study received approval from a NHS National Research Ethics Service (NRES) committee and was approved by research governance committees of the participating institutions. The study conformed to the Declaration of Helsinki and written consent from all participants was obtained prior to each focus group.

The study was designed and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) for interviews and focus groups[13].

Analysis

All focus groups were audio-recorded (with permission from the participants). The dialogue from the recordings was later transcribed and reviewed by the investigators. Field notes were used to account for any information missed or incorrectly reported in the transcripts due to excessive background noise.

Data was analysed by two of the authors (HB and FCG) independently using the framework technique[14] displayed in Table 1. Each investigator read and re-read the transcripts and

manually identified the key themes from the data in addition to some example quotes to illustrate main points. One of the authors (FCG) was blind to the purpose of the study at the point of analysis. The qualitative software package NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the thematic framework by refining and condensing the predefined categories and to identify additional themes for exploration. Any differences of opinion regarding the meaning of sentences or the importance of themes were later discussed until a consensus was reached.

Table 1: Framework Technique used for data analysis (similar to that developed by the Independent Research body, Social and Community Planning Research, now the National Institute for Social Research[14])

Framework Technique		
1.	Familiarisation	Reading and re-reading the transcriptions
2.	Identifying a Thematic Framework	Condense data into categories
3.	Indexing	Codes systematically applied to the data
4.	Charting	Re-arranging the data according to the thematic content in a way which allows for a cross case and within case analysis
5.	Mapping and Interpretation	Interpretations and recommendations

Findings

Data was initially indexed according to themes central to the main research questions, such as opinions of the VF test, current experience regarding the frequency of VF testing and opinions about more frequent VF testing. Throughout the analysis a number of additional themes emerged, often with their own sub-themes; these generally related to specific areas perceived to affect the follow-up experience, and included points relating to clinical constraints (waiting times, booking appointments), travel to the clinic, the testing environment and aspects of patient-clinician communication. The themes and sub-themes are summarised in Figure 1.

Figure 1: Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Direct quotes taken from the transcripts are italicized. These quotes were chosen to illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a pseudonym for the corresponding participant based on their gender (“M” or “F”) and the order in which they spoke in the interview. The location of the focus group and the session number (1 or 2) are also shown for each quote.

Visual fields

Patients expressed a dislike for the VF test. They found the test time-consuming, old-fashioned and tiring.

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Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I don't like having one eye closed and having to concentrate, even if it's for just a couple of minutes, because then my mind wanders... F1, Portsmouth 1

It seems a bit antiquated, pressing the buttons... it doesn't seem positive enough to me.
F3 Norwich 2

Many put pressure on themselves to perform the test well, as they felt there could be a lot riding on their performance.

There is pressure: I think it is because your eyes are so important for everyday living, that, you know, you're frightened to [not do well]. F2 Portsmouth 1

There was a general appreciation that such testing was vital to preserve their vision.

Well... obviously I'm very grateful that I'm being monitored all... F4 London 1

....mine has been 10 years and you think, well how long will I have my sight? ... My mum had lost her sight by then, you know... F3 Norwich 2

Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular pressure measurement and imaging tests, less tiring and laborious. At the same time some patients felt the VF test was more 'valuable', providing more reassurance that their condition was being investigated.

*[with] the [imaging] there's just one person, one machine and you, and it's done and that's it,
it's over...within minutes. F3 Norwich 2*

*... they look in your eyes to measure your pressure but when you do that field test, they see
more.... F1 London 2*

Frequency of visual field testing

Current experience

VF tests were usually performed once or twice a year, either during or closely prior to the patient's general clinical appointment. Patients who visited the clinic more frequently would have a VF test at only some of their appointments. Some patients were often unaware as to whether they would have a VF test during their visit.

*I mean they just say you're going to come for your next appointment in whatsoever, whatever
time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you
know that you are going to have to be that little bit longer.. F2 Portsmouth 1*

When patients were asked whether they would be willing to visit the clinic for VF testing more frequently, there was a reluctant agreement. The test was viewed as a 'necessary evil' and most were open to more frequent testing if the clinician felt it would enhance their prognosis, although there was scepticism as to how useful the test actually was.

If it was necessary. F2 Portsmouth 2

You'd get on with it. M1 Portsmouth 2

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If it helps the cause so be it. M2 Portsmouth 2

I don't want to lose my sight, I'd come in whenever. F2 Portsmouth 2

If it holds it back for 10 years... I'm happy with another 10 years! M1 Norwich 2

... I suppose I'd accept it because I would hope that the reason for asking me was that they will get more information from that, which obviously deals with the whole problem but...I'm not really sure at all about how useful they are. I mean is it just statistics or whatever? ...I'm sure they're useful but I wonder in what proportion of use they are compared to, you know, looking in the eye and pressures and things....

F3 Norwich 2

Some patients associated more frequent testing with worsening vision; therefore being asked to attend for more testing could lead to increased anxiety.

... you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said to do it, I've always done ... because they're doing the best for me...

F3 Norwich 2

One recurrent topic regarding VF testing was issues relating to the learning effect, whereby performance improves with increased testing. Some suggested that more repeat testing would be helpful. However, the repeated tests may only be worthwhile if they took place at the beginning of their follow-up care.

...interestingly I went and did one once and they said to me, "this has improved from the last time" and I said "well I think I'm just getting better at computer games" ... I think you do know what's coming and you can improve and I just feel more comfortable with doing it.

F1 Norwich 1

I think to do a field test right at the beginning, and to take that as being the definitive field test is wrong...because I think you need to do a test and think, and revise it in your mind what you've done and then do it again. M1 Portsmouth 2

There was some debate about the period of time between VF tests.

I think you need to do a field test and then perhaps a month later do the second one.

M1 Portsmouth 2

Well not if you have a long gap between them. F1 Norwich 2

I've got used to it now. F2 Norwich 2

I don't think it's any different really. F3 Norwich 2

The idea was raised that routine VF testing could be carried out in a more convenient location. Some patients had previously visited a local optometrist to carry out a VF test for the purpose of assessing their legal fitness to drive. On the positive side, patients liked the convenience of doing so and described a better testing environment. Conversely, they questioned the competency of the staff, the quality of the equipment and the information trail back to the hospital.

The principle of having routine tests done locally is acceptable providing they are trained.

M1 London 1

I would be concerned about how often the machine was calibrated to get an accurate reading.

M2 London 1

*Is the information going back to where it matters in my notes? Things do get lost, and will
someone actually look at the test?*

M1 London 2

Some felt they had built up a level of trust with the hospital eye service and would therefore prefer to have VFs conducted in this environment.

*I've been here for quite a while now and I like coming to them: I don't want to go anywhere
else.* F1 London 2

I would feel the same because it's a matter of trust. M2 London 2

Perceived issues and barriers for successful follow-up care

Some additional themes emerged during the analysis, highlighting a number of areas perceived to be important and potentially representing barriers to successful follow-up.

Communication

Visual Field Instructions

Regardless of how long they had been attending the glaucoma clinic, patients appreciated having the VF test procedure fully explained to them. It was rare for a staff member to stay with the patient throughout the test, but on the occasions it did happen, patients found the experience reassuring and felt the encouragement helped their performance.

... They say, "Have you done this before?" You say "Yes". And that's it, you're left there and eventually they say, "Have you finished?"

M1 Portsmouth 2

I had one about three weeks ago and it was a young nurse and it was a completely different experience. She was professional, polite, kind; she told me exactly what they were doing.... it was almost a pleasant experience. F1 Portsmouth 1

There was discussion about understanding aspects of the testing procedure and how the procedure was explained. For example, some patients expressed uncertainty and felt test pressure would influence their results. Again, explanation and reassurance before and after the test helped.

The staff told me: "don't worry about missing [a light] because it'll come later", so you know you get a second chance. F1 Norwich 1

... if in doubt press the button, don't you? F1 Portsmouth 2

Explanation of results

Most patients said they had to specifically enquire about their results to find out information about their vision and whether their condition had progressed since the last appointment. Some patients felt intimidated to ask the clinician for feedback as to how they had performed, feeling they were being a nuisance or wasting the clinician's time.

My wife always says "how did you get on?" and I say "I don't know", and that's one of the problems. M2 Portsmouth 2

I don't think they've got time to listen to you, or they don't appear to, and I don't know whether they would listen.... You feel pathetic asking these questions. F3 Portsmouth 1

It was felt that a better explanation of the test results after completing the VF would ease some of the pressure felt when performing the test.

IF THE DOCTOR ACTUALLY SPENT A BIT MORE TIME DISCUSSING IT WITH YOU, WOULD IT MAYBE EASE THE PRESSURE OF ACTUALLY DOING THE TEST?

Interviewer.

I would... M1 Portsmouth 1

I think possibly. F3 Portsmouth 1

Yes, I mean I would still panic, but if I knew, yes. F1 Portsmouth 1

Patients may be more inclined to have VF tests more frequently should they be informed clearly about what the results indicate about their prognosis.

I don't mind how many times I do it providing I get a result of the test at that time compared to what the previous one was. Is there any improvement? Is there any downgrade?

M1 Portsmouth 1

The patient-clinician relationship

The quality of relationship with the clinical staff and aspects of patient-clinician communication also emerged as key factors influencing perceptions of the follow-up process.

An apparent lack of personalised care caused unease: there was a sentiment that sometimes the clinician simply looked at the eyes and failed to consider the person's individual needs.

You're not a person, you know, you've just got eyes, they're just going to deal with that and that's it. F3 Portsmouth 1

The experience was seen to be much more bearable if they felt the staff member dealing with them was empathic.

Even buying a chop, you know: if the butcher's interested, it helps doesn't it?

M3 Norwich 1

The opportunity to spend more time with their consultant ophthalmologist was a key factor that influenced whether or not patients were open to visiting the clinic more frequently.

Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.

M2 London 2

Testing environment

The testing environment was another important theme. The dark room, especially if it was warm, made focusing on the tests difficult. Patients felt they performed better in the morning when they were more alert. Ambient noise in the room made it difficult to concentrate; staff members talking and doing the test at the same time as several other patients all had deleterious effects.

I will also say that the staff chatter a lot, which is difficult for concentration; the doors open and close, there's a lot of noise. F1 Norwich 1

The times that I've had the visual field test done in a room where there's just one [machine], I felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot quicker too. F3 Norwich 2

I think having the quieter atmosphere would generally help I'm sure....just that feeling of slight calm, you can relax more and then it probably would be a lot quicker because maybe you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.

Clinic constraints

Waiting times

Waiting times were a major concern at all locations. The standard time taken per visit was estimated to be two hours, although the wait was often unpredictable. Established patients were used to the wait and tried not to let it affect them but they still found the system frustrating. Patients were scared of missing their slots and, therefore, would not leave their seat in the waiting area.

No way I'm going to nip off ... especially as now I'm on my own, no way.... just even nipping off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour and he'll call me the minute I go to the [bathroom]'. F2 Portsmouth 1

Likewise, the waiting environment outside the clinic was viewed extremely unfavourably.

The first time I came in I thought, 'Oh my....' There were hundreds of people, it felt like hundreds, but we were all sat in a line. There's nothing on the walls. There's tiny writing on the notice board and you think, 'Hang on, we've all got eye problems in here, how are we supposed to read these signs?' The walls are just blank- it's a really miserable place, isn't it?

F3 Portsmouth 1

Although it was repeatedly acknowledged that the clinics were very busy, which had the knock-on effect of increased waiting times, patients felt they were getting adequate treatment

overall. It was suggested that there was a trade-off between longer waiting times and higher quality treatment:

I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of excellence. There's a trade-off in that you're getting state of the art treatment but the price is you've got to sit around for it. M1 London 1

Travelling to the clinic

Several sub-themes emerged including issues with long distances to travel, avoiding rush hours, travel costs and travelling alone.

I think the problem is because I live nearly an hour away, for me the nearest hospital is an hour away... F2 Norwich 2

Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly with help to get on the train but it's not easy.....It's horrific, frightening. M2 London 1

Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to have a negative effect on VF test performance.

Scheduling appointments

The scheduling of appointments was a major concern: often the systems were so overbooked that patients were unable to make their next appointment at their clinic visit. Some were

asked to call to make an appointment six weeks before they were due to attend whilst others were sent an appointment in the post at a much later date.

You can only make an appointment six weeks in advance. You used to get a twelve month appointment letter just after you had been for an appointment; now its six weeks before you are due. M2 Norwich 1

Some patients had been asked to attend on a Saturday to reduce the back-log of appointments. The day was not seen as a problem although the standard of care was questioned.

I've been asked to come on a Saturday which is not a problem but the trouble is you never see anyone who can make a decision. I ended up seeing a retina man. So after a couple of visits I asked to be seen on a weekday by a glaucoma specialist." F1 Norwich 1

Often patients would receive an appointment only to have it cancelled a couple of weeks before the clinic was due to take place. This was not only frustrating to people who had made arrangements for their appointment, such as asking a friend to accompany them or arranging cover for sick spouses, it caused concern that their appointment was to be at a much later date than the clinician had originally requested.

"So if you've been given a six month appointment and it's cancelled, and you're not given another one, you ring up and then they say "oh we can't give you an appointment now until October". That was 10 months. Now if your consultant says 6 [months] and it's 10 and something's gone wrong with your vision in between, you have no way of telling." F2

Portsmouth 2

Patient recommendations

At the end of the groups patients were asked to recommend changes to improve their follow-up care. The recommendations were similar across all locations and the most popular suggestions are displayed in table 2.

Table 2: Patient recommendations for improving follow-up care.

Patient Recommendations	
1.	Less waiting and clinics running to time.
2.	Flexible booking and changing of appointments.
3.	To have a calmer, quieter environment in the visual field room with less people doing the test at the same time.
4.	To modernise the visual field test.
5.	To have more continuity of care by seeing the same clinician at each visit.
6.	To receive better communication from the clinician.

Discussion

Data from this study supports evidence from elsewhere that patients find VF testing more laborious and demanding than other vision tests[9]. Nevertheless, patients were willing to complete more VF tests on the guidance of their clinician, as ultimately they were prepared to do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF testing during the first two years of their follow-up care as recommended by the research literature[3, 4] and some clinical guidelines[15]. Patients commented that it took time to feel comfortable with the test procedure, and that multiple attempts were needed to gain an accurate representation of their vision. These viewpoints complement existing evidence showing that performance can improve considerably during follow-up due to gaining experience with the testing process[16].

There were, however, a number of additional themes that emerged from the data which identified areas that could represent potential barriers to successful glaucoma monitoring. Patients felt that the environment in which they completed the VF test was linked to how well they were able to perform the task, with staff members talking loudly, the number of people in the room, and the time of day all listed as important interfering factors. These views coincide with other evidence showing that the environment, the technician and the time of day do have a significant influence on measurement variability from VF tests[17]. Fatigue, a topic mentioned frequently throughout the discussions, has also been shown to affect performance as test duration increases[18].

Patients highlighted the importance of effective task communication for influencing their VF test performance. Prior evidence has shown that the quality of instruction given before the VF test can significantly affect subsequent estimations of VF defect severity[19, 20]. Patients also

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felt that it was essential to have the task explained to them properly, even if they had been attending clinics for some time. Having a staff member in the room whilst they carried out the test was found to be reassuring. These findings reiterate the idea that ensuring that the task demands are communicated clearly and effectively before every VF test, and being on hand to alleviate any concerns or questions that the patient may have, may help maximise the quality of the data gained from the assessment[20-22].

Other discussion points relating to communication were also raised repeatedly throughout the focus groups. Patients felt that many clinicians treated them as an ‘eye’ rather than a person, with those staff members who took a more individualistic and empathic approach viewed favourably. Notably, patients felt that they had to ask explicitly about their results in order to learn details about their own condition. Evidence has shown that that the patient and clinician’s views of their condition are not always aligned, which may be due to miscommunication or misinterpretation of key information on both parts[23]. By explaining the results in a clear, simple and concise manner, the patient will inevitably improve their understanding of their condition, which in turn could influence how well they respond to important aspects of their follow-up care. For instance, it has been shown that the way in which clinicians communicate with the patient can influence future adherence to medication[23]. Providing better information about the purpose of VF testing, what is required of the patient, and their results and general prognosis could be vital for improving attendance for VF tests or for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about ways in which the complex measurement of the VF could be easily presented and communicated to patients. It is important to note that some patients associated more frequent testing with worsening vision, which caused some distress. Thus, should

patients require more frequent tests at some point in their care, it is also vital to involve the patient and explain reasons for the decision.

Excessive waiting times and difficulty booking appointments were also major concerns. In particular, patients worried that appointment cancellations could extend the interval between tests beyond what was recommended by the clinician, therefore leaving them exposed to undetected disease progression. It is known that whilst clinicians select appropriate monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate follow-up[6, 24, 25]. Moreover, it was typical for patients to wait at the clinic for hours in order to complete multiple vision tests, causing frustration and tiredness which some perceived to influence their subsequent performance. Potential solutions could involve conducting only the VF test during short independent appointment slots, or carrying out tests at a more convenient location. However, such strategies would involve further investigation as to their overall cost-effectiveness and should address other associated practicalities such as travel (a significant contributor to total patient costs[26]) and the information trail back to the hospital.

Previous research has relied on statistical analysis or computer simulations to help determine the most effective VF monitoring strategies for patients with glaucoma. This is the first study to use qualitative methods to investigate the patient's own perspective on their follow-up. Studies focusing on the patient's perspective in glaucoma, particularly with regard to the perceived effects of the disease on their day-to-day activities, have typically relied on questionnaires[27]. However, questionnaire responses can be restricted by the wording of the items and provide little opportunity for clarification or elaboration. This study allowed individuals to contextualise their experiences and expand on particular points and themes,

encouraging discussion about topics a certain patient may not have otherwise introduced or attributed to glaucoma without the encouragement of another[11]. The notion of the “expert patient” is beginning to be endorsed with regards to other chronic conditions, with focus groups demonstrating potential as a forum for the development of more effective management strategies[28-30]. Encouraging more patient involvement may also help devise the optimal strategies for glaucoma follow-up.

This study has its limitations with findings attached to the viewpoints of the groups who took part. Efforts were taken to reduce bias by involving multiple research sites but these findings may not necessarily translate to a wider population. It is also important to recognize possible selection bias; the people who chose to participate in a focus group may have more solid opinions with a certain area of their care. Moreover, initial patient selection was made on recommendation of consultants at the clinics and our selection process did not carefully monitor reasons for non-participation. The study was initially designed to involve 6 focus groups across 3 locations and so no direct decision was taken to cease data collection; however, similar themes and sub-themes continued to emerge in the latter focus groups and so it is likely that ‘data saturation’ was achieved. Also, some biases could have been introduced during interview and analysis due the preconceived ideas held by the experimenters about the areas of importance, although care was taken to adhere to expected practice by following the COREQ check-list for focus group research[13].

A number of important themes did emerge that give an insight into clinic visits and VFs from the patient’s perspective, and could help inform patient centred care in glaucoma. Although patients appeared frustrated by a number of aspects of their follow-up, they ultimately accepted that some compromises had to be made in order to save their eyesight. Some of the

viewpoints illustrated in the focus group discussions may in part explain why research-supported guidelines about more frequent VF testing are not being implemented effectively in clinical practice. A holistic approach that embraces patient opinion may therefore be vital to help devise the most effective strategies for follow-up care in this chronic disease.

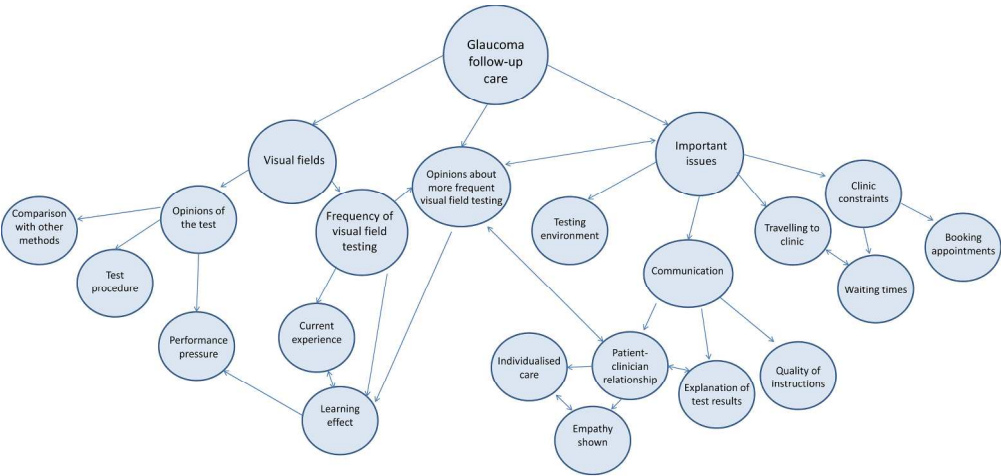
Conclusion

This is the first study to use qualitative methods to examine patient opinion about the glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they accepted it was important to their overall vision assessment. However, a number of actionable points were raised which were perceived to impact the effectiveness of follow-up care, including distracting testing environments, and hospital constraints relating to excessive waiting times and appointment booking. Some patients also expressed particular concerns about the VF technology used, the quality of test instructions and explanation of results. Anxiety associated with increased testing in the absence of clinical explanation was another theme. Ensuring that glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the confidence and cooperation of the patient. Addressing some or all of the perceived barriers highlighted in this study should help deliver more efficient strategies for VF monitoring in glaucoma.

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Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

237x111mm (300 x 300 DPI)



A qualitative investigation into patient views on visual field testing for glaucoma monitoring

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Primary Subject Heading:	Ophthalmology
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Manuscripts

Title: A qualitative investigation into patient views on visual field testing for glaucoma monitoring

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Abstract

Objectives: To investigate the views and experiences of patients regarding their glaucoma follow-up, particularly towards the type and frequency of visual field (VF) testing.

Design: A qualitative investigation using focus groups. The group discussion used broad open questions around the topics in a prompt guide relating to experiences of glaucoma follow-up, and in particular, VF monitoring. All groups were taped, transcribed and coded using manual and computer aided methods.

Setting: Three NHS hospitals in England; two focus groups took place at each hospital.

Participants: Twenty-eight patients (mean [SD] age: 74 [9] years; 54% female) diagnosed with glaucoma for at least 2 years. Each focus group consisted of 3-6 patients.

Primary and Secondary Outcomes:

- 1) Attitudes and experiences of patients with glaucoma regarding VF testing
- 2) Patients' opinions about successful follow-up in glaucoma.

Results: These patients did not enjoy the VF test but they recognised the importance of regular monitoring for preserving their vision. These patients would agree to more frequent VF testing on their clinician's recommendation. A number of themes recurred throughout the focus groups representing perceived barriers to follow-up care. The testing environment, waiting times, efficiency of appointment booking and travel to the clinic were all perceived to influence the general clinical experience and the quality of assessment data. Patients were also

concerned about aspects of patient-doctor communication, and often received little to no feedback about their results.

Conclusions: Patients trust the clinician to make the best decisions for their glaucoma follow-up. However, patients highlighted a number of issues that could compromise the effectiveness of VF testing. Addressing patient-perceived barriers could be an important step for devising optimal strategies for follow-up care.

Article Summary

Article Focus

- Glaucoma is a chronic and progressive eye disease and all diagnosed patients will require lifetime monitoring of their vision.
- Visual field (VF) testing is one of the most widely used assessments for glaucoma and places a large burden on NHS resources; research is needed to devise the most effective strategies for glaucoma VF monitoring.
- This study used focus groups to investigate patient views about VF testing in their follow-up care. Effective VF testing will require the confidence and cooperation of the patient.

Key Messages

- Although patients disliked VF testing, they accepted it as an important part of their vision assessment and disease management.
- Patients discussed a number of areas of perceived importance for VF monitoring, raising particular concerns about distracting testing environments, the quality of test

instructions, how results were explained to them and excessive pre-testing waiting times.

Strengths and Limitations of this study

- This is the first qualitative study to examine patients' views of visual field monitoring using focus groups.
- Focus groups took place at three selected hospitals in the South of England; it is assumed the views expressed represent the experiences of patients in a wider population.
- Not all patients approached by their ophthalmologist took part, but reasons for non-participation were not monitored. Patients who chose to volunteer may be more articulate, motivated and opinionated than the general patient population.

97 **Introduction**

98
99 Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively,
100 could lead to visual impairment or blindness. Currently, the only modifiable risk factor for
101 disease worsening (progression) in glaucoma is reduction of intraocular pressure (IOP). A
102 variety of different approaches to IOP lowering are available, meaning surveillance of the
103 patient is important in selecting the correct intensity of treatment. Over half a million people
104 in the United Kingdom (UK) are thought to have the condition, with patients receiving over a
105 million outpatient visits annually^{1 2}. Since the prevalence of glaucoma increases exponentially
106 with age, these figures can be expected to increase dramatically with an ageing population.
107 Glaucoma monitoring therefore represents a major workload for eye services in the National
108 Health Service (NHS).

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110 Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring
111 of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a
112 sophisticated automated instrument. The test is carried out in a darkened room and takes about
113 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a
114 large semi-circular bowl covering their entire field of view. The instrument presents a series
115 of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the
116 VF while the patient fixates on a central point. The patient responds by clicking a button when
117 a stimulus is detected. This process yields a map of the seeing parts of the patient's field of
118 view; this map is subjected to statistical analysis comparing a patient's results to normative
119 values for people with healthy vision. These measurements can be highly variable, and speed
120 (rate) of VF loss, determined from a series of measurements over a period of time, varies
121 considerably between treated individuals. The VF should therefore be monitored at
122 appropriate intervals in order to identify timely intervention of more intensified treatment to

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3 123 preserve visual function³. Yet, evidence regarding how frequently VF tests should be carried
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5 124 out to optimally detect disease progression is limited. The National Institute of Clinical
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7 125 Excellence (NICE) called for more research into examining the effectiveness of using
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9 126 different monitoring intervals to detect disease progression in people with glaucoma in 2009¹.
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11 127 Guidelines proposed by the European Glaucoma Society (EGS) recommend that the
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13 128 frequency of VF tests should be increased for newly diagnosed patients in order to better
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15 129 determine speed of VF progression. This notion is supported by research evidence based on
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17 130 statistical analyses of retrospective data which has indicated that three VF tests per year in the
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19 131 first 2 years of follow-up would be clinically useful for identifying patients that are
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21 132 deteriorating at fast rates⁴⁻⁶. However, a recent multicentre audit of glaucoma clinics in
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23 133 England indicated that most patients only have about one VF test a year⁷. In another recent
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25 134 study, VF monitoring intervals assigned by clinicians (for hypothetical patient scenarios) were
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27 135 shown to be highly variable⁸.
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34 137 Organisational and resource constraints in the current NHS setting will impact on the
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36 138 feasibility of translating research supported guidelines for VF monitoring to practice.
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38 139 Furthermore, the clinician ultimately drives decision-making based on their own estimates of
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40 140 the likelihood and speed of disease progression, and therefore their opinions towards the
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42 141 appropriateness of monitoring intervals will be important. At the same time, establishing
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44 142 effective monitoring strategies for this chronic condition likely also requires the input of the
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46 143 patients themselves, especially if it equates to more clinic visits. Care plans that place
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48 144 burdens on patients may result in a reduced willingness to return for follow-up and
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50 145 compromise the quality of the data obtained that is subsequently relied on during
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52 146 management^{9 10}. Studies have shown that the views of the clinician and the patient regarding
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54 147 aspects of their condition are not always aligned^{11 12}, implying the patient's perspective must
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148 also be considered. Nevertheless there has been limited use of patient-based research for
149 improving glaucoma care. A review of the literature found that most studies use
150 questionnaires to quickly gather information about the perceptions of patients, usually with
151 regards to their perceived outcomes ¹³. However, questionnaires can be impersonal and
152 subject to bias ^{14 15}. Qualitative techniques, such as focus groups, offer an alternative method
153 of gathering information about not only what a patient thinks, but also how they think or why
154 they may hold a particular view. Group interaction encourages participants to explore and
155 clarify individual and shared perspectives and supports the participation of people who may
156 be reluctant to contribute their views in a more formal one-to-one scenario¹⁶. Focus groups
157 have been used in a small number of studies to examine the general experiences of glaucoma
158 patients at diagnosis, their expectations and to identify potential barriers to treatment
159 adherence ^{10 17-19}. However, there is limited evidence regarding the opinions of patients about
160 the manner in which their vision loss is monitored. Anecdotal evidence suggests that patients
161 dislike doing the VF test, and one quantitative study showed that patients rate the VF test least
162 favourably of all the vision assessments ²⁰. However, no study has interviewed patients with
163 glaucoma in detail about their perceptions of the VF test and their follow-up care. The current
164 study therefore aims to shed light on the effectiveness of glaucoma monitoring from the
165 perspective of the patient by exploring patient views and experiences via focus groups. In
166 particular, the study aims to establish patients' views about VF testing in glaucoma
167 monitoring.
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Methods

Participants and methods

Focus groups took place between May 2012 and January 2013 in the following locations: The Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation Trust in London. The study was multi-centred to reduce the bias that might come from one geographical area and to encompass healthcare trusts in both urban and rural locations. The sites were chosen because they were involved in a wider programme work, of which the current study was a component. There were two focus groups at each site, with participants allocated to one of the two groups at the corresponding hospital.

The study used purposeful sampling whereby a consultant ophthalmologist at each participating eye hospital selected suitable participants during their routine eye appointment. Specifically, the participant was required to be aged 60 years and over and to be an established glaucoma patient who had been under review for at least two years. These criteria were chosen to reflect the age-related nature of the disease and to ensure that participants had sufficient experience of VFs as part of their glaucoma follow-up. The ophthalmologist gave potential participants an information sheet, and interested people were asked to sign a form indicating they were happy to be contacted by a researcher (it was stressed that they were not obliged to participate). Each consultant ophthalmologist approached 20 patients in this way. One of the study investigators (HB) then contacted the patients with further information and invited them to take part on one of two specific dates at the corresponding hospital. Those who declined did so because they were not available on the specific dates (no other reason was cited). Initially, 5-6 patients were signed up to participate on each of the six

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198 study dates. However, a small number (n=4) did not attend. A total of 28 participants (mean
199 age [standard deviation] 74 [9] years; 54% female) eventually took part across the six focus
200 groups. Each group consisted of three to six patients and included participants of both
201 genders.

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206 Procedure

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208 A topic guide was devised prior to beginning the study outlining broad question areas
209 regarding general glaucoma care, experiences of the VF test and opinions about VF test
210 frequency. Study topics were informed by an initial pilot exercise involving a discussion with
211 two patients with glaucoma, who also provided additional verbal and written information
212 about their experiences. The topics included in the guide acted only as suggestions; the
213 wording of questions was not predetermined and the order of the topics was not fixed.
214 Prompts were used to introduce topic areas and encourage respondents to elaborate but the
215 onus was on participants to supply the overall content of the discussion. Care was taken to
216 ensure questions were open and “non-leading”, although more specific questioning was
217 sometimes used to clarify a point made by a participant. If discussion went substantially off-
218 topic, or one participant was dominating the conversation, the interviewer would reflect back
219 to a previous topic and encourage other participants to contribute their views.

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221 Prior to the study, participants were informed that they would be involved in “an open
222 discussion about (their) experiences in the glaucoma clinic, with special attention to the visual

tests (they) undertake". Participants were not explicitly aware of the emphasis on VF testing, so as to avoid bias linked to the self-selection of participants with strong views on this one topic. All focus groups were conducted by one of the authors (HB), a post-doctoral researcher who had prior experience of qualitative research involving patients with glaucoma^{18 21}. The interviewer and participants had no prior knowledge of each other in a clinical or personal context, so each focus group began with general introductions. Field notes were taken during the sessions to aid later interpretation of the data, although note-taking was purposely minimal so that the interviewer could be fully attentive to the discussion. The focus groups lasted between 60 and 75 minutes.

The study received approval from a NHS National Research Ethics Service (NRES) committee and was approved by research governance committees of the participating institutions. The study conformed to the Declaration of Helsinki and written consent from all participants was obtained prior to each focus group.

The study was designed and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) for interviews and focus groups²².

Analysis

All focus groups were audio-recorded (with permission from the participants). The dialogue from the recordings was later transcribed and reviewed by the investigators. In a small number of instances certain words were inaudible on the recordings due to excessive background noise, so field notes were used to account for any unclear information.

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248 Data was analysed by two of the authors (HB and FCG) independently using framework
249 analysis ²³ as displayed in Table 1. Each investigator read and re-read the transcripts and
250 manually identified the key themes from the data in addition to some example quotes to
251 illustrate main points. One of the authors (FCG) was masked to the emphasis on VF testing at
252 this initial point of analysis, although became aware following a subsequent discussion about
253 the key categories that had emerged during that first stage. The qualitative software package
254 NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the
255 thematic framework by refining and condensing the categories that had been manually
256 identified and to identify additional themes for exploration. Any differences of opinion
257 regarding the meaning of sentences or the importance of themes were discussed until a
258 consensus was reached.

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Table 1: Framework Technique used for data analysis

Framework Technique		
1.	Familiarisation	Reading and re-reading the transcripts
2.	Identifying a Thematic Framework	Condense data into categories
3.	Indexing	Codes systematically applied to the data
4.	Charting	Re-arranging the data according to the thematic content in a way which allows for a cross case and within case analysis
5.	Mapping and Interpretation	Interpretations and recommendations

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Findings

Data was initially indexed according to themes central to the main research questions, such as opinions of the VF test, current experience regarding the frequency of VF testing and opinions about more frequent VF testing. Throughout the analysis a number of additional themes emerged, often with their own sub-themes; these generally related to specific areas perceived to affect the follow-up experience, and included points relating to clinical constraints (waiting times, booking appointments), travel to the clinic, the testing environment and aspects of patient-clinician communication. The themes and sub-themes are summarised in Figure 1.

Figure 1: Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Direct quotes taken from the transcripts are italicized. These quotes were examples chosen to illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a pseudonym for the corresponding participant based on their gender (“M” or “F”) and the order in which they spoke in the interview. The location of the focus group and the session number (1 or 2) are also shown for each quote.

Visual fields – Opinions about testing

Visual fields - Test procedure

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289 Patients expressed a dislike for the VF test. They found the test time-consuming, old-
290 fashioned and tiring.

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292 *Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I*
293 *don't like having one eye closed and having to concentrate, even if it's for just a couple of*
294 *minutes, because then my mind wanders... F1, Portsmouth 1*

295
296 *It seems a bit antiquated, pressing the buttons... it doesn't seem positive enough to me.*
297 F3 Norwich 2

298
299 *I appreciate the need for it...but it's so time consuming*
300 M2 London 1

301
302
303 Visual fields - Performance pressure

304
305 Many put pressure on themselves to perform the test well, as they felt there could be a lot
306 riding on their performance.

307
308 *There is pressure: I think it is because your eyes are so important for everyday living, that,*
309 *you know, you're frightened to [not do well]. F2 Portsmouth 1*

310
311 There was a general appreciation that such testing was vital to preserve their vision.

312
313 *Well... obviously I'm very grateful that I'm being monitored all... F4 London 1*

314

315 *....mine has been 10 years and you think, well how long will I have my sight? ... My mum had*
316 *lost her sight by then, you know... F3 Norwich 2*

317

318 Visuals fields - Comparison with other tests

319

320 Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular
321 pressure measurement and imaging tests, less tiring and laborious. At the same time some
322 patients felt the VF test was more 'valuable', providing more reassurance that their condition
323 was being investigated.

324

325 *[with] the [imaging] there's just one person, one machine and you, and it's done and that's it,*
326 *it's over...within minutes. F3 Norwich 2*

327

328 *... they look in your eyes to measure your pressure but when you do that field test, they see*
329 *more.... F1 London 2*

330

331

332 Frequency of visual field testing – Current experience

333 VF tests were usually performed once or twice a year, either during or closely prior to the
334 patient's general clinical appointment. Patients who visited the clinic more frequently would
335 have a VF test at only some of their appointments. Some patients were often unaware as to
336 whether they would have a VF test during their visit.

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338 *I mean they just say you're going to come for your next appointment in whatsoever, whatever*
339 *time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you*
340 *know that you are going to have to be that little bit longer.. F2 Portsmouth 1*

341

342 Frequency of visual field testing – Opinions about more testing

343

344 When patients were asked whether they would be willing to visit the clinic for VF testing
345 more frequently, there was a reluctant agreement. The test was viewed as a ‘*necessary evil*’
346 and most were open to more frequent testing if the clinician felt it would enhance their
347 prognosis, although there was scepticism as to how useful the test actually was.

348

349 *If it was necessary. F2 Portsmouth 2*

350 *You’d get on with it. M1 Portsmouth 2*

351 *If it helps the cause so be it. M2 Portsmouth 2*

352 *I don’t want to lose my sight, I’d come in whenever. F2 Portsmouth 2*

353

354 *If it holds it back for 10 years... I'm happy with another 10 years! M1 Norwich 2*

355

356 *That's a problem with glaucoma, you can't leave it for too long*
357 *M2 London 2*

358

359 *... I suppose I'd accept it because I would hope that the reason for asking me was that they*
360 *will get more information from that, which obviously deals with the whole problem but...I'm*
361 *not really sure at all about how useful they are. I mean is it just statistics or whatever? ...I'm*
362 *sure they're useful but I wonder in what proportion of use they are compared to, you know,*
363 *looking in the eye and pressures and things....*

364 *F3 Norwich 2*

365 Some patients associated more frequent testing with worsening vision; therefore being asked
366 to attend for more testing could lead to increased anxiety.

367

368 *... you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said*
369 *to do it, I've always done ... because they're doing the best for me...*

370 F3 Norwich 2

371

372 Frequency of visual field testing - Learning effect

373

374 One recurrent topic regarding VF testing was issues relating to the learning effect, whereby
375 performance improves with increased testing. Some suggested that more repeat testing would
376 be helpful. However, the repeated tests may only be worthwhile if they took place at the
377 beginning of their follow-up care.

378

379 *...interestingly I went and did one once and they said to me, "this has improved from the last*
380 *time" and I said "well I think I'm just getting better at computer games" ... I think you do*
381 *know what's coming and you can improve and I just feel more comfortable with doing it.*

382 F1 Norwich 1

383

384 *I think to do a field test right at the beginning, and to take that as being the definitive field*
385 *test is wrong...because I think you need to do a test and think, and revise it in your mind what*
386 *you've done and then do it again. M1 Portsmouth 2*

387

388 There was some debate about the period of time between VF tests.

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390 *I think you need to do a field test and then perhaps a month later do the second one.*

391 M1 Portsmouth 2

392

393 *Well not if you have a long gap between them.* F1 Norwich 2

394 *I've got used to it now.* F2 Norwich 2

395 *I don't think it's any different really.* F3 Norwich 2

396

397

398 Perceived issues and barriers for successful follow-up care

399

400 Some additional themes emerged during the analysis, highlighting a number of areas
401 perceived to be important and potentially representing barriers to successful follow-up.

402

403 Communication - Visual field instructions

404

405 Regardless of how long they had been attending the glaucoma clinic, patients appreciated
406 having the VF test procedure fully explained to them. It was rare for a staff member to stay
407 with the patient throughout the test, but on the occasions it did happen, patients found the
408 experience reassuring and felt the encouragement helped their performance.

409

410 *... They say, "Have you done this before?" You say "Yes". And that's it, you're left there*
411 *and eventually they say, "Have you finished?"*

412 M1 Portsmouth 2

413

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3 414 *I had one about three weeks ago and it was a young nurse and it was a completely different*
4
5 415 *experience. She was professional, polite, kind; she told me exactly what they were doing.... it*
6
7 416 *was almost a pleasant experience.* F1 Portsmouth 1
8
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10 417

11
12 418 There was discussion about understanding aspects of the testing procedure and how the
13
14 419 procedure was explained. For example, some patients expressed uncertainty and felt test
15
16 420 pressure would influence their results. Again, explanation and reassurance before and after the
17
18 421 test helped.
19
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21 422

22
23 423 *The staff told me: "don't worry about missing [a light] because it'll come later", so you know*
24
25 424 *you get a second chance.* F1 Norwich 1
26
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28 425

29
30 426 *... if in doubt press the button, don't you?* F1 Portsmouth 2
31
32 427

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34 428 Communication - Explanation of results
35
36 429

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38
39 430 Most patients said they had to specifically enquire about their results to find out information
40
41 431 about their vision and whether their condition had progressed since the last appointment.
42
43 432 Some patients felt intimidated to ask the clinician for feedback as to how they had performed,
44
45 433 feeling they were being a nuisance or wasting the clinician's time.
46
47 434

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50 435 *They never discuss the result of the field test unless I ask...*
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52 436

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54 437 *M2 London 2*
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438 *My wife always says “how did you get on?” and I say “I don’t know”, and that’s one of the*
439 *problems. M2 Portsmouth 2*

440
441 *I don't think they've got time to listen to you, or they don't appear to, and I don't know*
442 *whether they would listen.... You feel pathetic asking these questions. F3 Portsmouth 1*

443
444 Patients may be more inclined to have VF tests more frequently should they be informed
445 clearly about what the results indicate about their prognosis.

446
447 *I don't mind how many times I do it providing I get a result of the test at that time compared*
448 *to what the previous one was. Is there any improvement? Is there any downgrade?*

449 M1 Portsmouth 1

450
451
452 Communication - The patient-clinician relationship

453
454 The quality of relationship with the clinical staff and aspects of patient-clinician
455 communication also emerged as key factors influencing perceptions of the follow-up process.

456
457 An apparent lack of personalised care caused unease: there was a sentiment that sometimes
458 the clinician simply looked at the eyes and failed to consider the person’s individual needs.

459
460 *You're not a person, you know, you've just got eyes, they're just going to deal with that and*
461 *that's it. F3 Portsmouth 1*

462

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3 463 The experience was seen to be much more bearable if they felt the staff member dealing with
4
5 464 them was empathic.
6
7
8 465

9
10 466 *Even buying a chop, you know: if the butcher's interested, it helps doesn't it?*

11
12 467 *M3 Norwich 1*
13
14 468

15
16 469 The opportunity to spend more time with their consultant ophthalmologist was a key factor
17
18 470 that influenced whether or not patients were open to visiting the clinic more frequently.
19
20 471

21
22
23 472 *Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.*

24
25 473 *M2 London 2*
26
27 474

28
29 475 Testing environment
30
31 476

32
33
34 477 The testing environment was another important theme. The dark room, especially if it was
35
36 478 warm, made focusing on the tests difficult. Patients felt they performed better in the morning
37
38 479 when they were more alert. Ambient noise in the room made it difficult to concentrate; staff
39
40 480 members talking and doing the test at the same time as several other patients all had
41
42 481 deleterious effects.
43
44 482

45
46
47 483 *I will also say that the staff chatter a lot, which is difficult for concentration; the doors open*

48
49 484 *and close, there's a lot of noise. F1 Norwich 1*
50
51 485

52
53
54 486 *I find it difficult sometimes when people [move] about behind you...*

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56 487 *M1 London 1*
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488
489 *The times that I've had the visual field test done in a room where there's just one [machine], I*
490 *felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot*
491 *quicker too. F3 Norwich 2*

492
493 *I think having the quieter atmosphere would generally help I'm sure....just that feeling of*
494 *slight calm, you can relax more and then it probably would be a lot quicker because maybe*
495 *you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.*

496
497
498 The idea was raised that routine VF testing could be carried out in a more convenient location.
499 Some patients had previously visited a local optometrist to carry out a VF test for the purpose
500 of assessing their legal fitness to drive. On the positive side, patients liked the convenience of
501 doing so and described a better testing environment. Conversely, they questioned the
502 competency of the staff, the quality of the equipment and the information trail back to the
503 hospital.

504
505 *The principle of having routine tests done locally is acceptable providing they are trained.*
506 M1 London 1

507
508 *That way you would be there, dealt with by people you know probably more*
509 *intimately...you're in a more relaxed environment...*
510 M1 Norwich 1

511
512 *I would be concerned about how often the machine was calibrated to get an accurate reading.*
513 M2 London 1

514

1
2
3 515 *Is the information going back to where it matters in my notes? Things do get lost, and will*
4
5 516 *someone actually look at the test?*
6

7 517 M1 London 2
8
9 518

10
11 519 Some felt they had built up a level of trust with the hospital eye service and would therefore
12
13 520 prefer to have VFs conducted in this environment.
14
15 521

16
17
18 522 *I've been here for quite a while now and I like coming to them: I don't want to go anywhere*
19
20 523 *else.* F1 London 2
21

22 524 *I would feel the same because it's a matter of trust.* M2 London 2
23
24 525

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29 527 Clinic constraints -Waiting times
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33 529

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35 531

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37
38 531 Waiting times were a major concern at all locations. The standard time taken per visit was
39
40 532 estimated to be two hours, although the wait was often unpredictable. Established patients
41
42 533 were used to the wait and tried not to let it affect them but they still found the system
43
44 534 frustrating. Patients were scared of missing their slots and, therefore, would not leave their
45
46 535 seat in the waiting area.
47
48 536

49 537

50
51 537 *No way I'm going to nip off ... especially as now I'm on my own, no way just even nipping*
52
53 538 *off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour*
54

55 539 *and he'll call me the minute I go to the [bathroom].* F2 Portsmouth 1
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540
541 Although it was repeatedly acknowledged that the clinics were very busy, which had the
542 knock-on effect of increased waiting times, patients felt they were getting adequate treatment
543 overall. It was suggested that there was a trade-off between longer waiting times and higher
544 quality treatment:

545
546 *I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of*
547 *excellence. There's a trade-off in that you're getting state of the art treatment but the price is*
548 *you've got to sit around for it.* M1 London 1

549
550
551
552 Clinic constraints - Travelling to the clinic

553
554 Several sub-themes emerged including issues with long distances to travel, avoiding rush
555 hours, travel costs and travelling alone.

556
557 *I think the problem is because I live nearly an hour away, for me the nearest hospital is an*
558 *hour away...* F2 Norwich 2

559
560 *Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly*
561 *with help to get on the train but it's not easy.....It's horrific, frightening.* M2 London 1

562
563
564 Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to
565 have a negative effect on VF test performance.

566

567 *I think if you did the eye check later in the day, you know, if your eyes were tired, it might*
568 *make you feel [that you] wouldn't see so well... F2 Portsmouth 1*

569

570

571 Clinic constraints - Scheduling appointments

572

573 The scheduling of appointments was a major concern: often the systems were so overbooked
574 that patients were unable to make their next appointment at their clinic visit.

575

576 *You can only make an appointment six weeks in advance. You used to get a twelve month*
577 *appointment letter just after you had been for an appointment; now its six weeks before you*
578 *are due. M2 Norwich 1*

579

580 Often patients would receive an appointment only to have it cancelled just before the clinic
581 was due to take place. This was not only frustrating to people who had made arrangements for
582 their appointment, such as asking a friend to accompany them or arranging cover for sick
583 spouses, it caused concern that their appointment was to be at a much later date than the
584 clinician had originally requested.

585

586 *"So if you've been given a six month appointment and it's cancelled, and you're not given*
587 *another one, you ring up and then they say "oh we can't give you an appointment now until*
588 *October". That was 10 months. Now if your consultant says 6 [months] and it's 10 and*
589 *something's gone wrong with your vision in between, you have no way of telling."* F2

590

Portsmouth 2

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Patient recommendations

At the end of the focus groups, patients were asked to recommend changes to improve their follow-up care. The recommendations were similar across all locations and the most popular suggestions are displayed in table 2.

Table 2: Patient recommendations for improving follow-up care.

Patient Recommendations	
1.	Less waiting and clinics running to time.
2.	Flexible booking and changing of appointments.
3.	To have a calmer, quieter environment in the visual field room with less people doing the test at the same time.
4.	To modernise the visual field test.
5.	To have more continuity of care by seeing the same clinician at each visit.
6.	To receive better communication from the clinician.

Discussion

Data from this study supports evidence from elsewhere that patients find VF testing more laborious and demanding than other vision tests²⁰. Nevertheless, patients were willing to complete more VF tests on the guidance of their clinician, as ultimately they were prepared to do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF testing during the first two years of their follow-up care as recommended by the research literature^{4 5} and some clinical guidelines²⁴. Patients commented that it took time to feel comfortable with the test procedure, and that multiple attempts were needed to gain an accurate representation of their vision. These viewpoints complement existing evidence showing that performance can improve considerably during follow-up due to gaining experience with the testing process²⁵.

There were, however, a number of additional themes that emerged from the data which identified areas that could represent potential barriers to successful glaucoma monitoring. Patients felt that the environment in which they completed the VF test was linked to how well they were able to perform the task, with staff members talking loudly, the number of people in the room, and the time of day all listed as important interfering factors. These views coincide with other evidence showing that the environment, the technician and the time of day do have a significant influence on measurement variability from VF tests²⁶. Fatigue, a topic mentioned frequently throughout the discussions, has also been shown to affect performance as test duration increases²⁷.

Patients highlighted the importance of effective task communication for influencing their VF test performance. Prior evidence has shown that the quality of instruction given before the VF test can significantly affect subsequent estimations of VF defect severity^{28 29}. Patients also felt

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634 that it was essential to have the task explained to them properly, even if they had been
635 attending clinics for some time. Having a staff member in the room whilst they carried out the
636 test was found to be reassuring. These findings reiterate the idea that ensuring that the task
637 demands are communicated clearly and effectively before every VF test, and being on hand to
638 alleviate any concerns or questions that the patient may have, may help maximise the quality
639 of the data gained from the assessment²⁹⁻³¹.

640

641 Other discussion points relating to communication were also raised repeatedly throughout the
642 focus groups. Patients felt that many clinicians treated them as an ‘eye’ rather than a person,
643 with those staff members who took a more individualistic and empathic approach viewed
644 favourably. Notably, patients felt that they had to ask explicitly about their results in order to
645 learn details about their own condition. Evidence has shown that that the patient and
646 clinician’s views of their condition are not always aligned, which may be due to
647 miscommunication or misinterpretation of key information on both parts³². By explaining the
648 results in a clear, simple and concise manner, the patient will inevitably improve their
649 understanding of their condition, which in turn could influence how well they respond to
650 important aspects of their follow-up care. For instance, it has been shown that the way in
651 which clinicians communicate with the patient can influence future adherence to
652 medication³². It has been suggested that clinicians underestimate the importance of effective
653 communication to the patient¹¹, and in one study examining patient expectations for eye care,
654 the emphasised areas were all related to communication and interpersonal manner³³.
655 Providing better information about the purpose of VF testing, what is required of the patient,
656 and their results and general prognosis could be vital for improving attendance for VF tests or
657 for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about
658 ways in which the complex measurement of the VF could be easily presented and

communicated to patients. It is important to note that some patients associated more frequent testing with worsening vision, which caused some distress. Thus, should patients require more frequent tests at some point in their care, it is also vital to involve the patient and explain reasons for the decision.

Excessive waiting times and difficulty booking appointments were also major concerns. In particular, patients worried that appointment cancellations could extend the interval between tests beyond what was recommended by the clinician, therefore leaving them exposed to undetected disease progression. It is known that whilst clinicians select appropriate monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate follow-up^{7 34 35}. Moreover, it was typical for patients to wait at the clinic for hours in order to complete multiple vision tests, causing frustration and tiredness which some perceived to influence their subsequent performance. Potential solutions could involve conducting only the VF test during short independent appointment slots, or carrying out tests at a more convenient location. However, such strategies would involve further investigation as to their overall cost-effectiveness and should address other associated practicalities such as travel (a significant contributor to total patient costs³⁶) and the information trail back to the hospital.

Previous research has relied on statistical analysis or computer simulations to help determine the most effective VF monitoring strategies for patients with glaucoma. This is the first study to use qualitative methods to investigate the patient's own perspective on their follow-up. Studies focusing on the patient's perspective in glaucoma, particularly with regard to the perceived effects of the disease on their day-to-day activities, have typically relied on questionnaires¹³. However, questionnaire responses can be restricted by the wording of the items and provide little opportunity for clarification or elaboration. This study allowed

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684 individuals to contextualise their experiences and expand on particular points and themes,
685 encouraging discussion about topics a certain patient may not have otherwise introduced or
686 attributed to glaucoma without the encouragement of another¹⁸. The notion of the “expert
687 patient” is beginning to be endorsed with regards to other chronic conditions, with focus
688 groups demonstrating potential as a forum for the development of more effective management
689 strategies³⁷⁻³⁹. Furthermore, patient groups have aided the development of health education
690 programmes for age-related macular degeneration⁴⁰. A systematic review of patient centred
691 randomised controlled trials suggests there may be some benefits associated with involving
692 patients with chronic disease in programmes geared towards better educating service users
693 and devising general training for health professionals⁴¹. Future work that encourages more
694 patient involvement may therefore help devise the optimal strategies for glaucoma follow-up
695 and also help better inform both patients and health professionals about the condition.

696
697 This study has its limitations with findings attached to the viewpoints of the groups who took
698 part. Efforts were taken to reduce bias by involving multiple research sites- however, these
699 were all geographically limited to the South of England and (excluding the London groups)
700 involved patients of Caucasian ethnicity. Therefore the findings may not necessarily translate
701 to a wider population. Moreover, initial patient selection was made on recommendation of
702 consultants at the clinics and our selection process did not monitor reasons for non-
703 participation. People who choose to volunteer for focus groups are likely to be articulate and
704 confident; they may also be more motivated to take part due to having more severe disease or
705 holding strong opinions about a certain area of their care. Furthermore, participants were aged
706 60 years and older- younger service-users may have differing views and experiences that also
707 warrant investigation. The study was initially designed to involve 6 focus groups across 3
708 locations and so no direct decision was taken to cease data collection; however, similar

709 themes and sub-themes continued to emerge in the latter focus groups and so it is likely that
710 'data saturation' was achieved. Furthermore, some of the focus groups were small (one
711 consisting of only 3 participants) due to late cancellations but this is not a major limitation
712 due to the number of focus groups that took place⁴². Also, some biases could have been
713 introduced during interview and analysis due the preconceived ideas held by the
714 experimenters about the areas of importance, although care was taken to adhere to expected
715 practice by following the COREQ check-list for focus group research²².

716

717 A number of important themes did emerge that give an insight into clinic visits and VFs from
718 the patient's perspective, and could help inform patient centred care in glaucoma. Although
719 patients appeared frustrated by a number of aspects of their follow-up, they ultimately
720 accepted that some compromises had to be made in order to save their eyesight. Some of the
721 viewpoints illustrated in the focus group discussions may in part explain why research-
722 supported guidelines about more frequent VF testing are not being implemented effectively in
723 clinical practice. A holistic approach that embraces patient opinion may therefore be vital to
724 help devise the most effective strategies for follow-up care in this chronic disease.

725

726

727 Conclusion

728

729

730 This is the first study to use qualitative methods to examine patient opinion about the
731 glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they
732 accepted it was important to their overall vision assessment. However, a number of actionable
733 points were raised which were perceived to impact the effectiveness of follow-up care,
734 including distracting testing environments, and hospital constraints relating to excessive
735 waiting times and appointment booking. Some patients also expressed particular concerns

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736 about the VF technology used and the quality of test instructions. Anxiety associated with
737 increased testing in the absence of clinical explanation was another theme. Ensuring that
738 glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the
739 confidence and cooperation of the patient. Addressing some or all of the perceived barriers
740 highlighted in this study should help deliver more efficient strategies for VF monitoring in
741 glaucoma.

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For peer review only

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Contributions of authors

FCG: Conducted data analysis, and wrote and edited the manuscript (joint first author).

HB: Conducted focus groups and data analysis, and wrote the manuscript (joint first author).

DPC: Conceived and designed study, and reviewed and edited the manuscript.

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Competing Interest Statement

None of the authors have any competing interests in relation to this work.

Data Sharing Statement

Copies of the topic guide and participant information sheet can be obtained by emailing the corresponding author.

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Title: A qualitative investigation into patient views on visual field testing for glaucoma monitoring

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35 Department of Health.
36

37 **Competing Interest Statement**

38 None of the authors have any competing interests in relation to this work.
39

40 **Contributions of authors**

41 **FCG:** Conducted data analysis, and wrote and edited the manuscript (joint first author).

42 **HB:** Conducted focus groups and data analysis, and wrote the manuscript (joint first author).

43 **DPC:** Conceived and designed study, and reviewed and edited the manuscript.
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Abstract

Objectives: To investigate the views and experiences of patients regarding their glaucoma follow-up, particularly towards the type and frequency of visual field (VF) testing.

Design: A qualitative investigation using focus groups. The group discussion used broad open questions around the topics in a prompt guide relating to experiences of glaucoma follow-up, and in particular, VF monitoring. All groups were taped, transcribed and coded using manual and computer aided methods.

Setting: Three NHS hospitals in England; two focus groups took place at each hospital.

Participants: Twenty-eight patients (mean [SD] age: 74 [9] years; 54% female) diagnosed with glaucoma for at least 2 years. Each focus group consisted of 3-6 patients.

Primary and Secondary Outcomes:

1) Attitudes and experiences of patients with glaucoma regarding VF testing

2) Patients' opinions about successful follow-up in glaucoma.

Results: These patients did not enjoy the VF test but they recognised the importance of regular monitoring for preserving their vision. These patients would agree to more frequent VF testing on their clinician's recommendation. A number of themes recurred throughout the focus groups representing perceived barriers to follow-up care. The testing environment, waiting times, efficiency of appointment booking and travel to the clinic were all perceived to influence the general clinical experience and the quality of assessment data. Patients were also

71 concerned about aspects of patient-doctor communication, and often received little to no
72 feedback about their results.

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74 **Conclusions:** Patients trust the clinician to make the best decisions for their glaucoma follow-
75 up. However, patients highlighted a number of issues that could compromise the effectiveness
76 of VF testing. Addressing patient-perceived barriers could be an important step for devising
77 optimal strategies for follow-up care.

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80 **Article Summary**

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83 **Article Focus**

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- 85 • Glaucoma is a chronic and progressive eye disease and all diagnosed patients will
86 require lifetime monitoring of their vision.
 - 87 • Visual field (VF) testing is one of the most widely used assessments for glaucoma and
88 places a large burden on NHS resources; research is needed to devise the most
89 effective strategies for glaucoma VF monitoring.
 - 90 • This study used focus groups to investigate patient views about VF testing in their
91 follow-up care. Effective VF testing will require the confidence and cooperation of
92 the patient.
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95 **Key Messages**

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- 97 • Although patients disliked VF testing, they accepted it as an important part of their
98 vision assessment and disease management.
 - 99 • Patients discussed a number of areas of perceived importance for VF monitoring,
100 raising particular concerns about distracting testing environments, the quality of test

instructions, how results were explained to them and excessive pre-testing waiting times.

Strengths and Limitations of this study

- This is the first **qualitative** study to examine patients' views of visual field monitoring using focus groups.
- Focus groups took place at three selected hospitals **in the South of England; it is assumed the views expressed represent the experiences of patients in a wider population.**
- **Not all patients approached by their ophthalmologist took part, but reasons for non-participation were not monitored. Patients who chose to volunteer may be more articulate, motivated and opinionated than the general patient population.**

Introduction

Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively, could lead to visual impairment or blindness. Currently, the only modifiable risk factor for disease worsening (progression) in glaucoma is reduction of intraocular pressure (IOP). A variety of different approaches to IOP lowering are available, meaning surveillance of the patient is important in selecting the correct intensity of treatment. Over half a million people in the United Kingdom (UK) are thought to have the condition, with patients receiving over a million outpatient visits annually^{1 2}. Since the prevalence of glaucoma increases exponentially with age, these figures can be expected to increase dramatically with an ageing population. Glaucoma monitoring therefore represents a major workload for eye services in the National Health Service (NHS).

Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a sophisticated automated instrument. The test is carried out in a darkened room and takes about 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a large semi-circular bowl covering their entire field of view. The instrument presents a series of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the VF while the patient fixates on a central point. The patient responds by clicking a button when a stimulus is detected. This process yields a map of the seeing parts of the patient's field of view; this map is subjected to statistical analysis comparing a patient's results to normative values for people with healthy vision. These measurements can be highly variable, and speed (rate) of VF loss, determined from a series of measurements over a period of time, varies considerably between treated individuals. The VF should therefore be monitored at appropriate intervals in order to identify timely intervention of more intensified treatment to

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3 143 preserve visual function³. Yet, evidence regarding how frequently VF tests should be carried
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5 144 out to optimally detect disease progression is limited. The National Institute of Clinical
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7 145 Excellence (NICE) called for more research into examining the effectiveness of using
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9 146 different monitoring intervals to detect disease progression in people with glaucoma in 2009¹.
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11 147 Guidelines proposed by the European Glaucoma Society (EGS) recommend that the
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13 148 frequency of VF tests should be increased for newly diagnosed patients in order to better
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15 149 determine speed of VF progression. This notion is supported by research evidence based on
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17 150 statistical analyses of retrospective data which has indicated that three VF tests per year in the
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19 151 first 2 years of follow-up would be clinically useful for identifying patients that are
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21 152 deteriorating at fast rates⁴⁻⁶. However, a recent multicentre audit of glaucoma clinics in
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23 153 England indicated that most patients only have about one VF test a year⁷. In another recent
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25 154 study, VF monitoring intervals assigned by clinicians (for hypothetical patient scenarios) were
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27 155 shown to be highly variable⁸.
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34 157 Organisational and resource constraints in the current NHS setting will impact on the
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36 158 feasibility of translating research supported guidelines for VF monitoring to practice.
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38 159 Furthermore, the clinician ultimately drives decision-making based on their own estimates of
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40 160 the likelihood and speed of disease progression, and therefore their opinions towards the
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42 161 appropriateness of monitoring intervals will be important. At the same time, establishing
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44 162 effective monitoring strategies for this chronic condition likely also requires the input of the
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46 163 patients themselves, especially if it equates to more clinic visits. Care plans that place
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48 164 burdens on patients may result in a reduced willingness to return for follow-up and
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50 165 compromise the quality of the data obtained that is subsequently relied on during
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52 166 management^{9,10}. Studies have shown that the views of the clinician and the patient regarding
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54 167 aspects of their condition are not always aligned^{11,12}, implying the patient's perspective must
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168 also be considered. Nevertheless there has been limited use of patient-based research for
169 improving glaucoma care. A review of the literature found that most studies use
170 questionnaires to quickly gather information about the perceptions of patients, usually with
171 regards to their perceived outcomes ¹³. However, questionnaires can be impersonal and
172 subject to bias ^{14 15}. Qualitative techniques, such as focus groups, offer an alternative method
173 of gathering information about not only what a patient thinks, but also how they think or why
174 they may hold a particular view. Group interaction encourages participants to explore and
175 clarify individual and shared perspectives and supports the participation of people who may
176 be reluctant to contribute their views in a more formal one-to-one scenario¹⁶. Focus groups
177 have been used in a small number of studies to examine the general experiences of glaucoma
178 patients at diagnosis, their expectations and to identify potential barriers to treatment
179 adherence ^{10 17-19}. However, there is limited evidence regarding the opinions of patients about
180 the manner in which their vision loss is monitored. Anecdotal evidence suggests that patients
181 dislike doing the VF test, and one quantitative study showed that patients rate the VF test least
182 favourably of all the vision assessments ²⁰. However, no study has interviewed patients with
183 glaucoma in detail about their perceptions of the VF test and their follow-up care. The current
184 study therefore aims to shed light on the effectiveness of glaucoma monitoring from the
185 perspective of the patient by exploring patient views and experiences via focus groups. In
186 particular, the study aims to establish patients' views about VF testing in glaucoma
187 monitoring.

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Methods

Participants and methods

Focus groups took place between May 2012 and January 2013 in the following locations: The Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation Trust in London. The study was multi-centred to reduce the bias that might come from one geographical area and to encompass healthcare trusts in both urban and rural locations. The sites were chosen because they were involved in a wider programme work, of which the current study was a component. There were two focus groups at each site, with participants allocated to one of the two groups at the corresponding hospital.

The study used purposeful sampling whereby a consultant ophthalmologist at each participating eye hospital selected suitable participants during their routine eye appointment. Specifically, the participant was required to be aged 60 years and over and to be an established glaucoma patient who had been under review for at least two years. These criteria were chosen to reflect the age-related nature of the disease and to ensure that participants had sufficient experience of VFs as part of their glaucoma follow-up. The ophthalmologist gave potential participants an information sheet, and interested people were asked to sign a form indicating they were happy to be contacted by a researcher (it was stressed that they were not obliged to participate). Each consultant ophthalmologist approached 20 patients in this way. One of the study investigators (HB) then contacted the patients with further information and invited them to take part on one of two specific dates at the corresponding hospital. Those who declined did so because they were not available on the specific dates (no other reason was cited). Initially, 5-6 patients were signed up to participate on each of the six

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study dates. However, a small number (n=4) did not attend. A total of 28 participants (mean age [standard deviation] 74 [9] years; 54% female) eventually took part across the six focus groups. Each group consisted of three to six patients and included participants of both genders.

Procedure

A topic guide was devised prior to beginning the study outlining broad question areas regarding general glaucoma care, experiences of the VF test and opinions about VF test frequency. Study topics were informed by an initial pilot exercise involving a discussion with two patients with glaucoma, who also provided additional verbal and written information about their experiences. The topics included in the guide acted only as suggestions; the wording of questions was not predetermined and the order of the topics was not fixed. Prompts were used to introduce topic areas and encourage respondents to elaborate but the onus was on participants to supply the overall content of the discussion. Care was taken to ensure questions were open and “non-leading”, although more specific questioning was sometimes used to clarify a point made by a participant. If discussion went substantially off-topic, or one participant was dominating the conversation, the interviewer would reflect back to a previous topic and encourage other participants to contribute their views.

Prior to the study, participants were informed that they would be involved in “an open discussion about (their) experiences in the glaucoma clinic, with special attention to the visual

tests (they) undertake". Participants were not explicitly aware of the emphasis on VF testing, so as to avoid bias linked to the self-selection of participants with strong views on this one topic. All focus groups were conducted by one of the authors (HB), a post-doctoral researcher who had prior experience of qualitative research involving patients with glaucoma^{18 21}. The interviewer and participants had no prior knowledge of each other in a clinical or personal context, so each focus group began with general introductions. Field notes were taken during the sessions to aid later interpretation of the data, although note-taking was purposely minimal so that the interviewer could be fully attentive to the discussion. The focus groups lasted between 60 and 75 minutes.

The study received approval from a NHS National Research Ethics Service (NRES) committee and was approved by research governance committees of the participating institutions. The study conformed to the Declaration of Helsinki and written consent from all participants was obtained prior to each focus group.

The study was designed and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) for interviews and focus groups²².

Analysis

All focus groups were audio-recorded (with permission from the participants). The dialogue from the recordings was later transcribed and reviewed by the investigators. In a small number of instances certain words were inaudible on the recordings due to excessive background noise, so field notes were used to account for any unclear information.

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268 Data was analysed by two of the authors (HB and FCG) independently using framework
269 analysis²³ as displayed in Table 1. Each investigator read and re-read the transcripts and
270 manually identified the key themes from the data in addition to some example quotes to
271 illustrate main points. One of the authors (FCG) was masked to the emphasis on VF testing at
272 this initial point of analysis, although became aware following a subsequent discussion about
273 the key categories that had emerged during that first stage. The qualitative software package
274 NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the
275 thematic framework by refining and condensing the categories that had been manually
276 identified and to identify additional themes for exploration. Any differences of opinion
277 regarding the meaning of sentences or the importance of themes were discussed until a
278 consensus was reached.

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Table 1: Framework Technique used for data analysis

Framework Technique		
1.	Familiarisation	Reading and re-reading the transcripts
2.	Identifying a Thematic Framework	Condense data into categories
3.	Indexing	Codes systematically applied to the data
4.	Charting	Re-arranging the data according to the thematic content in a way which allows for a cross case and within case analysis
5.	Mapping and Interpretation	Interpretations and recommendations

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Findings

Data was initially indexed according to themes central to the main research questions, such as opinions of the VF test, current experience regarding the frequency of VF testing and opinions about more frequent VF testing. Throughout the analysis a number of additional themes emerged, often with their own sub-themes; these generally related to specific areas perceived to affect the follow-up experience, and included points relating to clinical constraints (waiting times, booking appointments), travel to the clinic, the testing environment and aspects of patient-clinician communication. The themes and sub-themes are summarised in Figure 1.

Figure 1: Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Direct quotes taken from the transcripts are italicized. These quotes were examples chosen to illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a pseudonym for the corresponding participant based on their gender (“M” or “F”) and the order in which they spoke in the interview. The location of the focus group and the session number (1 or 2) are also shown for each quote.

Visual fields – Opinions about testing

Visual fields - Test procedure

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310 Patients expressed a dislike for the VF test. They found the test time-consuming, old-
311 fashioned and tiring.

312
313 *Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I*
314 *don't like having one eye closed and having to concentrate, even if it's for just a couple of*
315 *minutes, because then my mind wanders...* F1, Portsmouth 1

316
317 *It seems a bit antiquated, pressing the buttons... it doesn't seem positive enough to me.*
318 F3 Norwich 2

319
320 *I appreciate the need for it...but it's so time consuming*
321 M2 London 1

322
323
324 Visual fields - Performance pressure

325
326 Many put pressure on themselves to perform the test well, as they felt there could be a lot
327 riding on their performance.

328
329 *There is pressure: I think it is because your eyes are so important for everyday living, that,*
330 *you know, you're frightened to [not do well].* F2 Portsmouth 1

331
332 There was a general appreciation that such testing was vital to preserve their vision.

333

334 *Well... obviously I'm very grateful that I'm being monitored all... F4 London 1*

335

336 *....mine has been 10 years and you think, well how long will I have my sight? ... My mum had*

337 *lost her sight by then, you know... F3 Norwich 2*

338

339 Visuals fields - Comparison with other tests

340

341 Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular
342 pressure measurement and imaging tests, less tiring and laborious. At the same time some
343 patients felt the VF test was more 'valuable', providing more reassurance that their condition
344 was being investigated.

345

346 *[with] the [imaging] there's just one person, one machine and you, and it's done and that's it,*

347 *it's over...within minutes. F3 Norwich 2*

348

349 *... they look in your eyes to measure your pressure but when you do that field test, they see*

350 *more.... F1 London 2*

351

352

353 Frequency of visual field testing – Current experience

354 VF tests were usually performed once or twice a year, either during or closely prior to the
355 patient's general clinical appointment. Patients who visited the clinic more frequently would
356 have a VF test at only some of their appointments. Some patients were often unaware as to
357 whether they would have a VF test during their visit.

358

359 *I mean they just say you're going to come for your next appointment in whatsoever, whatever*
360 *time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you*
361 *know that you are going to have to be that little bit longer..* F2 Portsmouth 1

362
363 Frequency of visual field testing – Opinions about more testing
364

365 When patients were asked whether they would be willing to visit the clinic for VF testing
366 more frequently, there was a reluctant agreement. The test was viewed as a ‘*necessary evil*’
367 and most were open to more frequent testing if the clinician felt it would enhance their
368 prognosis, although there was scepticism as to how useful the test actually was.

369
370 *If it was necessary.* F2 Portsmouth 2

371 *You’d get on with it.* M1 Portsmouth 2

372 *If it helps the cause so be it.* M2 Portsmouth 2

373 *I don’t want to lose my sight, I’d come in whenever.* F2 Portsmouth 2

374
375 *If it holds it back for 10 years... I'm happy with another 10 years!* M1 Norwich 2

376
377 *That's a problem with glaucoma, you can't leave it for too long*

378 M2 London 2
379

380 *... I suppose I'd accept it because I would hope that the reason for asking me was that they*
381 *will get more information from that, which obviously deals with the whole problem but...I'm*
382 *not really sure at all about how useful they are. I mean is it just statistics or whatever? ...I'm*
383 *sure they're useful but I wonder in what proportion of use they are compared to, you know,*
384 *looking in the eye and pressures and things....*

385 F3 Norwich 2

386 Some patients associated more frequent testing with worsening vision; therefore being asked
387 to attend for more testing could lead to increased anxiety.

388

389 ... you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said
390 to do it, I've always done ... because they're doing the best for me...

391 F3 Norwich 2

392

393 Frequency of visual field testing - Learning effect

394

395 One recurrent topic regarding VF testing was issues relating to the learning effect, whereby
396 performance improves with increased testing. Some suggested that more repeat testing would
397 be helpful. However, the repeated tests may only be worthwhile if they took place at the
398 beginning of their follow-up care.

399

400 ...interestingly I went and did one once and they said to me, "this has improved from the last
401 time" and I said "well I think I'm just getting better at computer games" ... I think you do
402 know what's coming and you can improve and I just feel more comfortable with doing it.

403 F1 Norwich 1

404

405 I think to do a field test right at the beginning, and to take that as being the definitive field
406 test is wrong...because I think you need to do a test and think, and revise it in your mind what
407 you've done and then do it again. M1 Portsmouth 2

408

409 There was some debate about the period of time between VF tests.

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411 *I think you need to do a field test and then perhaps a month later do the second one.*

412 M1 Portsmouth 2

413

414 *Well not if you have a long gap between them.* F1 Norwich 2

415 *I've got used to it now.* F2 Norwich 2

416 *I don't think it's any different really.* F3 Norwich 2

417

418

419 Perceived issues and barriers for successful follow-up care

420

421 Some additional themes emerged during the analysis, highlighting a number of areas
422 perceived to be important and potentially representing barriers to successful follow-up.

423

424 Communication - Visual field instructions

425

426 Regardless of how long they had been attending the glaucoma clinic, patients appreciated
427 having the VF test procedure fully explained to them. It was rare for a staff member to stay
428 with the patient throughout the test, but on the occasions it did happen, patients found the
429 experience reassuring and felt the encouragement helped their performance.

430

431 *... They say, "Have you done this before?" You say "Yes". And that's it, you're left there*
432 *and eventually they say, "Have you finished?"*

433 M1 Portsmouth 2

434

435 *I had one about three weeks ago and it was a young nurse and it was a completely different*
436 *experience. She was professional, polite, kind; she told me exactly what they were doing.... it*
437 *was almost a pleasant experience. F1 Portsmouth 1*

438

439 There was discussion about understanding aspects of the testing procedure and how the
440 procedure was explained. For example, some patients expressed uncertainty and felt test
441 pressure would influence their results. Again, explanation and reassurance before and after the
442 test helped.

443

444 *The staff told me: "don't worry about missing [a light] because it'll come later", so you know*
445 *you get a second chance. F1 Norwich 1*

446

447 *... if in doubt press the button, don't you? F1 Portsmouth 2*

448

449 Communication - Explanation of results

450

451 Most patients said they had to specifically enquire about their results to find out information
452 about their vision and whether their condition had progressed since the last appointment.
453 Some patients felt intimidated to ask the clinician for feedback as to how they had performed,
454 feeling they were being a nuisance or wasting the clinician's time.

455

456 *They never discuss the result of the field test unless I ask...*

457

M2 London 2

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459 *My wife always says “how did you get on?” and I say “I don’t know”, and that’s one of the*
460 *problems. M2 Portsmouth 2*

461
462 *I don't think they've got time to listen to you, or they don't appear to, and I don't know*
463 *whether they would listen.... You feel pathetic asking these questions. F3 Portsmouth 1*

464
465 Patients may be more inclined to have VF tests more frequently should they be informed
466 clearly about what the results indicate about their prognosis.

467
468 *I don't mind how many times I do it providing I get a result of the test at that time compared*
469 *to what the previous one was. Is there any improvement? Is there any downgrade?*

470 M1 Portsmouth 1

471
472

473 Communication - The patient-clinician relationship

474

475 The quality of relationship with the clinical staff and aspects of patient-clinician
476 communication also emerged as key factors influencing perceptions of the follow-up process.

477

478 An apparent lack of personalised care caused unease: there was a sentiment that sometimes
479 the clinician simply looked at the eyes and failed to consider the person’s individual needs.

480

481 *You're not a person, you know, you've just got eyes, they're just going to deal with that and*
482 *that's it. F3 Portsmouth 1*

483

1
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3 484 The experience was seen to be much more bearable if they felt the staff member dealing with
4
5 485 them was empathic.
6
7
8 486

9
10 487 *Even buying a chop, you know: if the butcher's interested, it helps doesn't it?*

11
12 488 *M3 Norwich 1*
13
14 489

15
16 490 The opportunity to spend more time with their consultant ophthalmologist was a key factor
17
18 491 that influenced whether or not patients were open to visiting the clinic more frequently.
19
20 492

21
22 493 *Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.*

23
24 494 *M2 London 2*
25
26 495

27
28
29 496 **Testing environment**
30
31 497

32
33 498 The testing environment was another important theme. The dark room, especially if it was
34
35 499 warm, made focusing on the tests difficult. Patients felt they performed better in the morning
36
37 500 when they were more alert. Ambient noise in the room made it difficult to concentrate; staff
38
39 501 members talking and doing the test at the same time as several other patients all had
40
41 502 deleterious effects.
42
43 503

44
45 504 *I will also say that the staff chatter a lot, which is difficult for concentration; the doors open*
46
47 505 *and close, there's a lot of noise. F1 Norwich 1*
48
49 506

50
51 507 *I find it difficult sometimes when people [move] about behind you...*
52
53 508

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55 509 **M1 London 1**
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509
510 *The times that I've had the visual field test done in a room where there's just one [machine], I*
511 *felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot*
512 *quicker too. F3 Norwich 2*

513
514 *I think having the quieter atmosphere would generally help I'm sure....just that feeling of*
515 *slight calm, you can relax more and then it probably would be a lot quicker because maybe*
516 *you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.*

517
518
519 The idea was raised that routine VF testing could be carried out in a more convenient location.
520 Some patients had previously visited a local optometrist to carry out a VF test for the purpose
521 of assessing their legal fitness to drive. On the positive side, patients liked the convenience of
522 doing so and described a better testing environment. Conversely, they questioned the
523 competency of the staff, the quality of the equipment and the information trail back to the
524 hospital.

525
526 *The principle of having routine tests done locally is acceptable providing they are trained.*
527 M1 London 1

528
529 *That way you would be there, dealt with by people you know probably more*
530 *intimately....you're in a more relaxed environment...*
531 M1 Norwich 1

532
533 *I would be concerned about how often the machine was calibrated to get an accurate reading.*
534 M2 London 1

535

536 *Is the information going back to where it matters in my notes? Things do get lost, and will*
537 *someone actually look at the test?*

538 M1 London 2

539

540 Some felt they had built up a level of trust with the hospital eye service and would therefore
541 prefer to have VFs conducted in this environment.

542

543 *I've been here for quite a while now and I like coming to them: I don't want to go anywhere*

544 *else.* F1 London 2

545 *I would feel the same because it's a matter of trust.* M2 London 2

546

547

548 Clinic constraints -Waiting times

549

550

551

552 Waiting times were a major concern at all locations. The standard time taken per visit was
553 estimated to be two hours, although the wait was often unpredictable. Established patients
554 were used to the wait and tried not to let it affect them but they still found the system
555 frustrating. Patients were scared of missing their slots and, therefore, would not leave their
556 seat in the waiting area.

557

558 *No way I'm going to nip off ... especially as now I'm on my own, no way just even nipping*
559 *off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour*

560 *and he'll call me the minute I go to the [bathroom].* F2 Portsmouth 1

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561
562 Although it was repeatedly acknowledged that the clinics were very busy, which had the
563 knock-on effect of increased waiting times, patients felt they were getting adequate treatment
564 overall. It was suggested that there was a trade-off between longer waiting times and higher
565 quality treatment:

566
567 *I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of*
568 *excellence. There's a trade-off in that you're getting state of the art treatment but the price is*
569 *you've got to sit around for it.* M1 London 1

570
571
572
573 Clinic constraints - Travelling to the clinic

574
575 Several sub-themes emerged including issues with long distances to travel, avoiding rush
576 hours, travel costs and travelling alone.

577
578 *I think the problem is because I live nearly an hour away, for me the nearest hospital is an*
579 *hour away...* F2 Norwich 2

580
581 *Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly*
582 *with help to get on the train but it's not easy.....It's horrific, frightening.* M2 London 1

583
584
585 Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to
586 have a negative effect on VF test performance.

587

588 *I think if you did the eye check later in the day, you know, if your eyes were tired, it might*
589 *make you feel [that you] wouldn't see so well... F2 Portsmouth 1*

590

591

592 Clinic constraints - Scheduling appointments

593

594 The scheduling of appointments was a major concern: often the systems were so overbooked
595 that patients were unable to make their next appointment at their clinic visit.

596

597 *You can only make an appointment six weeks in advance. You used to get a twelve month*
598 *appointment letter just after you had been for an appointment; now its six weeks before you*
599 *are due. M2 Norwich 1*

600

601 Often patients would receive an appointment only to have it cancelled just before the clinic
602 was due to take place. This was not only frustrating to people who had made arrangements for
603 their appointment, such as asking a friend to accompany them or arranging cover for sick
604 spouses, it caused concern that their appointment was to be at a much later date than the
605 clinician had originally requested.

606

607 *"So if you've been given a six month appointment and it's cancelled, and you're not given*
608 *another one, you ring up and then they say "oh we can't give you an appointment now until*
609 *October". That was 10 months. Now if your consultant says 6 [months] and it's 10 and*
610 *something's gone wrong with your vision in between, you have no way of telling."* F2

611

Portsmouth 2

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614 **Patient recommendations**

615

616 At the end of the focus groups, patients were asked to recommend changes to improve their
617 follow-up care. The recommendations were similar across all locations and the most popular
618 suggestions are displayed in table 2.

619

620

621 **Table 2:** Patient recommendations for improving follow-up care.

622

Patient Recommendations	
1.	Less waiting and clinics running to time.
2.	Flexible booking and changing of appointments.
3.	To have a calmer, quieter environment in the visual field room with less people doing the test at the same time.
4.	To modernise the visual field test.
5.	To have more continuity of care by seeing the same clinician at each visit.
6.	To receive better communication from the clinician.

623

624

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627

Discussion

Data from this study supports evidence from elsewhere that patients find VF testing more laborious and demanding than other vision tests²⁰. Nevertheless, patients were willing to complete more VF tests on the guidance of their clinician, as ultimately they were prepared to do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF testing during the first two years of their follow-up care as recommended by the research literature^{4 5} and some clinical guidelines²⁴. Patients commented that it took time to feel comfortable with the test procedure, and that multiple attempts were needed to gain an accurate representation of their vision. These viewpoints complement existing evidence showing that performance can improve considerably during follow-up due to gaining experience with the testing process²⁵.

There were, however, a number of additional themes that emerged from the data which identified areas that could represent potential barriers to successful glaucoma monitoring. Patients felt that the environment in which they completed the VF test was linked to how well they were able to perform the task, with staff members talking loudly, the number of people in the room, and the time of day all listed as important interfering factors. These views coincide with other evidence showing that the environment, the technician and the time of day do have a significant influence on measurement variability from VF tests²⁶. Fatigue, a topic mentioned frequently throughout the discussions, has also been shown to affect performance as test duration increases²⁷.

Patients highlighted the importance of effective task communication for influencing their VF test performance. Prior evidence has shown that the quality of instruction given before the VF test can significantly affect subsequent estimations of VF defect severity^{28 29}. Patients also felt

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655 that it was essential to have the task explained to them properly, even if they had been
656 attending clinics for some time. Having a staff member in the room whilst they carried out the
657 test was found to be reassuring. These findings reiterate the idea that ensuring that the task
658 demands are communicated clearly and effectively before every VF test, and being on hand to
659 alleviate any concerns or questions that the patient may have, may help maximise the quality
660 of the data gained from the assessment²⁹⁻³¹.

661
662 Other discussion points relating to communication were also raised repeatedly throughout the
663 focus groups. Patients felt that many clinicians treated them as an ‘eye’ rather than a person,
664 with those staff members who took a more individualistic and empathic approach viewed
665 favourably. Notably, patients felt that they had to ask explicitly about their results in order to
666 learn details about their own condition. Evidence has shown that that the patient and
667 clinician’s views of their condition are not always aligned, which may be due to
668 miscommunication or misinterpretation of key information on both parts³². By explaining the
669 results in a clear, simple and concise manner, the patient will inevitably improve their
670 understanding of their condition, which in turn could influence how well they respond to
671 important aspects of their follow-up care. For instance, it has been shown that the way in
672 which clinicians communicate with the patient can influence future adherence to
673 medication³². It has been suggested that clinicians underestimate the importance of effective

674 communication to the patient¹¹, and in one study examining patient expectations for eye care,
675 the emphasised areas were all related to communication and interpersonal manner³³.

676 Providing better information about the purpose of VF testing, what is required of the patient,
677 and their results and general prognosis could be vital for improving attendance for VF tests or
678 for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about
679 ways in which the complex measurement of the VF could be easily presented and

communicated to patients. It is important to note that some patients associated more frequent testing with worsening vision, which caused some distress. Thus, should patients require more frequent tests at some point in their care, it is also vital to involve the patient and explain reasons for the decision.

Excessive waiting times and difficulty booking appointments were also major concerns. In particular, patients worried that appointment cancellations could extend the interval between tests beyond what was recommended by the clinician, therefore leaving them exposed to undetected disease progression. It is known that whilst clinicians select appropriate monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate follow-up^{7 34 35}. Moreover, it was typical for patients to wait at the clinic for hours in order to complete multiple vision tests, causing frustration and tiredness which some perceived to influence their subsequent performance. Potential solutions could involve conducting only the VF test during short independent appointment slots, or carrying out tests at a more convenient location. However, such strategies would involve further investigation as to their overall cost-effectiveness and should address other associated practicalities such as travel (a significant contributor to total patient costs³⁶) and the information trail back to the hospital.

Previous research has relied on statistical analysis or computer simulations to help determine the most effective VF monitoring strategies for patients with glaucoma. This is the first study to use qualitative methods to investigate the patient's own perspective on their follow-up. Studies focusing on the patient's perspective in glaucoma, particularly with regard to the perceived effects of the disease on their day-to-day activities, have typically relied on questionnaires¹³. However, questionnaire responses can be restricted by the wording of the items and provide little opportunity for clarification or elaboration. This study allowed

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705 individuals to contextualise their experiences and expand on particular points and themes,
706 encouraging discussion about topics a certain patient may not have otherwise introduced or
707 attributed to glaucoma without the encouragement of another¹⁸. The notion of the “expert
708 patient” is beginning to be endorsed with regards to other chronic conditions, with focus
709 groups demonstrating potential as a forum for the development of more effective management
710 strategies³⁷⁻³⁹. Furthermore, patient groups have aided the development of health education
711 programmes for age-related macular degeneration⁴⁰. A systematic review of patient centred
712 randomised controlled trials suggests there may be some benefits associated with involving
713 patients with chronic disease in programmes geared towards better educating service users
714 and devising general training for health professionals⁴¹. Future work that encourages more
715 patient involvement may therefore help devise the optimal strategies for glaucoma follow-up
716 and also help better inform both patients and health professionals about the condition.

717

718 This study has its limitations with findings attached to the viewpoints of the groups who took
719 part. Efforts were taken to reduce bias by involving multiple research sites- however, these
720 were all geographically limited to the South of England and (excluding the London groups)
721 involved patients of Caucasian ethnicity. Therefore the findings may not necessarily translate
722 to a wider population. Moreover, initial patient selection was made on recommendation of
723 consultants at the clinics and our selection process did not monitor reasons for non-
724 participation. People who choose to volunteer for focus groups are likely to be articulate and
725 confident; they may also be more motivated to take part due to having more severe disease or
726 holding strong opinions about a certain area of their care. Furthermore, participants were aged
727 60 years and older- younger service-users may have differing views and experiences that also
728 warrant investigation. The study was initially designed to involve 6 focus groups across 3
729 locations and so no direct decision was taken to cease data collection; however, similar

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3 730 themes and sub-themes continued to emerge in the latter focus groups and so it is likely that
4
5 731 'data saturation' was achieved. Furthermore, some of the focus groups were small (one
6
7 732 consisting of only 3 participants) due to late cancellations but this is not a major limitation
8
9 733 due to the number of focus groups that took place⁴². Also, some biases could have been
10
11 734 introduced during interview and analysis due the preconceived ideas held by the
12
13 735 experimenters about the areas of importance, although care was taken to adhere to expected
14
15 736 practice by following the COREQ check-list for focus group research²².
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19 737

20
21 738 A number of important themes did emerge that give an insight into clinic visits and VFs from
22
23 739 the patient's perspective, and could help inform patient centred care in glaucoma. Although
24
25 740 patients appeared frustrated by a number of aspects of their follow-up, they ultimately
26
27 741 accepted that some compromises had to be made in order to save their eyesight. Some of the
28
29 742 viewpoints illustrated in the focus group discussions may in part explain why research-
30
31 743 supported guidelines about more frequent VF testing are not being implemented effectively in
32
33 744 clinical practice. A holistic approach that embraces patient opinion may therefore be vital to
34
35 745 help devise the most effective strategies for follow-up care in this chronic disease.
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41 Conclusion

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43 750

44
45 751 This is the first study to use qualitative methods to examine patient opinion about the
46
47 752 glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they
48
49 753 accepted it was important to their overall vision assessment. However, a number of actionable
50
51 754 points were raised which were perceived to impact the effectiveness of follow-up care,
52
53 755 including distracting testing environments, and hospital constraints relating to excessive
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55 756 waiting times and appointment booking. Some patients also expressed particular concerns
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757 about the VF technology used and the quality of test instructions. Anxiety associated with
758 increased testing in the absence of clinical explanation was another theme. Ensuring that
759 glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the
760 confidence and cooperation of the patient. Addressing some or all of the perceived barriers
761 highlighted in this study should help deliver more efficient strategies for VF monitoring in
762 glaucoma.

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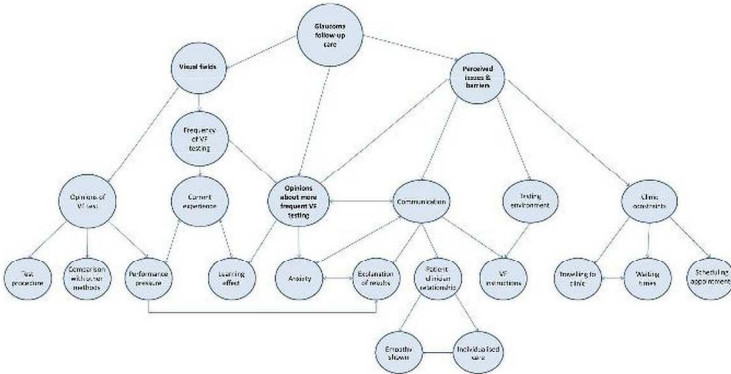
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Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

165x90mm (300 x 300 DPI)