



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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19 20 21 22 Article Summary

23 24 25 **Article Focus**

- 26
27 • Glaucoma is a chronic and progressive eye disease and all diagnosed patients will
28
29 require lifetime monitoring of their vision.
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31 • Visual field (VF) testing is one of the most widely used assessments for glaucoma and
32
33 places a large burden on NHS resources; research is needed to devise the most
34
35 effective strategies for glaucoma VF monitoring.
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37 • This study used focus groups to investigate patient views about VF testing in their
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39 follow-up care. Effective VF testing will require the confidence and cooperation of
40
41 the patient.
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46 47 **Key Messages**

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49 • Although patients disliked VF testing, they accepted it as an important part of their
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51 vision assessment and disease management.
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53 • Patients discussed a number of areas of perceived importance for VF monitoring,
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55 raising particular concerns about distracting testing environments, the quality of test
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3 instructions, how results were explained to them and excessive pre-testing waiting
4 times.
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10 **Strengths and Limitations of this study**
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13 • This is the first study to examine patient views of visual field monitoring using focus
14 groups.
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- 16 • Focus groups only took place at three selected hospitals - it is assumed that the views
17 expressed represent the experiences of patients in a wider UK population.
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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

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3 frequency of VF tests should be increased for newly diagnosed patients in order to better
4 determine speed of VF progression. This notion is supported by research evidence which has
5 indicated that three VF tests per year would be useful for identifying patients that are
6 deteriorating at fast rates in the first 2 years of follow-up[3-5]. However, a recent audit of
7 glaucoma clinics in England indicated that most patients only have about one VF test a
8 year[6]. Furthermore, VF monitoring intervals assigned by clinicians (for hypothetical patient
9 scenarios) are variable[7]. Many glaucoma specialists concede that better tracking of the VF
10 would be helpful in managing patients but view it as impractical in the current health
11 setting[7]. This finding suggests that personal attitudes regarding the frequency of testing
12 could play an important role in translating research to practice.
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27 The clinician ultimately drives decision-making based on their own estimates of the
28 likelihood and speed of disease progression, but establishing effective monitoring strategies
29 may also require the input of the patients themselves. Care plans that place burdens on
30 patients may result in a reduced willingness to return for follow-up and compromise the
31 quality of the data obtained that is subsequently relied on during management[8]. Anecdotal
32 evidence suggests that patients dislike doing the VF test, and one study showed that patients
33 rate the VF test least favourably of all the vision assessments[9]. However, no study has asked
34 patients with glaucoma in detail about their perceptions of the VF test and their follow-up
35 care.
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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.

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3 Qualitative techniques, such as focus groups, offer an alternative method of gathering
4 information about not only what a patient thinks, but also how they think or why they may
5 hold a particular view. Group interaction encourages participants to explore and clarify
6 individual and shared perspectives and supports the participation of people who may be
7 reluctant to contribute their views in a more formal one-to-one scenario[10].
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12 For the first time, the current study aims to explore patient views and experiences of
13 glaucoma monitoring via focus groups. One objective was to establish patients' views about
14 VF testing.
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17 **Method**

18 **Participants and methods**

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21 Focus groups took place between May 2012 and January 2013 in the following locations: The
22 Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University
23 Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation
24 Trust in London. The study was multi-centred to reduce the bias that might come from one
25 geographical area and to encompass healthcare trusts in both urban and rural locations. The
26 sites were chosen because they were involved in a wider programme work, of which the
27 current study was a component. There were two focus groups at each site, with participants
28 randomly allocated to one of the two groups at the corresponding hospital.
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33 The study used purposeful sampling whereby a consultant ophthalmologist at each
34 participating eye hospital selected participants that were suitable for the study. To take part,
35 the participant was required to be aged 60 years and over and to be an established glaucoma
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3 patient who had been under review for at least two years. These criteria were chosen to ensure
4 that participants had had sufficient experience of VFs as part of their glaucoma follow-up.
5 One of the authors (HB) then telephoned patients who had given their permission to be
6 contacted to invite them to take part in the study. Interested participants were subsequently
7 sent further information by post.
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16 A total of 28 participants (mean age [standard deviation] 74 [9] years; 54% female) took part
17 across the six focus groups. Each group consisted of three to six patients and included
18 participants of both genders.
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24 25 Procedure 26

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29 A topic guide was devised prior to beginning the study outlining question areas regarding
30 general glaucoma care, leading on to more specific questions about experiences of the VF test
31 and opinions about VF test frequency. Study topics were informed by an initial pilot exercise
32 involving a discussion with two patients with glaucoma, who also provided additional verbal
33 and written information about their experiences. Questions were broad, open and “non-
34 leading”. Prompts were used to introduce topic areas and encourage respondents to elaborate;
35 however the onus was on the participants to supply the overall content of the discussion. If
36 discussion went substantially off-topic, or one participant was dominating the conversation,
37 the interviewer would reflect back to a previous topic and encourage other participants to
38 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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3 All focus groups were conducted by one of the authors (HB), a post-doctoral researcher who
4 had prior experience of qualitative research involving patients with glaucoma[11, 12]. The
5 interviewer and participants had no prior knowledge of each other in a clinical or personal
6 context, so each focus group began with general introductions. Field notes were taken during
7 the sessions to aid later interpretation of the data, although note-taking was purposely minimal
8 so that the interviewer could be fully attentive to the discussion. The focus groups lasted
9 between 60 and 75 minutes.
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21 The study received approval from a NHS National Research Ethics Service (NRES)
22 committee and was approved by research governance committees of the participating
23 institutions. The study conformed to the Declaration of Helsinki and written consent from all
24 participants was obtained prior to each focus group.
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32 The study was designed and reported in accordance with the Consolidated Criteria for
33 Reporting Qualitative Research (COREQ) for interviews and focus groups[13].
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38 Analysis

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43 All focus groups were audio-recorded (with permission from the participants). The dialogue
44 from the recordings was later transcribed and reviewed by the investigators. Field notes were
45 used to account for any information missed or incorrectly reported in the transcripts due to
46 excessive background noise.
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53 Data was analysed by two of the authors (HB and FCG) independently using the framework
54 technique[14] displayed in Table 1. Each investigator read and re-read the transcripts and
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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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3 *Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I*
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5 *don't like having one eye closed and having to concentrate, even if it's for just a couple of*
6
7 *minutes, because then my mind wanders... F1, Portsmouth 1*
8
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12 *It seems a bit antiquated, pressing the buttons... it doesn't seem positive enough to me.*
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14 F3 Norwich 2
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18 Many put pressure on themselves to perform the test well, as they felt there could be a lot
19 riding on their performance.
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25 *There is pressure: I think it is because your eyes are so important for everyday living, that,*
26
27 *you know, you're frightened to [not do well]. F2 Portsmouth 1*
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32 There was a general appreciation that such testing was vital to preserve their vision.
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36 *Well... obviously I'm very grateful that I'm being monitored all... F4 London 1*
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41 *...mine has been 10 years and you think, well how long will I have my sight? ... My mum had*
42
43 *lost her sight by then, you know... F3 Norwich 2*
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47 Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular
48 pressure measurement and imaging tests, less tiring and laborious. At the same time some
49 patients felt the VF test was more 'valuable', providing more reassurance that their condition
50 was being investigated.
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3 *[with] the [imaging] there's just one person, one machine and you, and it's done and that's it,*
4
5 *it's over...within minutes. F3 Norwich 2*
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9 *... they look in your eyes to measure your pressure but when you do that field test, they see*
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11 *more.... F1 London 2*
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14 15 16 Frequency of visual field testing

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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.

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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

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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.

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If it was necessary. F2 Portsmouth 2

You'd get on with it. M1 Portsmouth 2

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

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

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

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

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25 F3 Norwich 2

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

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

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40 F3 Norwich 2

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44 One recurrent topic regarding VF testing was issues relating to the learning effect, whereby
45 performance improves with increased testing. Some suggested that more repeat testing would
46 be helpful. However, the repeated tests may only be worthwhile if they took place at the
47 beginning of their follow-up care.
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3 ...interestingly I went and did one once and they said to me, "this has improved from the last
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5 time" and I said "well I think I'm just getting better at computer games" ... I think you do
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7 know what's coming and you can improve and I just feel more comfortable with doing it.
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10 F1 Norwich 1
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14 I think to do a field test right at the beginning, and to take that as being the definitive field
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16 test is wrong...because I think you need to do a test and think, and revise it in your mind what
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18 you've done and then do it again. M1 Portsmouth 2
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23 There was some debate about the period of time between VF tests.
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27 I think you need to do a field test and then perhaps a month later do the second one.
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30 M1 Portsmouth 2
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34 Well not if you have a long gap between them. F1 Norwich 2
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37 I've got used to it now. F2 Norwich 2
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40 I don't think it's any different really. F3 Norwich 2
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43 The idea was raised that routine VF testing could be carried out in a more convenient location.
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45 Some patients had previously visited a local optometrist to carry out a VF test for the purpose
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47 of assessing their legal fitness to drive. On the positive side, patients liked the convenience of
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49 doing so and described a better testing environment. Conversely, they questioned the
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51 competency of the staff, the quality of the equipment and the information trail back to the
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53 hospital.
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3 *The principle of having routine tests done locally is acceptable providing they are trained.*

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5 M1 London 1
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10 *I would be concerned about how often the machine was calibrated to get an accurate reading.*

11 M2 London 1
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16 *Is the information going back to where it matters in my notes? Things do get lost, and will*
17
18 *someone actually look at the test?*
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20 M1 London 2
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24 Some felt they had built up a level of trust with the hospital eye service and would therefore
25 prefer to have VFs conducted in this environment.
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31 *I've been here for quite a while now and I like coming to them: I don't want to go anywhere*
32
33 *else.* F1 London 2
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37 *I would feel the same because it's a matter of trust.* M2 London 2
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44 Perceived issues and barriers for successful follow-up care
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48 Some additional themes emerged during the analysis, highlighting a number of areas
49 perceived to be important and potentially representing barriers to successful follow-up.
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3 Communication
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7 Visual Field Instructions
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11 Regardless of how long they had been attending the glaucoma clinic, patients appreciated
12 having the VF test procedure fully explained to them. It was rare for a staff member to stay
13 with the patient throughout the test, but on the occasions it did happen, patients found the
14 experience reassuring and felt the encouragement helped their performance.
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23 *... They say, "Have you done this before?" You say "Yes". And that's it, you're left there*
24 *and eventually they say, "Have you finished?"*

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27 M1 Portsmouth 2
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31 *I had one about three weeks ago and it was a young nurse and it was a completely different*
32 *experience. She was professional, polite, kind; she told me exactly what they were doing... it*
33 *was almost a pleasant experience.* F1 Portsmouth 1
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41 There was discussion about understanding aspects of the testing procedure and how the
42 procedure was explained. For example, some patients expressed uncertainty and felt test
43 pressure would influence their results. Again, explanation and reassurance before and after the
44 test helped.
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51 *The staff told me: "don't worry about missing [a light] because it'll come later", so you know*
52 *you get a second chance.* F1 Norwich 1
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3 ... if in doubt press the button, don't you? F1 Portsmouth 2
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7 Explanation of results
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11 Most patients said they had to specifically enquire about their results to find out information
12 about their vision and whether their condition had progressed since the last appointment.
13
14 Some patients felt intimidated to ask the clinician for feedback as to how they had performed,
15
16 feeling they were being a nuisance or wasting the clinician's time.
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23 *My wife always says "how did you get on?" and I say "I don't know", and that's one of the*
24
25 *problems.* M2 Portsmouth 2
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29 *I don't think they've got time to listen to you, or they don't appear to, and I don't know*
30
31 *whether they would listen.... You feel pathetic asking these questions.* F3 Portsmouth 1
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35
36 It was felt that a better explanation of the test results after completing the VF would ease
37
38 some of the pressure felt when performing the test.
39
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42
43 *IF THE DOCTOR ACTUALLY SPENT A BIT MORE TIME DISCUSSING IT WITH YOU,*
44
45 *WOULD IT MAYBE EASE THE PRESSURE OF ACTUALLY DOING THE TEST?*
46

47 Interviewer.

48
49 *I would...* M1 Portsmouth 1
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52 *I think possibly.* F3 Portsmouth 1
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54 *Yes, I mean I would still panic, but if I knew, yes.* F1 Portsmouth 1
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3 Patients may be more inclined to have VF tests more frequently should they be informed
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5 clearly about what the results indicate about their prognosis.
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10 *I don't mind how many times I do it providing I get a result of the test at that time compared*
11
12 *to what the previous one was. Is there any improvement? Is there any downgrade?*
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14 M1 Portsmouth 1
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20 The patient-clinician relationship 21 22

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25 The quality of relationship with the clinical staff and aspects of patient-clinician
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27 communication also emerged as key factors influencing perceptions of the follow-up process.
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32 An apparent lack of personalised care caused unease: there was a sentiment that sometimes
33
34 the clinician simply looked at the eyes and failed to consider the person's individual needs.
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38 *You're not a person, you know, you've just got eyes, they're just going to deal with that and*
39
40 *that's it.* F3 Portsmouth 1
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45 The experience was seen to be much more bearable if they felt the staff member dealing with
46
47 them was empathic.
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52 *Even buying a chop, you know: if the butcher's interested, it helps doesn't it?*
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54 M3 Norwich 1
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3 The opportunity to spend more time with their consultant ophthalmologist was a key factor
4 that influenced whether or not patients were open to visiting the clinic more frequently.
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10 *Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.*

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12 M2 London 2
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16 Testing environment
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20 The testing environment was another important theme. The dark room, especially if it was
21 warm, made focusing on the tests difficult. Patients felt they performed better in the morning
22 when they were more alert. Ambient noise in the room made it difficult to concentrate; staff
23 members talking and doing the test at the same time as several other patients all had
24 deleterious effects.
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34 *I will also say that the staff chatter a lot, which is difficult for concentration; the doors open
35 and close, there's a lot of noise.* F1 Norwich 1
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40 *The times that I've had the visual field test done in a room where there's just one [machine], I
41 felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot
42 quicker too.* F3 Norwich 2
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49 *I think having the quieter atmosphere would generally help I'm sure....just that feeling of
50 slight calm, you can relax more and then it probably would be a lot quicker because maybe
51 you're not going to miss as many [lights] as you haven't got other distractions.* F3 Norwich 2.
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3 Clinic constraints
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7 Waiting times
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11 Waiting times were a major concern at all locations. The standard time taken per visit was
12 estimated to be two hours, although the wait was often unpredictable. Established patients
13 were used to the wait and tried not to let it affect them but they still found the system
14 frustrating. Patients were scared of missing their slots and, therefore, would not leave their
15 seat in the waiting area.
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24
25 *No way I'm going to nip off ... especially as now I'm on my own, no way.... just even nipping*
26 *off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour*
27 *and he'll call me the minute I go to the [bathroom].* F2 Portsmouth 1
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34 Likewise, the waiting environment outside the clinic was viewed extremely unfavourably.
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38 *The first time I came in I thought, 'Oh my....' There were hundreds of people, it felt like*
39 *hundreds, but we were all sat in a line. There's nothing on the walls. There's tiny writing on*
40 *the notice board and you think, 'Hang on, we've all got eye problems in here, how are we*
41 *supposed to read these signs?' The walls are just blank- it's a really miserable place, isn't it?*
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48 F3 Portsmouth 1
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52 Although it was repeatedly acknowledged that the clinics were very busy, which had the
53 knock-on effect of increased waiting times, patients felt they were getting adequate treatment
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3 overall. It was suggested that there was a trade-off between longer waiting times and higher
4
5 quality treatment:
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10 *I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of*
11 *excellence. There's a trade-off in that you're getting state of the art treatment but the price is*
12 *you've got to sit around for it. M1 London 1*
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20 Travelling to the clinic

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24 Several sub-themes emerged including issues with long distances to travel, avoiding rush
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26 hours, travel costs and travelling alone.
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31 *I think the problem is because I live nearly an hour away, for me the nearest hospital is an*
32 *hour away... F2 Norwich 2*
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37 *Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly*
38 *with help to get on the train but it's not easy.....It's horrific, frightening. M2 London 1*
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41 Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to
42
43 have a negative effect on VF test performance.
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50 Scheduling appointments

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55 The scheduling of appointments was a major concern: often the systems were so overbooked
56
57 that patients were unable to make their next appointment at their clinic visit. Some were
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3 asked to call to make an appointment six weeks before they were due to attend whilst others
4
5 were sent an appointment in the post at a much later date.
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10 *You can only make an appointment six weeks in advance. You used to get a twelve month*
11 *appointment letter just after you had been for an appointment; now its six weeks before you*
12 *are due.* M2 Norwich 1
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18 Some patients had been asked to attend on a Saturday to reduce the back-log of appointments.
19
20 The day was not seen as a problem although the standard of care was questioned.
21
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25 *I've been asked to come on a Saturday which is not a problem but the trouble is you never see*
26 *anyone who can make a decision. I ended up seeing a retina man. So after a couple of visits I*
27 *asked to be seen on a weekday by a glaucoma specialist."* F1 Norwich 1
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34 Often patients would receive an appointment only to have it cancelled a couple of weeks
35
36 before the clinic was due to take place. This was not only frustrating to people who had made
37
38 arrangements for their appointment, such as asking a friend to accompany them or arranging
39
40 cover for sick spouses, it caused concern that their appointment was to be at a much later date
41
42 than the clinician had originally requested.
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46
47 *"So if you've been given a six month appointment and it's cancelled, and you're not given*
48 *another one, you ring up and then they say "oh we can't give you an appointment now until*
49 *October". That was 10 months. Now if your consultant says 6 [months] and it's 10 and*
50 *something's gone wrong with your vision in between, you have no way of telling."* F2
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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

1
2
3 felt that it was essential to have the task explained to them properly, even if they had been
4
5 attending clinics for some time. Having a staff member in the room whilst they carried out the
6
7 test was found to be reassuring. These findings reiterate the idea that ensuring that the task
8
9 demands are communicated clearly and effectively before every VF test, and being on hand to
10
11 alleviate any concerns or questions that the patient may have, may help maximise the quality
12
13 of the data gained from the assessment[20-22].
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18 Other discussion points relating to communication were also raised repeatedly throughout the
19
20 focus groups. Patients felt that many clinicians treated them as an 'eye' rather than a person,
21
22 with those staff members who took a more individualistic and empathic approach viewed
23
24 favourably. Notably, patients felt that they had to ask explicitly about their results in order to
25
26 learn details about their own condition. Evidence has shown that that the patient and
27
28 clinician's views of their condition are not always aligned, which may be due to
29
30 miscommunication or misinterpretation of key information on both parts[23]. By explaining
31
32 the results in a clear, simple and concise manner, the patient will inevitably improve their
33
34 understanding of their condition, which in turn could influence how well they respond to
35
36 important aspects of their follow-up care. For instance, it has been shown that the way in
37
38 which clinicians communicate with the patient can influence future adherence to
39
40 medication[23]. Providing better information about the purpose of VF testing, what is
41
42 required of the patient, and their results and general prognosis could be vital for improving
43
44 attendance for VF tests or for the subsequent quality of data obtained. Perhaps developers of
45
46 SAP ought to think about ways in which the complex measurement of the VF could be easily
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48 presented and communicated to patients. It is important to note that some patients associated
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50 more frequent testing with worsening vision, which caused some distress. Thus, should
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3 patients require more frequent tests at some point in their care, it is also vital to involve the
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5 patient and explain reasons for the decision.
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10 Excessive waiting times and difficulty booking appointments were also major concerns. In
11
12 particular, patients worried that appointment cancellations could extend the interval between
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14 tests beyond what was recommended by the clinician, therefore leaving them exposed to
15
16 undetected disease progression. It is known that whilst clinicians select appropriate
17
18 monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate
19
20 follow-up[6, 24, 25]. Moreover, it was typical for patients to wait at the clinic for hours in
21
22 order to complete multiple vision tests, causing frustration and tiredness which some
23
24 perceived to influence their subsequent performance. Potential solutions could involve
25
26 conducting only the VF test during short independent appointment slots, or carrying out tests
27
28 at a more convenient location. However, such strategies would involve further investigation
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30 as to their overall cost-effectiveness and should address other associated practicalities such as
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32 travel (a significant contributor to total patient costs[26]) and the information trail back to the
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34 hospital.
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40 Previous research has relied on statistical analysis or computer simulations to help determine
41
42 the most effective VF monitoring strategies for patients with glaucoma. This is the first study
43
44 to use qualitative methods to investigate the patient's own perspective on their follow-up.
45
46 Studies focusing on the patient's perspective in glaucoma, particularly with regard to the
47
48 perceived effects of the disease on their day-to-day activities, have typically relied on
49
50 questionnaires[27]. However, questionnaire responses can be restricted by the wording of the
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52 items and provide little opportunity for clarification or elaboration. This study allowed
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54 individuals to contextualise their experiences and expand on particular points and themes,
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3 encouraging discussion about topics a certain patient may not have otherwise introduced or
4 attributed to glaucoma without the encouragement of another[11]. The notion of the “expert
5 patient” is beginning to be endorsed with regards to other chronic conditions, with focus
6 groups demonstrating potential as a forum for the development of more effective management
7 strategies[28-30]. Encouraging more patient involvement may also help devise the optimal
8 strategies for glaucoma follow-up.
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12 This study has its limitations with findings attached to the viewpoints of the groups who took
13 part. Efforts were taken to reduce bias by involving multiple research sites but these findings
14 may not necessarily translate to a wider population. It is also important to recognize possible
15 selection bias; the people who chose to participate in a focus group may have more solid
16 opinions with a certain area of their care. Moreover, initial patient selection was made on
17 recommendation of consultants at the clinics and our selection process did not carefully
18 monitor reasons for non-participation. The study was initially designed to involve 6 focus
19 groups across 3 locations and so no direct decision was taken to cease data collection;
20 however, similar themes and sub-themes continued to emerge in the latter focus groups and so
21 it is likely that ‘data saturation’ was achieved. Also, some biases could have been introduced
22 during interview and analysis due the preconceived ideas held by the experimenters about the
23 areas of importance, although care was taken to adhere to expected practice by following the
24 COREQ check-list for focus group research[13].
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49 A number of important themes did emerge that give an insight into clinic visits and VFs from
50 the patient’s perspective, and could help inform patient centred care in glaucoma. Although
51 patients appeared frustrated by a number of aspects of their follow-up, they ultimately
52 accepted that some compromises had to be made in order to save their eyesight. Some of the
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3 viewpoints illustrated in the focus group discussions may in part explain why research-
4 supported guidelines about more frequent VF testing are not being implemented effectively in
5 clinical practice. A holistic approach that embraces patient opinion may therefore be vital to
6 help devise the most effective strategies for follow-up care in this chronic disease.
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Conclusion

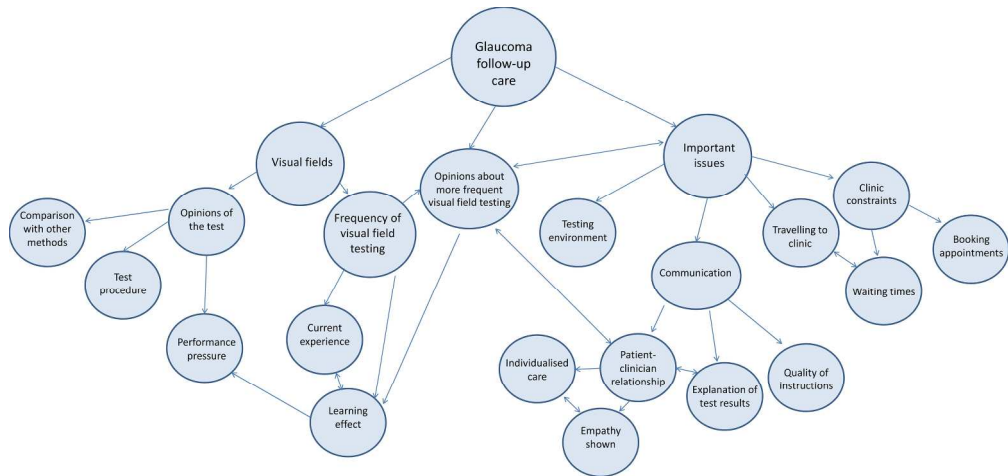
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21 This is the first study to use qualitative methods to examine patient opinion about the
22 glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they
23 accepted it was important to their overall vision assessment.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

1. National Institute of Health and Clinical Excellence, *CG85 Glaucoma: NICE guideline*, in *Published Clinical Guidelines*, NICE, Editor. 2009, National Institute of Health and Clinical Excellence.
2. Heijl, A., et al., *Natural history of open-angle glaucoma* S0161-6420(09)00670-8 [pii] 10.1016/j.ophtha.2009.06.042. *Ophthalmology*, 2009. **116** [http://www.ncbi.nlm.nih.gov/pubmed/19854514\(12\)](http://www.ncbi.nlm.nih.gov/pubmed/19854514(12)); p. 2271-6.
3. Chauhan, B.C., et al., *Practical recommendations for measuring rates of visual field change in glaucoma*. *Br J Ophthalmol*, 2008. **92**(4): p. 569-73.
4. Gardiner, S.K. and D.P. Crabb, *Frequency of testing for detecting visual field progression*. *Br J Ophthalmol*, 2002. **86**(5): p. 560-4.
5. Crabb, D.P. and D.F. Garway-Heath, *Intervals between visual field tests when monitoring the glaucomatous patient: wait-and-see approach*. *Invest Ophthalmol Vis Sci*, 2012. **53**(6): p. 2770-6.
6. Fung, S.S., et al., *Are practical recommendations practiced? A national multi-centre cross-sectional study on frequency of visual field testing in glaucoma*. *British Journal of Ophthalmology*, 2013.
7. Malik, R., et al., *A survey of attitudes of glaucoma subspecialists in England and Wales to visual field test intervals in relation to NICE guidelines*. *BMJ open*, 2013. **3**(5).
8. Lacy, N.L., et al., *Why We Don't Come: Patient Perceptions on No-Shows*. *The Annals of Family Medicine*, 2004. **2**(6): p. 541-545.
9. Gardiner, S.K. and S. Demirel, *Assessment of Patient Opinions of Different Clinical Tests Used in the Management of Glaucoma*. *Ophthalmology*, 2008. **115**(12): p. 2127-2131.
10. Kitzinger, J., *Qualitative Research: Introducing focus groups*. *Bmj*, 1995. **311**(7000): p. 299-302.
11. Green, J., H. Siddall, and I. Murdoch, *Learning to live with glaucoma: a qualitative study of diagnosis and the impact of sight loss*. *Soc Sci Med*, 2002. **55**(2): p. 257-67.
12. Patel, D., H. Baker, and I. Murdoch, *Barriers to uptake of eye care services by the Indian population living in Ealing, west London*. *Health Education Journal*, 2006. **65**(3): p. 267-276.
13. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups*. *International Journal for Quality in Health Care*, 2007. **19**(6): p. 349-357.
14. Ritchie, J., *Qualitative data analysis for applied policy research.*, in *Analysing Qualitative Data*, B.A.B.R., Editor. 1994, Routledge: London.
15. European Glaucoma Society, *Terminology and guidelines for glaucoma*. 3rd edition ed. Vol. http://www.eugs.org/eng/egs_guidelines.asp. 2008: Savona, Italy Editrice Dogma 2008.
16. Wild, J.M., et al., *Long-term follow-up of baseline learning and fatigue effects in the automated perimetry of glaucoma and ocular hypertensive patients*. *Acta Ophthalmologica*, 1991. **69**(2): p. 210-216.
17. Junoy Montolio, F.G., et al., *Factors that influence standard automated perimetry test results in glaucoma: test reliability, technician experience, time of day, and season*. *Investigative ophthalmology & visual science*, 2012. **53**(11): p. 7010-7.

18. Henson, D.B. and T. Emuh, *Monitoring Vigilance during Perimetry by Using Pupillography*. Investigative Ophthalmology & Visual Science, 2010. **51**(7): p. 3540-3543.
19. Kutzko, K.E., C.F. Brito, and M. Wall, *Effect of instructions on conventional automated perimetry*. Invest Ophthalmol Vis Sci, 2000. **41**(7): p. 2006-13.
20. Sherafat, H., et al., *Effect of a patient training video on visual field test reliability*. British Journal of Ophthalmology, 2003. **87**(2): p. 153-156.
21. Heijl, A. and P. Asman, *Pitfalls of automated perimetry in glaucoma diagnosis*. Current opinion in ophthalmology, 1995. **6**(2): p. 46-51.
22. Van Coevorden, R.E., et al., *Continuous visual field test supervision may not always be necessary*. Ophthalmology, 1999. **106**(1): p. 178-181.
23. Friedman, D.S., et al., *Doctor-patient communication in glaucoma care: analysis of videotaped encounters in community-based office practice*. Ophthalmology, 2009. **116**(12): p. 2277-85 e1-3.
24. Tatham, A. and I. Murdoch, *The effect of appointment rescheduling on monitoring interval and patient attendance in the glaucoma outpatient clinic*. Eye, 2012. **26**(5): p. 729-33.
25. Agency, N.P.S. *Preventing delay to follow-up for patients with glaucoma. Rapid Response Report*. 2009 [cited 2013 08 May 2013]; Available from: <http://www.nrls.npsa.nhs.uk/resources/?entryid45=61908&p=2>.
26. Sharma, A., et al., *Hospital-based glaucoma clinics: what are the costs to patients?* Eye, 2009. **24**(6): p. 999-1005.
27. Glen, F.C., D.P. Crabb, and D.F. Garway-Heath, *The direction of research into visual disability and quality of life in glaucoma*. BMC Ophthalmology, 2011. **11**(1): p. 19.
28. Wilson, P.M., S. Kendall, and F. Brooks, *The Expert Patients Programme: a paradox of patient empowerment and medical dominance*. Health & social care in the community, 2007. **15**(5): p. 426-438.
29. Holman, H. and K. Lorig, *Patients as partners in managing chronic disease: partnership is a prerequisite for effective and efficient health care*. BMJ: British Medical Journal, 2000. **320**(7234): p. 526.
30. Holman, H. and K. Lorig, *Patient self-management: a key to effectiveness and efficiency in care of chronic disease*. Public health reports, 2004. **119**(3): p. 239.

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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)

review only



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

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Keywords:	Glaucoma < OPHTHALMOLOGY, Visual Fields, Patient views

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3 1 **Title: A qualitative investigation into patient views on visual field testing for glaucoma**
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5 2 **monitoring**
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42

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3 26 **Abstract**
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28 ***Objectives:*** To investigate the views and experiences of patients regarding their glaucoma
29 follow-up, particularly towards the type and frequency of visual field (VF) testing.

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

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

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

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41 ***Primary and Secondary Outcomes:***

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

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

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3 51 concerned about aspects of patient-doctor communication, and often received little to no
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5 52 feedback about their results.
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10 54 **Conclusions:** Patients trust the clinician to make the best decisions for their glaucoma follow-
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12 55 up. However, patients highlighted a number of issues that could compromise the effectiveness
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14 56 of VF testing. Addressing patient-perceived barriers could be an important step for devising
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16 57 optimal strategies for follow-up care.
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22 23 60 **Article Summary**

24 61 25 62 26 63 **Article Focus**

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28 64
- 29 65 • Glaucoma is a chronic and progressive eye disease and all diagnosed patients will
30 66 require lifetime monitoring of their vision.
 - 31 67 • Visual field (VF) testing is one of the most widely used assessments for glaucoma and
32 68 places a large burden on NHS resources; research is needed to devise the most
33 69 effective strategies for glaucoma VF monitoring.
 - 34 70 • This study used focus groups to investigate patient views about VF testing in their
35 71 follow-up care. Effective VF testing will require the confidence and cooperation of
36 72 the patient.
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75 76 **Key Messages**

- 77 77 • Although patients disliked VF testing, they accepted it as an important part of their
78 78 vision assessment and disease management.
- 79 79 • Patients discussed a number of areas of perceived importance for VF monitoring,
80 80 raising particular concerns about distracting testing environments, the quality of test

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3 81 instructions, how results were explained to them and excessive pre-testing waiting
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5 82 times.
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10 85 **Strengths and Limitations of this study**
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- 12
13 87 • This is the first qualitative study to examine patients' views of visual field monitoring
14 88 using focus groups.
15
16 89 • Focus groups took place at three selected hospitals in the South of England; it is
17 90 assumed the views expressed represent the experiences of patients in a wider
18 91 population.
19
20 92 • Not all patients approached by their ophthalmologist took part, but reasons for non-
21 93 participation were not monitored. Patients who chose to volunteer may be more
22 94 articulate, motivated and opinionated than the general patient population.
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3 97 **Introduction**
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6 99 Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively,
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8
9 100 could lead to visual impairment or blindness. Currently, the only modifiable risk factor for
10
11 101 disease worsening (progression) in glaucoma is reduction of intraocular pressure (IOP). A
12
13 102 variety of different approaches to IOP lowering are available, meaning surveillance of the
14
15 103 patient is important in selecting the correct intensity of treatment. Over half a million people
16
17 104 in the United Kingdom (UK) are thought to have the condition, with patients receiving over a
18
19 105 million outpatient visits annually^{1 2}. Since the prevalence of glaucoma increases exponentially
20
21 106 with age, these figures can be expected to increase dramatically with an ageing population.
22
23 107 Glaucoma monitoring therefore represents a major workload for eye services in the National
24
25 108 Health Service (NHS).
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31 110 Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring
32
33 111 of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a
34
35 112 sophisticated automated instrument. The test is carried out in a darkened room and takes about
36
37 113 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a
38
39 114 large semi-circular bowl covering their entire field of view. The instrument presents a series
40
41 115 of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the
42
43 116 VF while the patient fixates on a central point. The patient responds by clicking a button when
44
45 117 a stimulus is detected. This process yields a map of the seeing parts of the patient's field of
46
47 118 view; this map is subjected to statistical analysis comparing a patient's results to normative
48
49 119 values for people with healthy vision. These measurements can be highly variable, and speed
50
51 120 (rate) of VF loss, determined from a series of measurements over a period of time, varies
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53 121 considerably between treated individuals. The VF should therefore be monitored at
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55 122 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
4
5 124 out to optimally detect disease progression is limited. The National Institute of Clinical
6
7 125 Excellence (NICE) called for more research into examining the effectiveness of using
8
9 126 different monitoring intervals to detect disease progression in people with glaucoma in 2009¹.
10
11 127 Guidelines proposed by the European Glaucoma Society (EGS) recommend that the
12
13 128 frequency of VF tests should be increased for newly diagnosed patients in order to better
14
15 129 determine speed of VF progression. This notion is supported by research evidence based on
16
17 130 statistical analyses of retrospective data which has indicated that three VF tests per year in the
18
19 131 first 2 years of follow-up would be clinically useful for identifying patients that are
20
21 132 deteriorating at fast rates⁴⁻⁶. However, a recent multicentre audit of glaucoma clinics in
22
23 133 England indicated that most patients only have about one VF test a year⁷. In another recent
24
25 134 study, VF monitoring intervals assigned by clinicians (for hypothetical patient scenarios) were
26
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
35
36 138 feasibility of translating research supported guidelines for VF monitoring to practice.
37
38 139 Furthermore, the clinician ultimately drives decision-making based on their own estimates of
39
40 140 the likelihood and speed of disease progression, and therefore their opinions towards the
41
42 141 appropriateness of monitoring intervals will be important. At the same time, establishing
43
44 142 effective monitoring strategies for this chronic condition likely also requires the input of the
45
46 143 patients themselves, especially if it equates to more clinic visits. Care plans that place
47
48 144 burdens on patients may result in a reduced willingness to return for follow-up and
49
50 145 compromise the quality of the data obtained that is subsequently relied on during
51
52 146 management^{9 10}. Studies have shown that the views of the clinician and the patient regarding
53
54 147 aspects of their condition are not always aligned^{11 12}, implying the patient's perspective must
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3 148 also be considered. Nevertheless there has been limited use of patient-based research for
4
5 149 improving glaucoma care. A review of the literature found that most studies use
6
7 150 questionnaires to quickly gather information about the perceptions of patients, usually with
8
9 151 regards to their perceived outcomes¹³. However, questionnaires can be impersonal and
10
11 152 subject to bias^{14 15}. Qualitative techniques, such as focus groups, offer an alternative method
13
14 153 of gathering information about not only what a patient thinks, but also how they think or why
15
16 154 they may hold a particular view. Group interaction encourages participants to explore and
17
18 155 clarify individual and shared perspectives and supports the participation of people who may
19
20 156 be reluctant to contribute their views in a more formal one-to-one scenario¹⁶. Focus groups
21
22 157 have been used in a small number of studies to examine the general experiences of glaucoma
23
24 158 patients at diagnosis, their expectations and to identify potential barriers to treatment
25
26 159 adherence^{10 17-19}. However, there is limited evidence regarding the opinions of patients about
27
28 160 the manner in which their vision loss is monitored. Anecdotal evidence suggests that patients
29
30 161 dislike doing the VF test, and one quantitative study showed that patients rate the VF test least
31
32 162 favourably of all the vision assessments²⁰. However, no study has interviewed patients with
33
34 163 glaucoma in detail about their perceptions of the VF test and their follow-up care. The current
35
36 164 study therefore aims to shed light on the effectiveness of glaucoma monitoring from the
37
38 165 perspective of the patient by exploring patient views and experiences via focus groups. In
39
40 166 particular, the study aims to establish patients' views about VF testing in glaucoma
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42 167 monitoring.
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3 172 **Methods**
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6 174 **Participants and methods**
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10 176 Focus groups took place between May 2012 and January 2013 in the following locations: The
11 Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University
12 Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation
13 Trust in London. The study was multi-centred to reduce the bias that might come from one
14 geographical area and to encompass healthcare trusts in both urban and rural locations. The
15 sites were chosen because they were involved in a wider programme work, of which the
16 current study was a component. There were two focus groups at each site, with participants
17 allocated to one of the two groups at the corresponding hospital.
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30 185 The study used purposeful sampling whereby a consultant ophthalmologist at each
31 participating eye hospital selected suitable participants during their routine eye appointment.
32 Specifically, the participant was required to be aged 60 years and over and to be an
33 established glaucoma patient who had been under review for at least two years. These criteria
34 were chosen to reflect the age-related nature of the disease and to ensure that participants had
35 had sufficient experience of VFs as part of their glaucoma follow-up. The ophthalmologist
36 gave potential participants an information sheet, and interested people were asked to sign a
37 form indicating they were happy to be contacted by a researcher (it was stressed that they
38 were not obliged to participate). Each consultant ophthalmologist approached 20 patients in
39 this way. One of the study investigators (HB) then contacted the patients with further
40 information and invited them to take part on one of two specific dates at the corresponding
41 hospital. Those who declined did so because they were not available on the specific dates (no
42 other reason was cited). Initially, 5-6 patients were signed up to participate on each of the six
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3 198 study dates. However, a small number (n=4) did not attend. A total of 28 participants (mean
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5 199 age [standard deviation] 74 [9] years; 54% female) eventually took part across the six focus
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7 200 groups. Each group consisted of three to six patients and included participants of both
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9
10 201 genders.

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21 206 Procedure

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25 208 A topic guide was devised prior to beginning the study outlining broad question areas
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27 209 regarding general glaucoma care, experiences of the VF test and opinions about VF test
28
29 210 frequency. Study topics were informed by an initial pilot exercise involving a discussion with
30
31 211 two patients with glaucoma, who also provided additional verbal and written information
32
33 212 about their experiences. The topics included in the guide acted only as suggestions; the
34
35 213 wording of questions was not predetermined and the order of the topics was not fixed.
36
37 214 Prompts were used to introduce topic areas and encourage respondents to elaborate but the
38
39 215 onus was on participants to supply the overall content of the discussion. Care was taken to
40
41 216 ensure questions were open and “non-leading”, although more specific questioning was
42
43 217 sometimes used to clarify a point made by a participant. If discussion went substantially off-
44
45 218 topic, or one participant was dominating the conversation, the interviewer would reflect back
46
47 219 to a previous topic and encourage other participants to contribute their views.

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54 221 Prior to the study, participants were informed that they would be involved in “an open
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56 222 discussion about (their) experiences in the glaucoma clinic, with special attention to the visual
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3 223 tests (they) undertake". Participants were not explicitly aware of the emphasis on VF testing,
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5 224 so as to avoid bias linked to the self-selection of participants with strong views on this one
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7 225 topic. All focus groups were conducted by one of the authors (HB), a post-doctoral researcher
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9 226 who had prior experience of qualitative research involving patients with glaucoma^{18 21}. The
10
11 227 interviewer and participants had no prior knowledge of each other in a clinical or personal
12
13 228 context, so each focus group began with general introductions. Field notes were taken during
14
15 229 the sessions to aid later interpretation of the data, although note-taking was purposely minimal
16
17 230 so that the interviewer could be fully attentive to the discussion. The focus groups lasted
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19 231 between 60 and 75 minutes.
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25 233 The study received approval from a NHS National Research Ethics Service (NRES)
26
27 234 committee and was approved by research governance committees of the participating
28
29 235 institutions. The study conformed to the Declaration of Helsinki and written consent from all
30
31 236 participants was obtained prior to each focus group.
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35
36 238 The study was designed and reported in accordance with the Consolidated Criteria for
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38 239 Reporting Qualitative Research (COREQ) for interviews and focus groups²².
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41 240 42 43 241 Analysis 44

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47 243 All focus groups were audio-recorded (with permission from the participants). The dialogue
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49 244 from the recordings was later transcribed and reviewed by the investigators. In a small
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51 245 number of instances certain words were inaudible on the recordings due to excessive
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53 246 background noise, so field notes were used to account for any unclear information.
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3 248 Data was analysed by two of the authors (HB and FCG) independently using framework
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5 249 analysis²³ as displayed in Table 1. Each investigator read and re-read the transcripts and
6
7 250 manually identified the key themes from the data in addition to some example quotes to
8
9 251 illustrate main points. One of the authors (FCG) was masked to the emphasis on VF testing at
10
11 252 this initial point of analysis, although became aware following a subsequent discussion about
12
13 253 the key categories that had emerged during that first stage. The qualitative software package
14
15 254 NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the
16
17 255 thematic framework by refining and condensing the categories that had been manually
18
19 256 identified and to identify additional themes for exploration. Any differences of opinion
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21 257 regarding the meaning of sentences or the importance of themes were discussed until a
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23 258 consensus was reached.
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30 **Table 1:** Framework Technique used for data analysis
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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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3 264 **Findings**
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7 266 Data was initially indexed according to themes central to the main research questions, such as
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10 267 opinions of the VF test, current experience regarding the frequency of VF testing and opinions
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12 268 about more frequent VF testing. Throughout the analysis a number of additional themes
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14 269 emerged, often with their own sub-themes; these generally related to specific areas perceived
15
16 270 to affect the follow-up experience, and included points relating to clinical constraints (waiting
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18 271 times, booking appointments), travel to the clinic, the testing environment and aspects of
19
20
21 272 patient-clinician communication. The themes and sub-themes are summarised in Figure 1.
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23 273

24
25 274 **Figure 1:** Coding tree showing main themes and sub-themes that emerged from the analysis,
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27 275 and how the categories relate to each other.
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34 278 Direct quotes taken from the transcripts are italicized. These quotes were examples chosen to
35
36 279 illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a
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38 280 pseudonym for the corresponding participant based on their gender (“M” or “F”) and the
39
40 281 order in which they spoke in the interview. The location of the focus group and the session
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42 282 number (1 or 2) are also shown for each quote.
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49 285 **Visual fields – Opinions about testing**
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54 287 **Visual fields - Test procedure**
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3 289 Patients expressed a dislike for the VF test. They found the test time-consuming, old-
4
5 290 fashioned and tiring.

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10 292 *Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I*
11
12 293 *don't like having one eye closed and having to concentrate, even if it's for just a couple of*
13
14 294 *minutes, because then my mind wanders... F1, Portsmouth 1*

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16 295

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18 296 *It seems a bit antiquated, pressing the buttons... it doesn't seem positive enough to me.*

19
20 297

F3 Norwich 2

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22 298

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24 299 *I appreciate the need for it...but it's so time consuming*

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26 300

M2 London 1

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34 303 Visual fields - Performance pressure

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38 305 Many put pressure on themselves to perform the test well, as they felt there could be a lot
39
40 306 riding on their performance.

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44 308 *There is pressure: I think it is because your eyes are so important for everyday living, that,*
45
46 309 *you know, you're frightened to [not do well]. F2 Portsmouth 1*

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50 311 There was a general appreciation that such testing was vital to preserve their vision.

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55 313 *Well... obviously I'm very grateful that I'm being monitored all... F4 London 1*

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3 3144
5 315 *....mine has been 10 years and you think, well how long will I have my sight? ... My mum had*6
7 316 *lost her sight by then, you know... F3 Norwich 2*8
9 31710
11 318 Visuals fields - Comparison with other tests12
13 31914
15 320 Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular16
17 321 pressure measurement and imaging tests, less tiring and laborious. At the same time some18
19 322 patients felt the VF test was more 'valuable', providing more reassurance that their condition20
21 323 was being investigated.22
23 32424
25 325 *[with] the [imaging] there's just one person, one machine and you, and it's done and that's it,*26
27 326 *it's over...within minutes. F3 Norwich 2*28
29 32730
31 328 *... they look in your eyes to measure your pressure but when you do that field test, they see*32
33 329 *more.... F1 London 2*34
35 33036
37 33138
39 332 Frequency of visual field testing – Current experience40
41 333 VF tests were usually performed once or twice a year, either during or closely prior to the42
43 334 patient's general clinical appointment. Patients who visited the clinic more frequently would44
45 335 have a VF test at only some of their appointments. Some patients were often unaware as to46
47 336 whether they would have a VF test during their visit.48
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3 338 *I mean they just say you're going to come for your next appointment in whatsoever, whatever*
4
5 339 *time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you*
6
7 340 *know that you are going to have to be that little bit longer.. F2 Portsmouth 1*
8

9 341

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11 342 Frequency of visual field testing – Opinions about more testing
12

13 343

14
15 344 When patients were asked whether they would be willing to visit the clinic for VF testing
16
17 345 more frequently, there was a reluctant agreement. The test was viewed as a 'necessary evil'
18
19 346 and most were open to more frequent testing if the clinician felt it would enhance their
20
21 347 prognosis, although there was scepticism as to how useful the test actually was.
22
23

24 348

25
26
27 349 *If it was necessary. F2 Portsmouth 2*
28

29 350 *You'd get on with it. M1 Portsmouth 2*
30

31 351 *If it helps the cause so be it. M2 Portsmouth 2*
32

33 352 *I don't want to lose my sight, I'd come in whenever. F2 Portsmouth 2*
34

35 353

36
37 354 *If it holds it back for 10 years... I'm happy with another 10 years! M1 Norwich 2*
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40 355

41 356 *That's a problem with glaucoma, you can't leave it for too long*
42

43 357 *M2 London 2*
44

45 358

46 359 *... I suppose I'd accept it because I would hope that the reason for asking me was that they*
47

48 360 *will get more information from that, which obviously deals with the whole problem but...I'm*
49

50 361 *not really sure at all about how useful they are. I mean is it just statistics or whatever? ...I'm*
51

52 362 *sure they're useful but I wonder in what proportion of use they are compared to, you know,*
53

54 363 *looking in the eye and pressures and things....*
55

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57 364 *F3 Norwich 2*
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3 365 Some patients associated more frequent testing with worsening vision; therefore being asked
4
5 366 to attend for more testing could lead to increased anxiety.
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10 368 ... you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said
11
12 369 to do it, I've always done ... because they're doing the best for me...

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14 370

F3 Norwich 2

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16 371

17
18 372 Frequency of visual field testing - Learning effect
19

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21 373

22
23 374 One recurrent topic regarding VF testing was issues relating to the learning effect, whereby
24
25 375 performance improves with increased testing. Some suggested that more repeat testing would
26
27 376 be helpful. However, the repeated tests may only be worthwhile if they took place at the
28
29 377 beginning of their follow-up care.
30

31
32 378

33
34 379 ...interestingly I went and did one once and they said to me, "this has improved from the last
35
36 380 time" and I said "well I think I'm just getting better at computer games" ... I think you do
37
38 381 know what's coming and you can improve and I just feel more comfortable with doing it.

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40 382

F1 Norwich 1

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42 383

43
44 384 I think to do a field test right at the beginning, and to take that as being the definitive field
45
46 385 test is wrong...because I think you need to do a test and think, and revise it in your mind what
47
48 386 you've done and then do it again. M1 Portsmouth 2
49

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51 387

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53 388 There was some debate about the period of time between VF tests.
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56 389
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1
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3 390 *I think you need to do a field test and then perhaps a month later do the second one.*

4
5 391 M1 Portsmouth 2

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7 392

8
9 393 *Well not if you have a long gap between them. F1 Norwich 2*

10
11 394 *I've got used to it now. F2 Norwich 2*

12
13 395 *I don't think it's any different really. F3 Norwich 2*

14
15 396

16
17 397

18
19 398 Perceived issues and barriers for successful follow-up care

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21 399

22
23 400 Some additional themes emerged during the analysis, highlighting a number of areas
24
25 401 perceived to be important and potentially representing barriers to successful follow-up.

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27 402

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29 403 Communication - Visual field instructions

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31 404

32
33 405 Regardless of how long they had been attending the glaucoma clinic, patients appreciated
34
35 406 having the VF test procedure fully explained to them. It was rare for a staff member to stay
36
37 407 with the patient throughout the test, but on the occasions it did happen, patients found the
38
39 408 experience reassuring and felt the encouragement helped their performance.

40
41 409

42
43 410 *... They say, "Have you done this before?" You say "Yes". And that's it, you're left there*

44
45 411 *and eventually they say, "Have you finished?"*

46
47 412 M1 Portsmouth 2

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49 413

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2
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
9

10 417

11 418 There was discussion about understanding aspects of the testing procedure and how the
12 procedure was explained. For example, some patients expressed uncertainty and felt test
13 419 pressure would influence their results. Again, explanation and reassurance before and after the
14 420 test helped.
15
16 421
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20 422

21 423 *The staff told me: "don't worry about missing [a light] because it'll come later", so you know*
22
23 424 *you get a second chance. F1 Norwich 1*
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26

27 425

28 426 *... if in doubt press the button, don't you? F1 Portsmouth 2*
29
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32 427

33
34 428 Communication - Explanation of results
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37
38 430 Most patients said they had to specifically enquire about their results to find out information
39 431 about their vision and whether their condition had progressed since the last appointment.
40
41 432 Some patients felt intimidated to ask the clinician for feedback as to how they had performed,
42
43 433 feeling they were being a nuisance or wasting the clinician's time.
44
45
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47 434

48 435 *They never discuss the result of the field test unless I ask...*
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50 436

M2 London 2

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3 438 *My wife always says “how did you get on?” and I say “I don't know”, and that's one of the*
4
5 439 *problems. M2 Portsmouth 2*

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7 440
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9 441 *I don't think they've got time to listen to you, or they don't appear to, and I don't know*
10
11 442 *whether they would listen.... You feel pathetic asking these questions. F3 Portsmouth 1*

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13 443
14
15 444 Patients may be more inclined to have VF tests more frequently should they be informed
16
17 445 clearly about what the results indicate about their prognosis.

18
19 446
20
21 447 *I don't mind how many times I do it providing I get a result of the test at that time compared*
22
23 448 *to what the previous one was. Is there any improvement? Is there any downgrade?*

24
25 449 M1 Portsmouth 1

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31 452 Communication - The patient-clinician relationship

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33 453

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35 454 The quality of relationship with the clinical staff and aspects of patient-clinician
36
37 455 communication also emerged as key factors influencing perceptions of the follow-up process.

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39 456

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41 457 An apparent lack of personalised care caused unease: there was a sentiment that sometimes
42
43 458 the clinician simply looked at the eyes and failed to consider the person's individual needs.

44
45 459

46
47 460 *You're not a person, you know, you've just got eyes, they're just going to deal with that and*
48
49 461 *that's it. F3 Portsmouth 1*

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51 462

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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.
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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*

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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

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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*

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27 474

28
29 475 Testing environment

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31 476

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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
45 482

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*

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51 485

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

54
55 487 *M1 London 1*

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3 4884
5 489 *The times that I've had the visual field test done in a room where there's just one [machine], I*6
7 490 *felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot*8
9 491 *quicker too. F3 Norwich 2*10
11 49212
13 493 *I think having the quieter atmosphere would generally help I'm sure....just that feeling of*14
15 494 *slight calm, you can relax more and then it probably would be a lot quicker because maybe*16
17 495 *you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.*18
19 49620
21 49722
23 498 The idea was raised that routine VF testing could be carried out in a more convenient location.24
25 499 Some patients had previously visited a local optometrist to carry out a VF test for the purpose26
27 500 of assessing their legal fitness to drive. On the positive side, patients liked the convenience of28
29 501 doing so and described a better testing environment. Conversely, they questioned the30
31 502 competency of the staff, the quality of the equipment and the information trail back to the32
33 503 hospital.34
35 50436
37 505 *The principle of having routine tests done locally is acceptable providing they are trained.*38
39 506 *M1 London 1*40
41 50742
43 508 *That way you would be there, dealt with by people you know probably more*44
45 509 *intimately...you're in a more relaxed environment...*46
47 510 *M1 Norwich 1*48
49 51150
51 512 *I would be concerned about how often the machine was calibrated to get an accurate reading.*52
53 513 *M2 London 1*54
55 514

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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
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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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26
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29 527 Clinic constraints -Waiting times
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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
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
56 539 *and he'll call me the minute I go to the [bathroom].* F2 Portsmouth 1
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5 541 Although it was repeatedly acknowledged that the clinics were very busy, which had the
6
7 542 knock-on effect of increased waiting times, patients felt they were getting adequate treatment
8
9
10 543 overall. It was suggested that there was a trade-off between longer waiting times and higher
11
12 544 quality treatment:
13

14 545

15
16 546 *I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of*
17
18 547 *excellence. There's a trade-off in that you're getting state of the art treatment but the price is*
19
20
21 548 *you've got to sit around for it.* M1 London 1
22

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28
29 552 Clinic constraints - Travelling to the clinic
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31 553

32
33 554 Several sub-themes emerged including issues with long distances to travel, avoiding rush
34
35 555 hours, travel costs and travelling alone.
36

37 556

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39
40 557 *I think the problem is because I live nearly an hour away, for me the nearest hospital is an*
41
42 558 *hour away...* F2 Norwich 2
43

44 559

45 560 *Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly*
46
47 561 *with help to get on the train but it's not easy.....It's horrific, frightening.* M2 London 1
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49 562

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52
53 564 Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to
54
55 565 have a negative effect on VF test performance.
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57 566
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1
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3 567 *I think if you did the eye check later in the day, you know, if your eyes were tired, it might*
4 568 *make you feel [that you] wouldn't see so well... F2 Portsmouth 1*
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11 570

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13 571 Clinic constraints - Scheduling appointments
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16 572

17 573 The scheduling of appointments was a major concern: often the systems were so overbooked
18 574 that patients were unable to make their next appointment at their clinic visit.
19

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21 575

22 576 *You can only make an appointment six weeks in advance. You used to get a twelve month*
23 577 *appointment letter just after you had been for an appointment; now its six weeks before you*
24 578 *are due. M2 Norwich 1*
25
26
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29 579

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31 580 Often patients would receive an appointment only to have it cancelled just before the clinic
32 581 was due to take place. This was not only frustrating to people who had made arrangements for
33 582 their appointment, such as asking a friend to accompany them or arranging cover for sick
34 583 spouses, it caused concern that their appointment was to be at a much later date than the
35 584 clinician had originally requested.
36
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41 585

42
43 586 *“So if you’ve been given a six month appointment and it’s cancelled, and you’re not given*
44 587 *another one, you ring up and then they say “oh we can’t give you an appointment now until*
45 588 *October”. That was 10 months. Now if your consultant says 6 [months] and it’s 10 and*
46 589 *something’s gone wrong with your vision in between, you have no way of telling.” F2*
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3 593 **Patient recommendations**
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7 595 At the end of the focus groups, patients were asked to recommend changes to improve their
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9
10 596 follow-up care. The recommendations were similar across all locations and the most popular
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12 597 suggestions are displayed in table 2.
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14 598

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16
17 600 **Table 2:** Patient recommendations for improving follow-up care.
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19 601
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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.

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3 607 **Discussion**
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6 610 Data from this study supports evidence from elsewhere that patients find VF testing more
7
8 611 laborious and demanding than other vision tests²⁰. Nevertheless, patients were willing to
9
10 612 complete more VF tests on the guidance of their clinician, as ultimately they were prepared to
11
12 613 do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF
13
14 614 testing during the first two years of their follow-up care as recommended by the research
15
16 615 literature^{4 5} and some clinical guidelines²⁴. Patients commented that it took time to feel
17
18 616 comfortable with the test procedure, and that multiple attempts were needed to gain an
19
20 617 accurate representation of their vision. These viewpoints complement existing evidence
21
22 618 showing that performance can improve considerably during follow-up due to gaining
23
24 619 experience with the testing process²⁵.
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28 620
29
30 621 There were, however, a number of additional themes that emerged from the data which
31
32 622 identified areas that could represent potential barriers to successful glaucoma monitoring.
33
34 623 Patients felt that the environment in which they completed the VF test was linked to how well
35
36 624 they were able to perform the task, with staff members talking loudly, the number of people in
37
38 625 the room, and the time of day all listed as important interfering factors. These views coincide
39
40 626 with other evidence showing that the environment, the technician and the time of day do have
41
42 627 a significant influence on measurement variability from VF tests²⁶. Fatigue, a topic mentioned
43
44 628 frequently throughout the discussions, has also been shown to affect performance as test
45
46 629 duration increases²⁷.
47
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50 630
51
52 631 Patients highlighted the importance of effective task communication for influencing their VF
53
54 632 test performance. Prior evidence has shown that the quality of instruction given before the VF
55
56 633 test can significantly affect subsequent estimations of VF defect severity^{28 29}. Patients also felt
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3 634 that it was essential to have the task explained to them properly, even if they had been
4
5 635 attending clinics for some time. Having a staff member in the room whilst they carried out the
6
7 636 test was found to be reassuring. These findings reiterate the idea that ensuring that the task
8
9 637 demands are communicated clearly and effectively before every VF test, and being on hand to
10
11 638 alleviate any concerns or questions that the patient may have, may help maximise the quality
12
13 639 of the data gained from the assessment²⁹⁻³¹.

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18 641 Other discussion points relating to communication were also raised repeatedly throughout the
19
20 642 focus groups. Patients felt that many clinicians treated them as an ‘eye’ rather than a person,
21
22 643 with those staff members who took a more individualistic and empathic approach viewed
23
24 644 favourably. Notably, patients felt that they had to ask explicitly about their results in order to
25
26 645 learn details about their own condition. Evidence has shown that that the patient and
27
28 646 clinician’s views of their condition are not always aligned, which may be due to
29
30 647 miscommunication or misinterpretation of key information on both parts³². By explaining the
31
32 648 results in a clear, simple and concise manner, the patient will inevitably improve their
33
34 649 understanding of their condition, which in turn could influence how well they respond to
35
36 650 important aspects of their follow-up care. For instance, it has been shown that the way in
37
38 651 which clinicians communicate with the patient can influence future adherence to
39
40 652 medication³². It has been suggested that clinicians underestimate the importance of effective
41
42 653 communication to the patient¹¹, and in one study examining patient expectations for eye care,
43
44 654 the emphasised areas were all related to communication and interpersonal manner³³.
45
46 655 Providing better information about the purpose of VF testing, what is required of the patient,
47
48 656 and their results and general prognosis could be vital for improving attendance for VF tests or
49
50 657 for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about
51
52 658 ways in which the complex measurement of the VF could be easily presented and
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3 659 communicated to patients. It is important to note that some patients associated more frequent
4
5 660 testing with worsening vision, which caused some distress. Thus, should patients require more
6
7 661 frequent tests at some point in their care, it is also vital to involve the patient and explain
8
9 662 reasons for the decision.
10

11 663
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13
14 664 Excessive waiting times and difficulty booking appointments were also major concerns. In
15
16 665 particular, patients worried that appointment cancellations could extend the interval between
17
18 666 tests beyond what was recommended by the clinician, therefore leaving them exposed to
19
20 667 undetected disease progression. It is known that whilst clinicians select appropriate
21
22 668 monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate
23
24 669 follow-up^{7 34 35}. Moreover, it was typical for patients to wait at the clinic for hours in order to
25
26 670 complete multiple vision tests, causing frustration and tiredness which some perceived to
27
28 671 influence their subsequent performance. Potential solutions could involve conducting only the
29
30 672 VF test during short independent appointment slots, or carrying out tests at a more convenient
31
32 673 location. However, such strategies would involve further investigation as to their overall cost-
33
34 674 effectiveness and should address other associated practicalities such as travel (a significant
35
36 675 contributor to total patient costs³⁶) and the information trail back to the hospital.
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41 676
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43 677 Previous research has relied on statistical analysis or computer simulations to help determine
44
45 678 the most effective VF monitoring strategies for patients with glaucoma. This is the first study
46
47 679 to use qualitative methods to investigate the patient's own perspective on their follow-up.
48
49 680 Studies focusing on the patient's perspective in glaucoma, particularly with regard to the
50
51 681 perceived effects of the disease on their day-to-day activities, have typically relied on
52
53 682 questionnaires¹³. However, questionnaire responses can be restricted by the wording of the
54
55 683 items and provide little opportunity for clarification or elaboration. This study allowed
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3 684 individuals to contextualise their experiences and expand on particular points and themes,
4
5 685 encouraging discussion about topics a certain patient may not have otherwise introduced or
6
7 686 attributed to glaucoma without the encouragement of another¹⁸. The notion of the “expert
8
9
10 687 patient” is beginning to be endorsed with regards to other chronic conditions, with focus
11
12 688 groups demonstrating potential as a forum for the development of more effective management
13
14 689 strategies³⁷⁻³⁹. Furthermore, patient groups have aided the development of health education
15
16 690 programmes for age-related macular degeneration⁴⁰. A systematic review of patient centred
17
18 691 randomised controlled trials suggests there may be some benefits associated with involving
19
20
21 692 patients with chronic disease in programmes geared towards better educating service users
22
23 693 and devising general training for health professionals⁴¹. Future work that encourages more
24
25 694 patient involvement may therefore help devise the optimal strategies for glaucoma follow-up
26
27 695 and also help better inform both patients and health professionals about the condition.
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31
32 697 This study has its limitations with findings attached to the viewpoints of the groups who took
33
34 698 part. Efforts were taken to reduce bias by involving multiple research sites- however, these
35
36 699 were all geographically limited to the South of England and (excluding the London groups)
37
38 700 involved patients of Caucasian ethnicity. Therefore the findings may not necessarily translate
39
40 701 to a wider population. Moreover, initial patient selection was made on recommendation of
41
42 702 consultants at the clinics and our selection process did not monitor reasons for non-
43
44 703 participation. People who choose to volunteer for focus groups are likely to be articulate and
45
46 704 confident; they may also be more motivated to take part due to having more severe disease or
47
48 705 holding strong opinions about a certain area of their care. Furthermore, participants were aged
49
50 706 60 years and older- younger service-users may have differing views and experiences that also
51
52 707 warrant investigation. The study was initially designed to involve 6 focus groups across 3
53
54 708 locations and so no direct decision was taken to cease data collection; however, similar
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2
3 709 themes and sub-themes continued to emerge in the latter focus groups and so it is likely that
4
5 710 ‘data saturation’ was achieved. Furthermore, some of the focus groups were small (one
6
7 711 consisting of only 3 participants) due to late cancellations but this is not a major limitation
8
9 712 due to the number of focus groups that took place ⁴². Also, some biases could have been
10
11 713 introduced during interview and analysis due the preconceived ideas held by the
12
13 714 experimenters about the areas of importance, although care was taken to adhere to expected
14
15 715 practice by following the COREQ check-list for focus group research²².
16
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20

21 717 A number of important themes did emerge that give an insight into clinic visits and VFs from
22
23 718 the patient’s perspective, and could help inform patient centred care in glaucoma. Although
24
25 719 patients appeared frustrated by a number of aspects of their follow-up, they ultimately
26
27 720 accepted that some compromises had to be made in order to save their eyesight. Some of the
28
29 721 viewpoints illustrated in the focus group discussions may in part explain why research-
30
31 722 supported guidelines about more frequent VF testing are not being implemented effectively in
32
33 723 clinical practice. A holistic approach that embraces patient opinion may therefore be vital to
34
35 724 help devise the most effective strategies for follow-up care in this chronic disease.
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41 727 **Conclusion**

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45 730 This is the first study to use qualitative methods to examine patient opinion about the
46
47 731 glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they
48
49 732 accepted it was important to their overall vision assessment. However, a number of actionable
50
51 733 points were raised which were perceived to impact the effectiveness of follow-up care,
52
53 734 including distracting testing environments, and hospital constraints relating to excessive
54
55 735 waiting times and appointment booking. Some patients also expressed particular concerns
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2
3 736 about the VF technology used and the quality of test instructions. Anxiety associated with
4
5 737 increased testing in the absence of clinical explanation was another theme. Ensuring that
6
7 738 glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the
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10 739 confidence and cooperation of the patient. Addressing some or all of the perceived barriers
11
12 740 highlighted in this study should help deliver more efficient strategies for VF monitoring in
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14 741 glaucoma.

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2
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18
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22
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24
25 754 **FCG:** Conducted data analysis, and wrote and edited the manuscript (joint first author).
26

27 755 **HB:** Conducted focus groups and data analysis, and wrote the manuscript (joint first author).
28

29 756 **DPC:** Conceived and designed study, and reviewed and edited the manuscript.
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31

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33
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43
44 763 of the NHS, the NIHR or the Department of Health.
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48 764

49 765 **Competing Interest Statement**

50
51 766 None of the authors have any competing interests in relation to this work.
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53
54 767 **Data Sharing Statement**

55 768

56 769 Copies of the topic guide and participant information sheet can be obtained by emailing the
57 770 corresponding author.
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References

1. National Institute of Health and Clinical Excellence. CG85 Glaucoma: NICE guideline. In: NICE, editor. *Published Clinical Guidelines*: National Institute of Health and Clinical Excellence, 2009.
2. Burr JM, Mowatt G, Hernández RA, Siddiqui MAR, Cook JA, Lourenco T, et al. The clinical effectiveness and cost-effectiveness of screening for open angle glaucoma: a systematic review and economic evaluation. *Health Technology Assessment* 2007;11(41):1-190.
3. Heijl A, Bengtsson B, Hyman L, Leske MC. Natural history of open-angle glaucoma S0161-6420(09)00670-8 [pii] 10.1016/j.optha.2009.06.042. *Ophthalmology* 2009;116 [http://www.ncbi.nlm.nih.gov/pubmed/19854514\(12\):2271-6](http://www.ncbi.nlm.nih.gov/pubmed/19854514(12):2271-6).
4. Chauhan BC, Garway-Heath DF, Goni FJ, Rossetti L, Bengtsson B, Viswanathan AC, et al. Practical recommendations for measuring rates of visual field change in glaucoma. *Br J Ophthalmol* 2008;92(4):569-73.
5. Gardiner SK, Crabb DP. Frequency of testing for detecting visual field progression. *Br J Ophthalmol* 2002;86(5):560-4.
6. Crabb DP, Garway-Heath DF. Intervals between visual field tests when monitoring the glaucomatous patient: wait-and-see approach. *Invest Ophthalmol Vis Sci* 2012;53(6):2770-6.
7. Fung SS, Lemer C, Russell RA, Malik R, Crabb DP. Are practical recommendations practiced? A national multi-centre cross-sectional study on frequency of visual field testing in glaucoma. *British Journal of Ophthalmology* 2013.
8. Malik R, Baker H, Russell RA, Crabb DP. A survey of attitudes of glaucoma subspecialists in England and Wales to visual field test intervals in relation to NICE guidelines. *BMJ open* 2013;3(5).
9. Lacy NL, Paulman A, Reuter MD, Lovejoy B. Why We Don't Come: Patient Perceptions on No-Shows. *The Annals of Family Medicine* 2004;2(6):541-45.
10. Owsley C, McGwin G, Scilley K, Girkin CA, Phillips JM, Searcey K. Perceived Barriers to Care and Attitudes about Vision and Eye Care: Focus Groups with Older African Americans and Eye Care Providers. *Investigative Ophthalmology & Visual Science* 2006;47(7):2797-802.
11. Laine C, Davidoff F, Lewis CE, Nelson EC, Nelson E, Kessler RC, et al. Important Elements of Outpatient Care: A Comparison of Patients' and Physicians' Opinions. *Annals of Internal Medicine* 1996;125(8):640-45.
12. Brown GC, Brown MM, Sharma S. Difference between ophthalmologists' and patients' perceptions of quality of life associated with age-related macular degeneration. *Can J Ophthalmol* 2000;35(3):127-33.
13. Glen FC, Crabb DP, Garway-Heath DF. The direction of research into visual disability and quality of life in glaucoma. *BMC Ophthalmology* 2011;11(1):19.
14. Ormel J, Kempen GI, Penninx BW, Brilman EI, Beekman AT, van Sonderen E. Chronic medical conditions and mental health in older people: disability and psychosocial resources mediate specific mental health effects. *Psychol Med* 1997;27(5):1065-77.
15. Friedman SM, Munoz B, Rubin GS, West SK, Bandeen-Roche K, Fried LP. Characteristics of discrepancies between self-reported visual function and measured

- 1
2
3 821 reading speed. Salisbury Eye Evaluation Project Team. *Invest Ophthalmol Vis Sci*
4 822 1999;40(5):858-64.
- 5 823 16. Kitzinger J. Qualitative Research: Introducing focus groups. *Bmj* 1995;311(7000):299-
6 824 302.
- 7 825 17. Lacey J, Cate H, Broadway D. Barriers to adherence with glaucoma medications: a
8 826 qualitative research study. *Eye* 2008;23(4):924-32.
- 9 827 18. Green J, Siddall H, Murdoch I. Learning to live with glaucoma: a qualitative study of
10 828 diagnosis and the impact of sight loss. *Soc Sci Med* 2002;55(2):257-67.
- 11 829 19. Prior M, Francis JJ, Azuara-Blanco A, Anand N, Burr JM. Why do people present late
12 830 with advanced glaucoma? A qualitative interview study. *British Journal of*
13 831 *Ophthalmology* 2013;bjophthalmol-2013-303813.
- 14 832 20. Gardiner SK, Demirel S. Assessment of Patient Opinions of Different Clinical Tests Used
15 833 in the Management of Glaucoma. *Ophthalmology* 2008;115(12):2127-31.
- 16 834 21. Patel D, Baker H, Murdoch I. Barriers to uptake of eye care services by the Indian
17 835 population living in Ealing, west London. *Health Education Journal* 2006;65(3):267-
18 836 76.
- 19 837 22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
20 838 (COREQ): a 32-item checklist for interviews and focus groups. *International Journal*
21 839 *for Quality in Health Care* 2007;19(6):349-57.
- 22 840 23. Pope C, Ziebland S, Mays N. Qualitative research in health care: Analysing qualitative
23 841 data. *BMJ: British Medical Journal* 2000;320(7227):114.
- 24 842 24. European Glaucoma Society. *Terminology and guidelines for glaucoma*. 3rd edition ed:
25 843 Savona, Italy Editrice Dogma 2008, 2008.
- 26 844 25. Wild JM, Searle AET, Dengler-Harles M, O'Neill EC. Long-term follow-up of baseline
27 845 learning and fatigue effects in the automated perimetry of glaucoma and ocular
28 846 hypertensive patients. *Acta Ophthalmologica* 1991;69(2):210-16.
- 29 847 26. Junoy Montolio FG, Wesselink C, Gordijn M, Jansonius NM. Factors that influence
30 848 standard automated perimetry test results in glaucoma: test reliability, technician
31 849 experience, time of day, and season. *Investigative ophthalmology & visual science*
32 850 2012;53(11):7010-7.
- 33 851 27. Henson DB, Emuh T. Monitoring Vigilance during Perimetry by Using Pupillography.
34 852 *Investigative Ophthalmology & Visual Science* 2010;51(7):3540-43.
- 35 853 28. Kutzko KE, Brito CF, Wall M. Effect of instructions on conventional automated
36 854 perimetry. *Invest Ophthalmol Vis Sci* 2000;41(7):2006-13.
- 37 855 29. Sherafat H, Spry PGD, Waldock A, Sparrow JM, Diamond JP. Effect of a patient training
38 856 video on visual field test reliability. *British Journal of Ophthalmology*
39 857 2003;87(2):153-56.
- 40 858 30. Heijl A, Asman P. Pitfalls of automated perimetry in glaucoma diagnosis. *Curr Opin*
41 859 *Ophthalmol* 1995;6(2):46-51.
- 42 860 31. Van Coevorden RE, Mills RP, Chen YY, Barnebey HS. Continuous visual field test
43 861 supervision may not always be necessary. *Ophthalmology* 1999;106(1):178-81.
- 44 862 32. Friedman DS, Hahn SR, Quigley HA, Kotak S, Kim E, Onofrey M, et al. Doctor-patient
45 863 communication in glaucoma care: analysis of videotaped encounters in community-
46 864 based office practice. *Ophthalmology* 2009;116(12):2277-85 e1-3.
- 47 865 33. Dawn AG, Santiago-Turla C, Lee PP. Patient expectations regarding eye care: Focus
48 866 group results. *Archives of ophthalmology* 2003;121(6):762-68.
- 49 867 34. Tatham A, Murdoch I. The effect of appointment rescheduling on monitoring interval and
50 868 patient attendance in the glaucoma outpatient clinic. *Eye (Lond)* 2012;26(5):729-33.
- 51 869 35. Agency NPS. Preventing delay to follow-up for patients with glaucoma. Rapid Response
52 870 Report, 2009.

- 1
2
3 871 36. Sharma A, Jofre-Bonet M, Panca M, Lawrenson J, Murdoch I. Hospital-based glaucoma
4 872 clinics: what are the costs to patients? *Eye* 2009;24(6):999-1005.
5 873 37. Wilson PM, Kendall S, Brooks F. The Expert Patients Programme: a paradox of patient
6 874 empowerment and medical dominance. *Health & social care in the community*
7 875 2007;15(5):426-38.
8 876 38. Holman H, Lorig K. Patients as partners in managing chronic disease: partnership is a
9 877 prerequisite for effective and efficient health care. *BMJ: British Medical Journal*
10 878 2000;320(7234):526.
11 879 39. Holman H, Lorig K. Patient self-management: a key to effectiveness and efficiency in
12 880 care of chronic disease. *Public health reports* 2004;119(3):239.
13 881 40. Dahlin-Ivanoff S, Klepp K, Sjöstrand J. Development of a health education programme
14 882 for elderly with age-related macular degeneration: a focus group study. *Patient*
15 883 *Education and Counseling* 1998;34(1):63-73.
16 884 41. McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, et al. Patient-Centered
17 885 Approaches to Health Care: A Systematic Review of Randomized Controlled Trials.
18 886 *Medical Care Research and Review* 2013;70(6):567-96.
19 887 42. Carlsen B, Glenton C. What about N? A methodological study of sample-size reporting in
20 888 focus group studies. *BMC medical research methodology* 2011;11(1):26.
21 889
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3 1 **Title: A qualitative investigation into** patient views on visual field testing for glaucoma
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5 2 **monitoring**

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37

38 **Competing Interest Statement**

39
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41 None of the authors have any competing interests in relation to this work.
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44

45 **Contributions of authors**

46
47 **FCG:** Conducted data analysis, and wrote and edited the manuscript (joint first author).
48
49

50 **HB:** Conducted focus groups and data analysis, and wrote the manuscript (joint first author).
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52 **DPC:** Conceived and designed study, and reviewed and edited the manuscript.
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1
2
3 **Abstract**
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48 **Objectives:** To investigate the views and experiences of patients regarding their glaucoma
49 follow-up, particularly towards the type and frequency of visual field (VF) testing.

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

55

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

57

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

60

61 **Primary and Secondary Outcomes:**

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

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

64

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

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3 71 concerned about aspects of patient-doctor communication, and often received little to no
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5 72 feedback about their results.
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10 74 **Conclusions:** Patients trust the clinician to make the best decisions for their glaucoma follow-
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12 75 up. However, patients highlighted a number of issues that could compromise the effectiveness
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14 76 of VF testing. Addressing patient-perceived barriers could be an important step for devising
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16 77 optimal strategies for follow-up care.
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22 23 80 Article Summary

24 81 25 82 26 83 **Article Focus**

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28 84
- 29 85 • Glaucoma is a chronic and progressive eye disease and all diagnosed patients will
30 86 require lifetime monitoring of their vision.
 - 31 87 • Visual field (VF) testing is one of the most widely used assessments for glaucoma and
32 88 places a large burden on NHS resources; research is needed to devise the most
33 89 effective strategies for glaucoma VF monitoring.
 - 34 90 • This study used focus groups to investigate patient views about VF testing in their
35 91 follow-up care. Effective VF testing will require the confidence and cooperation of
36 92 the patient.
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40 95 **Key Messages**

- 41 96
42 97 • Although patients disliked VF testing, they accepted it as an important part of their
43 98 vision assessment and disease management.
- 44 99 • Patients discussed a number of areas of perceived importance for VF monitoring,
45 100 raising particular concerns about distracting testing environments, the quality of test

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3 101 instructions, how results were explained to them and excessive pre-testing waiting
4 102 times.
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10 105 **Strengths and Limitations of this study**
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- 12
13 107 • This is the first **qualitative** study to examine patients' views of visual field monitoring
14 108 using focus groups.
15
16 109 • **Focus groups took place at three selected hospitals in the South of England; it is**
17 110 **assumed the views expressed represent the experiences of patients in a wider**
18 111 **population.**
19
20 112 • **Not all patients approached by their ophthalmologist took part, but reasons for non-**
21 113 **participation were not monitored. Patients who chose to volunteer may be more**
22 114 **articulate, motivated and opinionated than the general patient population.**
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117 **Introduction**

118

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

129

130 Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring
131 of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a
132 sophisticated automated instrument. The test is carried out in a darkened room and takes about
133 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a
134 large semi-circular bowl covering their entire field of view. The instrument presents a series
135 of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the
136 VF while the patient fixates on a central point. The patient responds by clicking a button when
137 a stimulus is detected. This process yields a map of the seeing parts of the patient's field of
138 view; this map is subjected to statistical analysis comparing a patient's results to normative
139 values for people with healthy vision. These measurements can be highly variable, and speed
140 (rate) of VF loss, determined from a series of measurements over a period of time, varies
141 considerably between treated individuals. The VF should therefore be monitored at
142 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
4
5 144 out to optimally detect disease progression is limited. The National Institute of Clinical
6
7 145 Excellence (NICE) called for more research into examining the effectiveness of using
8
9 146 different monitoring intervals to detect disease progression in people with glaucoma in 2009¹.
10
11 147 Guidelines proposed by the European Glaucoma Society (EGS) recommend that the
12
13 148 frequency of VF tests should be increased for newly diagnosed patients in order to better
14
15 149 determine speed of VF progression. This notion is supported by research evidence based on
16
17 150 statistical analyses of retrospective data which has indicated that three VF tests per year in the
18
19 151 first 2 years of follow-up would be clinically useful for identifying patients that are
20
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
49
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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3 168 also be considered. Nevertheless there has been limited use of patient-based research for
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5 169 improving glaucoma care. A review of the literature found that most studies use
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7 170 questionnaires to quickly gather information about the perceptions of patients, usually with
8
9 171 regards to their perceived outcomes¹³. However, questionnaires can be impersonal and
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11 172 subject to bias^{14 15}. Qualitative techniques, such as focus groups, offer an alternative method
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14 173 of gathering information about not only what a patient thinks, but also how they think or why
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16 174 they may hold a particular view. Group interaction encourages participants to explore and
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18 175 clarify individual and shared perspectives and supports the participation of people who may
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21 176 be reluctant to contribute their views in a more formal one-to-one scenario¹⁶. Focus groups
22
23 177 have been used in a small number of studies to examine the general experiences of glaucoma
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25 178 patients at diagnosis, their expectations and to identify potential barriers to treatment
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27 179 adherence^{10 17-19}. However, there is limited evidence regarding the opinions of patients about
28
29 180 the manner in which their vision loss is monitored. Anecdotal evidence suggests that patients
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32 181 dislike doing the VF test, and one quantitative study showed that patients rate the VF test least
33
34 182 favourably of all the vision assessments²⁰. However, no study has interviewed patients with
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36 183 glaucoma in detail about their perceptions of the VF test and their follow-up care. The current
37
38 184 study therefore aims to shed light on the effectiveness of glaucoma monitoring from the
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40 185 perspective of the patient by exploring patient views and experiences via focus groups. In
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42 186 particular, the study aims to establish patients' views about VF testing in glaucoma
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3 192 **Methods**
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6 194 **Participants and methods**
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10 196 Focus groups took place between May 2012 and January 2013 in the following locations: The
11 Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University
12 Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation
13 Trust in London. The study was multi-centred to reduce the bias that might come from one
14 geographical area and to encompass healthcare trusts in both urban and rural locations. The
15 sites were chosen because they were involved in a wider programme work, of which the
16 current study was a component. There were two focus groups at each site, with participants
17 allocated to one of the two groups at the corresponding hospital.
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31 205 The study used purposeful sampling whereby a consultant ophthalmologist at each
32 participating eye hospital selected suitable participants during their routine eye appointment.
33 Specifically, the participant was required to be aged 60 years and over and to be an
34 established glaucoma patient who had been under review for at least two years. These criteria
35 were chosen to reflect the age-related nature of the disease and to ensure that participants had
36 sufficient experience of VFs as part of their glaucoma follow-up. The ophthalmologist
37 gave potential participants an information sheet, and interested people were asked to sign a
38 form indicating they were happy to be contacted by a researcher (it was stressed that they
39 were not obliged to participate). Each consultant ophthalmologist approached 20 patients in
40 this way. One of the study investigators (HB) then contacted the patients with further
41 information and invited them to take part on one of two specific dates at the corresponding
42 hospital. Those who declined did so because they were not available on the specific dates (no
43 other reason was cited). Initially, 5-6 patients were signed up to participate on each of the six
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3 218 study dates. However, a small number (n=4) did not attend. A total of 28 participants (mean
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5 219 age [standard deviation] 74 [9] years; 54% female) eventually took part across the six focus
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7 220 groups. Each group consisted of three to six patients and included participants of both
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9 221 genders.
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226 Procedure

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228 A topic guide was devised prior to beginning the study outlining broad question areas
229 regarding general glaucoma care, experiences of the VF test and opinions about VF test
230 frequency. Study topics were informed by an initial pilot exercise involving a discussion with
231 two patients with glaucoma, who also provided additional verbal and written information
232 about their experiences. The topics included in the guide acted only as suggestions; the
233 wording of questions was not predetermined and the order of the topics was not fixed.
234 Prompts were used to introduce topic areas and encourage respondents to elaborate but the
235 onus was on participants to supply the overall content of the discussion. Care was taken to
236 ensure questions were open and “non-leading”, although more specific questioning was
237 sometimes used to clarify a point made by a participant. If discussion went substantially off-
238 topic, or one participant was dominating the conversation, the interviewer would reflect back
239 to a previous topic and encourage other participants to contribute their views.
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241 Prior to the study, participants were informed that they would be involved in “an open
242 discussion about (their) experiences in the glaucoma clinic, with special attention to the visual
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3 243 tests (they) undertake". Participants were not explicitly aware of the emphasis on VF testing,
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5 244 so as to avoid bias linked to the self-selection of participants with strong views on this one
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7 245 topic. All focus groups were conducted by one of the authors (HB), a post-doctoral researcher
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9 246 who had prior experience of qualitative research involving patients with glaucoma^{18 21}. The
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11 247 interviewer and participants had no prior knowledge of each other in a clinical or personal
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13 248 context, so each focus group began with general introductions. Field notes were taken during
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15 249 the sessions to aid later interpretation of the data, although note-taking was purposely minimal
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17 250 so that the interviewer could be fully attentive to the discussion. The focus groups lasted
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19 251 between 60 and 75 minutes.
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25 253 The study received approval from a NHS National Research Ethics Service (NRES)
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27 254 committee and was approved by research governance committees of the participating
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29 255 institutions. The study conformed to the Declaration of Helsinki and written consent from all
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31 256 participants was obtained prior to each focus group.
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36 258 The study was designed and reported in accordance with the Consolidated Criteria for
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38 259 Reporting Qualitative Research (COREQ) for interviews and focus groups²².
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47 263 All focus groups were audio-recorded (with permission from the participants). The dialogue
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49 264 from the recordings was later transcribed and reviewed by the investigators. In a small
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51 265 number of instances certain words were inaudible on the recordings due to excessive
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53 266 background noise, so field notes were used to account for any unclear information.
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3 268 Data was analysed by two of the authors (HB and FCG) independently using framework
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5 269 analysis²³ as displayed in Table 1. Each investigator read and re-read the transcripts and
6
7 270 manually identified the key themes from the data in addition to some example quotes to
8
9 271 illustrate main points. One of the authors (FCG) was masked to the emphasis on VF testing at
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11 272 this initial point of analysis, although became aware following a subsequent discussion about
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13 273 the key categories that had emerged during that first stage. The qualitative software package
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15 274 NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the
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17 275 thematic framework by refining and condensing the categories that had been manually
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19 276 identified and to identify additional themes for exploration. Any differences of opinion
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21 277 regarding the meaning of sentences or the importance of themes were discussed until a
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23 278 consensus was reached.
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280 **Table 1:** Framework Technique used for data analysis
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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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3 284 **Findings**
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7 286 Data was initially indexed according to themes central to the main research questions, such as
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10 287 opinions of the VF test, current experience regarding the frequency of VF testing and opinions
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12 288 about more frequent VF testing. Throughout the analysis a number of additional themes
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14 289 emerged, often with their own sub-themes; these generally related to specific areas perceived
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16 290 to affect the follow-up experience, and included points relating to clinical constraints (waiting
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18 291 times, booking appointments), travel to the clinic, the testing environment and aspects of
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21 292 patient-clinician communication. The themes and sub-themes are summarised in Figure 1.
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25 294 **Figure 1:** Coding tree showing main themes and sub-themes that emerged from the analysis,
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27 295 and how the categories relate to each other.
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34 298 Direct quotes taken from the transcripts are italicized. These quotes were examples chosen to
35
36 299 illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a
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38 300 pseudonym for the corresponding participant based on their gender (“M” or “F”) and the
39
40 301 order in which they spoke in the interview. The location of the focus group and the session
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42 302 number (1 or 2) are also shown for each quote.
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50 305 Visual fields – Opinions about testing
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56 308 Visual fields - Test procedure
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5 310 Patients expressed a dislike for the VF test. They found the test time-consuming, old-
6
7 311 fashioned and tiring.

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11 313 *Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I*
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13 314 *don't like having one eye closed and having to concentrate, even if it's for just a couple of*
14
15 315 *minutes, because then my mind wanders...* F1, Portsmouth 1

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20 317 *It seems a bit antiquated, pressing the buttons... it doesn't seem positive enough to me.*

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23 318 F3 Norwich 224
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27 320 *I appreciate the need for it...but it's so time consuming*

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29 321 M2 London 130
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36 324 Visual fields - Performance pressure

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40 326 Many put pressure on themselves to perform the test well, as they felt there could be a lot
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42 327 riding on their performance.

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47 329 *There is pressure: I think it is because your eyes are so important for everyday living, that,*
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49 330 *you know, you're frightened to [not do well].* F2 Portsmouth 1

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53 332 There was a general appreciation that such testing was vital to preserve their vision.

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3 334 *Well... obviously I'm very grateful that I'm being monitored all... F4 London 1*

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7 336 *....mine has been 10 years and you think, well how long will I have my sight? ... My mum had*

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9 337 *lost her sight by then, you know... F3 Norwich 2*

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13 339 Visuals fields - Comparison with other tests

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17 341 Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular
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19 342 pressure measurement and imaging tests, less tiring and laborious. At the same time some
20
21 343 patients felt the VF test was more 'valuable', providing more reassurance that their condition
22
23 344 was being investigated.

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27 346 *[with] the [imaging] there's just one person, one machine and you, and it's done and that's it,*

28
29 347 *it's over...within minutes. F3 Norwich 2*

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31 348

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33 349 *... they look in your eyes to measure your pressure but when you do that field test, they see*

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35 350 *more.... F1 London 2*

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41 353 Frequency of visual field testing – Current experience

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43 354 VF tests were usually performed once or twice a year, either during or closely prior to the
44
45 355 patient's general clinical appointment. Patients who visited the clinic more frequently would
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47 356 have a VF test at only some of their appointments. Some patients were often unaware as to
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49 357 whether they would have a VF test during their visit.

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3 359 *I mean they just say you're going to come for your next appointment in whatsoever, whatever*
4
5 360 *time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you*
6
7 361 *know that you are going to have to be that little bit longer.. F2 Portsmouth 1*
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9 362

11 363 Frequency of visual field testing – Opinions about more testing

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15 365 When patients were asked whether they would be willing to visit the clinic for VF testing
16
17 366 more frequently, there was a reluctant agreement. The test was viewed as a 'necessary evil'
18
19 367 and most were open to more frequent testing if the clinician felt it would enhance their
20
21 368 prognosis, although there was scepticism as to how useful the test actually was.
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26 370 *If it was necessary. F2 Portsmouth 2*28 371 *You'd get on with it. M1 Portsmouth 2*30 372 *If it helps the cause so be it. M2 Portsmouth 2*32 373 *I don't want to lose my sight, I'd come in whenever. F2 Portsmouth 2*

34 374

36 375 *If it holds it back for 10 years... I'm happy with another 10 years! M1 Norwich 2*

38 376

40 377 *That's a problem with glaucoma, you can't leave it for too long*

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M2 London 2

44 379

46 380 *... I suppose I'd accept it because I would hope that the reason for asking me was that they*48 381 *will get more information from that, which obviously deals with the whole problem but...I'm*50 382 *not really sure at all about how useful they are. I mean is it just statistics or whatever? ...I'm*52 383 *sure they're useful but I wonder in what proportion of use they are compared to, you know,*

54 384

looking in the eye and pressures and things....

56 385

F3 Norwich 2

1
2
3 386 Some patients associated more frequent testing with worsening vision; therefore being asked
4
5 387 to attend for more testing could lead to increased anxiety.
6
7
8

9 388

10 389 ... you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said
11
12 390 to do it, I've always done ... because they're doing the best for me...

13
14 391

F3 Norwich 2

15
16 392

17
18 393 **Frequency of visual field testing - Learning effect**
19

20
21 394

22
23 395 One recurrent topic regarding VF testing was issues relating to the learning effect, whereby
24
25 396 performance improves with increased testing. Some suggested that more repeat testing would
26
27 397 be helpful. However, the repeated tests may only be worthwhile if they took place at the
28
29 398 beginning of their follow-up care.
30

31
32 399

33
34 400 ...interestingly I went and did one once and they said to me, "this has improved from the last
35
36 401 time" and I said "well I think I'm just getting better at computer games" ... I think you do
37
38 402 know what's coming and you can improve and I just feel more comfortable with doing it.
39

40
41 403

F1 Norwich 1

42
43 404

44
45 405 I think to do a field test right at the beginning, and to take that as being the definitive field
46
47 406 test is wrong...because I think you need to do a test and think, and revise it in your mind what
48
49 407 you've done and then do it again. M1 Portsmouth 2
50

51
52 408

53
54 409 There was some debate about the period of time between VF tests.
55

56
57 410
58
59
60

1
2
3 411 *I think you need to do a field test and then perhaps a month later do the second one.*

4
5 412 M1 Portsmouth 2

6
7 413

8
9 414 *Well not if you have a long gap between them. F1 Norwich 2*

10
11 415 *I've got used to it now. F2 Norwich 2*

12
13 416 *I don't think it's any different really. F3 Norwich 2*

14
15 417

16
17 418

18
19 419 Perceived issues and barriers for successful follow-up care

20
21 420

22
23 421 Some additional themes emerged during the analysis, highlighting a number of areas
24
25 422 perceived to be important and potentially representing barriers to successful follow-up.

26
27 423

28
29 424 Communication - Visual field instructions

30
31 425

32
33 426 Regardless of how long they had been attending the glaucoma clinic, patients appreciated
34
35 427 having the VF test procedure fully explained to them. It was rare for a staff member to stay
36
37 428 with the patient throughout the test, but on the occasions it did happen, patients found the
38
39 429 experience reassuring and felt the encouragement helped their performance.

40
41 430

42
43 431 *... They say, "Have you done this before?" You say "Yes". And that's it, you're left there*

44
45 432 *and eventually they say, "Have you finished?"*

46
47 433 M1 Portsmouth 2

48
49 434

1
2
3 435 *I had one about three weeks ago and it was a young nurse and it was a completely different*
4
5 436 *experience. She was professional, polite, kind; she told me exactly what they were doing... it*
6
7 437 *was almost a pleasant experience.* F1 Portsmouth 1
8
9
10 438

11 439 There was discussion about understanding aspects of the testing procedure and how the
12
13
14 440 procedure was explained. For example, some patients expressed uncertainty and felt test
15
16 441 pressure would influence their results. Again, explanation and reassurance before and after the
17
18 442 test helped.
19

20
21 443
22
23 444 *The staff told me: “don't worry about missing [a light] because it'll come later”, so you know*
24
25 445 *you get a second chance.* F1 Norwich 1
26
27
28 446

29
30 447 *... if in doubt press the button, don't you?* F1 Portsmouth 2
31
32 448

33
34 449 Communication - Explanation of results
35

36 450
37
38
39 451 Most patients said they had to specifically enquire about their results to find out information
40
41 452 about their vision and whether their condition had progressed since the last appointment.
42
43 453 Some patients felt intimidated to ask the clinician for feedback as to how they had performed,
44
45 454 feeling they were being a nuisance or wasting the clinician's time.
46
47

48 455
49
50 456 *They never discuss the result of the field test unless I ask...*
51

52 457 *M2 London 2*
53
54
55 458

1
2
3 459 *My wife always says “how did you get on?” and I say “I don’t know”, and that’s one of the*
4
5 460 *problems. M2 Portsmouth 2*

6
7 461
8
9
10 462 *I don't think they've got time to listen to you, or they don't appear to, and I don't know*
11
12 463 *whether they would listen.... You feel pathetic asking these questions. F3 Portsmouth 1*

13 464
14
15
16 465 Patients may be more inclined to have VF tests more frequently should they be informed
17
18 466 clearly about what the results indicate about their prognosis.

19
20 467
21
22
23 468 *I don't mind how many times I do it providing I get a result of the test at that time compared*
24
25 469 *to what the previous one was. Is there any improvement? Is there any downgrade?*

26
27 470 M1 Portsmouth 1

28
29 471

30
31 472

32
33
34 473 Communication - The patient-clinician relationship

35
36 474

37
38 475 The quality of relationship with the clinical staff and aspects of patient-clinician
39
40 476 communication also emerged as key factors influencing perceptions of the follow-up process.

41
42 477

43
44
45 478 An apparent lack of personalised care caused unease: there was a sentiment that sometimes
46
47 479 the clinician simply looked at the eyes and failed to consider the person’s individual needs.

48
49 480

50
51
52 481 *You're not a person, you know, you've just got eyes, they're just going to deal with that and*
53
54 482 *that's it. F3 Portsmouth 1*

55
56 483

1
2
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
21 492

22
23 493 *Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.*

24
25 494 *M2 London 2*

26
27 495

28
29
30 496 **Testing environment**

31
32 497

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

44
45 503

46
47 504 *I will also say that the staff chatter a lot, which is difficult for concentration; the doors open*

48
49 505 *and close, there's a lot of noise. F1 Norwich 1*

50
51 506

52
53
54 507 *I find it difficult sometimes when people [move] about behind you...*

55
56 508

57
58
59
60 **M1 London 1**

1
2
3 5094
5 510 *The times that I've had the visual field test done in a room where there's just one [machine], I*6
7 511 *felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot*8
9 512 *quicker too. F3 Norwich 2*10
11 51312
13
14 514 *I think having the quieter atmosphere would generally help I'm sure....just that feeling of*15
16 515 *slight calm, you can relax more and then it probably would be a lot quicker because maybe*17
18 516 *you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.*19
20
21 51722
23 51824
25 519 The idea was raised that routine VF testing could be carried out in a more convenient location.26
27 520 Some patients had previously visited a local optometrist to carry out a VF test for the purpose28
29 521 of assessing their legal fitness to drive. On the positive side, patients liked the convenience of30
31 522 doing so and described a better testing environment. Conversely, they questioned the32
33 523 competency of the staff, the quality of the equipment and the information trail back to the34
35 524 hospital.36
37
38 52539
40
41 526 *The principle of having routine tests done locally is acceptable providing they are trained.*42
43 527 M1 London 144
45 52846
47 529 *That way you would be there, dealt with by people you know probably more*48
49 530 *intimately....you're in a more relaxed environment...*50
51 531 M1 Norwich 152
53 53254
55 533 *I would be concerned about how often the machine was calibrated to get an accurate reading.*56
57 534 M2 London 158
59 535

1
2
3 536 *Is the information going back to where it matters in my notes? Things do get lost, and will*
4
5 537 *someone actually look at the test?*
6

7 538 M1 London 2
8

9 539

10
11 540 Some felt they had built up a level of trust with the hospital eye service and would therefore
12
13 541 prefer to have VFs conducted in this environment.
14

15 542

16
17 543 *I've been here for quite a while now and I like coming to them: I don't want to go anywhere*
18

19 544 *else.* F1 London 2
20

21 545 *I would feel the same because it's a matter of trust.* M2 London 2
22

23 546
24
25 547
26
27 548

28 Clinic constraints -Waiting times
29

30 549
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32 550
33
34 551
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36 552

37
38 552 Waiting times were a major concern at all locations. The standard time taken per visit was
39
40 553 estimated to be two hours, although the wait was often unpredictable. Established patients
41
42 554 were used to the wait and tried not to let it affect them but they still found the system
43
44 555 frustrating. Patients were scared of missing their slots and, therefore, would not leave their
45
46 556 seat in the waiting area.
47

48 557
49
50 558

51 558 *No way I'm going to nip off ... especially as now I'm on my own, no way just even nipping*
52
53 559 *off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour*
54

55 560 *and he'll call me the minute I go to the [bathroom].* F2 Portsmouth 1
56
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3 561

4
5 562 Although it was repeatedly acknowledged that the clinics were very busy, which had the
6
7 563 knock-on effect of increased waiting times, patients felt they were getting adequate treatment
8
9
10 564 overall. It was suggested that there was a trade-off between longer waiting times and higher
11
12 565 quality treatment:

13
14 566

15
16 567 *I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of*
17
18 568 *excellence. There's a trade-off in that you're getting state of the art treatment but the price is*
19
20
21 569 *you've got to sit around for it.* M1 London 1

22
23 570

24 571

25
26
27 572

28
29 573 Clinic constraints - Travelling to the clinic

30
31 574

32
33 575 Several sub-themes emerged including issues with long distances to travel, avoiding rush
34
35 576 hours, travel costs and travelling alone.

36
37
38 577

39
40 578 *I think the problem is because I live nearly an hour away, for me the nearest hospital is an*
41
42 579 *hour away...* F2 Norwich 2

43
44 580

45
46 581 *Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly*
47
48 582 *with help to get on the train but it's not easy.....It's horrific, frightening.* M2 London 1

49 583

50
51 584

52
53 585 Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to
54
55 586 have a negative effect on VF test performance.

56
57 587

1
2
3 588 *I think if you did the eye check later in the day, you know, if your eyes were tired, it might*
4 589 *make you feel [that you] wouldn't see so well... F2 Portsmouth 1*
5
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590

591

10
11 592 **Clinic constraints - Scheduling appointments**
12

13 593

14
15 594 The scheduling of appointments was a major concern: often the systems were so overbooked
16
17 595 that patients were unable to make their next appointment at their clinic visit.
18
19

20 596

21
22 597 *You can only make an appointment six weeks in advance. You used to get a twelve month*
23
24 598 *appointment letter just after you had been for an appointment; now its six weeks before you*
25
26 599 *are due. M2 Norwich 1*
27

28 600

29
30
31 601 Often patients would receive an appointment only to have it cancelled just before the clinic
32
33 602 was due to take place. This was not only frustrating to people who had made arrangements for
34
35 603 their appointment, such as asking a friend to accompany them or arranging cover for sick
36
37 604 spouses, it caused concern that their appointment was to be at a much later date than the
38
39 605 clinician had originally requested.
40

41 606

42
43
44 607 *“So if you’ve been given a six month appointment and it’s cancelled, and you’re not given*
45
46 608 *another one, you ring up and then they say “oh we can’t give you an appointment now until*
47
48 609 *October”. That was 10 months. Now if your consultant says 6 [months] and it’s 10 and*
49
50 610 *something’s gone wrong with your vision in between, you have no way of telling.” F2*
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52 611

Portsmouth 2

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1
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3 614 **Patient recommendations**
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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

625

626

627

1
2
3 628 **Discussion**
4 629
5 630

6 631 Data from this study supports evidence from elsewhere that patients find VF testing more
7
8 632 laborious and demanding than other vision tests²⁰. Nevertheless, patients were willing to
9
10 633 complete more VF tests on the guidance of their clinician, as ultimately they were prepared to
11
12 634 do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF
13
14 635 testing during the first two years of their follow-up care as recommended by the research
15
16 636 literature^{4 5} and some clinical guidelines²⁴. Patients commented that it took time to feel
17
18 637 comfortable with the test procedure, and that multiple attempts were needed to gain an
19
20 638 accurate representation of their vision. These viewpoints complement existing evidence
21
22 639 showing that performance can improve considerably during follow-up due to gaining
23
24 640 experience with the testing process²⁵.
25
26
27

28 641
29
30 642 There were, however, a number of additional themes that emerged from the data which
31
32 643 identified areas that could represent potential barriers to successful glaucoma monitoring.
33
34 644 Patients felt that the environment in which they completed the VF test was linked to how well
35
36 645 they were able to perform the task, with staff members talking loudly, the number of people in
37
38 646 the room, and the time of day all listed as important interfering factors. These views coincide
39
40 647 with other evidence showing that the environment, the technician and the time of day do have
41
42 648 a significant influence on measurement variability from VF tests²⁶. Fatigue, a topic mentioned
43
44 649 frequently throughout the discussions, has also been shown to affect performance as test
45
46 650 duration increases²⁷.
47
48
49

50 651
51
52 652 Patients highlighted the importance of effective task communication for influencing their VF
53
54 653 test performance. Prior evidence has shown that the quality of instruction given before the VF
55
56 654 test can significantly affect subsequent estimations of VF defect severity^{28 29}. Patients also felt
57
58
59
60

1
2
3 655 that it was essential to have the task explained to them properly, even if they had been
4
5 656 attending clinics for some time. Having a staff member in the room whilst they carried out the
6
7 657 test was found to be reassuring. These findings reiterate the idea that ensuring that the task
8
9 658 demands are communicated clearly and effectively before every VF test, and being on hand to
10
11 659 alleviate any concerns or questions that the patient may have, may help maximise the quality
12
13 660 of the data gained from the assessment²⁹⁻³¹.

14
15
16 661

17
18 662 Other discussion points relating to communication were also raised repeatedly throughout the
19
20 663 focus groups. Patients felt that many clinicians treated them as an ‘eye’ rather than a person,
21
22 664 with those staff members who took a more individualistic and empathic approach viewed
23
24 665 favourably. Notably, patients felt that they had to ask explicitly about their results in order to
25
26 666 learn details about their own condition. Evidence has shown that that the patient and
27
28 667 clinician’s views of their condition are not always aligned, which may be due to
29
30 668 miscommunication or misinterpretation of key information on both parts³². By explaining the
31
32 669 results in a clear, simple and concise manner, the patient will inevitably improve their
33
34 670 understanding of their condition, which in turn could influence how well they respond to
35
36 671 important aspects of their follow-up care. For instance, it has been shown that the way in
37
38 672 which clinicians communicate with the patient can influence future adherence to
39
40 673 medication³². It has been suggested that clinicians underestimate the importance of effective

41
42
43 674 communication to the patient¹¹, and in one study examining patient expectations for eye care,
44
45 675 the emphasised areas were all related to communication and interpersonal manner³³.

46
47
48 676 Providing better information about the purpose of VF testing, what is required of the patient,
49
50 677 and their results and general prognosis could be vital for improving attendance for VF tests or
51
52 678 for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about
53
54 679 ways in which the complex measurement of the VF could be easily presented and
55
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1
2
3 680 communicated to patients. It is important to note that some patients associated more frequent
4
5 681 testing with worsening vision, which caused some distress. Thus, should patients require more
6
7 682 frequent tests at some point in their care, it is also vital to involve the patient and explain
8
9 683 reasons for the decision.
10

11
12 684

13
14 685 Excessive waiting times and difficulty booking appointments were also major concerns. In
15
16 686 particular, patients worried that appointment cancellations could extend the interval between
17
18 687 tests beyond what was recommended by the clinician, therefore leaving them exposed to
19
20 688 undetected disease progression. It is known that whilst clinicians select appropriate
21
22 689 monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate
23
24 690 follow-up^{7 34 35}. Moreover, it was typical for patients to wait at the clinic for hours in order to
25
26 691 complete multiple vision tests, causing frustration and tiredness which some perceived to
27
28 692 influence their subsequent performance. Potential solutions could involve conducting only the
29
30 693 VF test during short independent appointment slots, or carrying out tests at a more convenient
31
32 694 location. However, such strategies would involve further investigation as to their overall cost-
33
34 695 effectiveness and should address other associated practicalities such as travel (a significant
35
36 696 contributor to total patient costs³⁶) and the information trail back to the hospital.
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41 697

42
43 698 Previous research has relied on statistical analysis or computer simulations to help determine
44
45 699 the most effective VF monitoring strategies for patients with glaucoma. This is the first study
46
47 700 to use qualitative methods to investigate the patient's own perspective on their follow-up.
48
49 701 Studies focusing on the patient's perspective in glaucoma, particularly with regard to the
50
51 702 perceived effects of the disease on their day-to-day activities, have typically relied on
52
53 703 questionnaires¹³. However, questionnaire responses can be restricted by the wording of the
54
55 704 items and provide little opportunity for clarification or elaboration. This study allowed
56
57
58
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60

1
2
3 705 individuals to contextualise their experiences and expand on particular points and themes,
4
5 706 encouraging discussion about topics a certain patient may not have otherwise introduced or
6
7 707 attributed to glaucoma without the encouragement of another¹⁸. The notion of the “expert
8
9
10 708 patient” is beginning to be endorsed with regards to other chronic conditions, with focus
11
12 709 groups demonstrating potential as a forum for the development of more effective management
13
14 710 strategies³⁷⁻³⁹. Furthermore, patient groups have aided the development of health education
15
16 711 programmes for age-related macular degeneration⁴⁰. A systematic review of patient centred
17
18 712 randomised controlled trials suggests there may be some benefits associated with involving
19
20
21 713 patients with chronic disease in programmes geared towards better educating service users
22
23 714 and devising general training for health professionals⁴¹. Future work that encourages more
24
25 715 patient involvement may therefore help devise the optimal strategies for glaucoma follow-up
26
27 716 and also help better inform both patients and health professionals about the condition.
28
29
30 717

31
32 718 This study has its limitations with findings attached to the viewpoints of the groups who took
33
34 719 part. Efforts were taken to reduce bias by involving multiple research sites- however, these
35
36 720 were all geographically limited to the South of England and (excluding the London groups)
37
38 721 involved patients of Caucasian ethnicity. Therefore the findings may not necessarily translate
39
40 722 to a wider population. Moreover, initial patient selection was made on recommendation of
41
42 723 consultants at the clinics and our selection process did not monitor reasons for non-
43
44 724 participation. People who choose to volunteer for focus groups are likely to be articulate and
45
46 725 confident; they may also be more motivated to take part due to having more severe disease or
47
48 726 holding strong opinions about a certain area of their care. Furthermore, participants were aged
49
50 727 60 years and older- younger service-users may have differing views and experiences that also
51
52 728 warrant investigation. The study was initially designed to involve 6 focus groups across 3
53
54
55
56 729 locations and so no direct decision was taken to cease data collection; however, similar
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1
2
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.
16
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19
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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39 746

40 747

41 748 **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
54
55 756 waiting times and appointment booking. Some patients also expressed particular concerns
56
57
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1
2
3 757 about the VF technology used and the quality of test instructions. Anxiety associated with
4
5 758 increased testing in the absence of clinical explanation was another theme. Ensuring that
6
7 759 glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the
8
9
10 760 confidence and cooperation of the patient. Addressing some or all of the perceived barriers
11
12 761 highlighted in this study should help deliver more efficient strategies for VF monitoring in
13
14 762 glaucoma.

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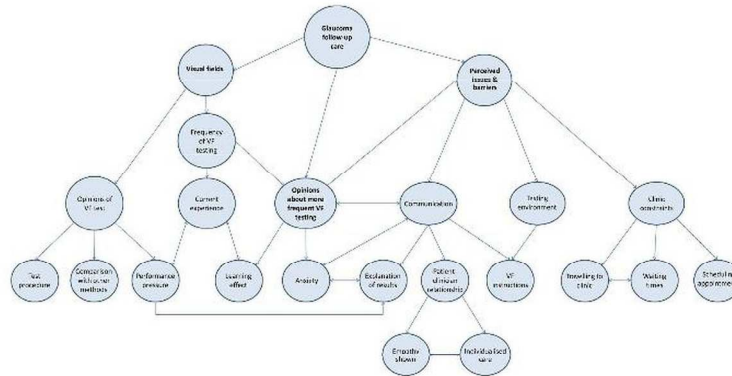
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3 765
4 766
5 767 **References**
6 768
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1. National Institute of Health and Clinical Excellence. CG85 Glaucoma: NICE guideline. In: NICE, editor. *Published Clinical Guidelines*: National Institute of Health and Clinical Excellence, 2009.
2. Burr JM, Mowatt G, Hernández RA, Siddiqui MAR, Cook JA, Lourenco T, et al. The clinical effectiveness and cost-effectiveness of screening for open angle glaucoma: a systematic review and economic evaluation. *Health Technology Assessment* 2007;11(41):1-190.
3. Heijl A, Bengtsson B, Hyman L, Leske MC. Natural history of open-angle glaucoma S0161-6420(09)00670-8 [pii] 10.1016/j.ophtha.2009.06.042. *Ophthalmology* 2009;116 [http://www.ncbi.nlm.nih.gov/pubmed/19854514\(12\):2271-6](http://www.ncbi.nlm.nih.gov/pubmed/19854514(12):2271-6).
4. Chauhan BC, Garway-Heath DF, Goni FJ, Rossetti L, Bengtsson B, Viswanathan AC, et al. Practical recommendations for measuring rates of visual field change in glaucoma. *Br J Ophthalmol* 2008;92(4):569-73.
5. Gardiner SK, Crabb DP. Frequency of testing for detecting visual field progression. *Br J Ophthalmol* 2002;86(5):560-4.
6. Crabb DP, Garway-Heath DF. Intervals between visual field tests when monitoring the glaucomatous patient: wait-and-see approach. *Invest Ophthalmol Vis Sci* 2012;53(6):2770-6.
7. Fung SS, Lemer C, Russell RA, Malik R, Crabb DP. Are practical recommendations practiced? A national multi-centre cross-sectional study on frequency of visual field testing in glaucoma. *British Journal of Ophthalmology* 2013.
8. Malik R, Baker H, Russell RA, Crabb DP. A survey of attitudes of glaucoma subspecialists in England and Wales to visual field test intervals in relation to NICE guidelines. *BMJ open* 2013;3(5).
9. Lacy NL, Paulman A, Reuter MD, Lovejoy B. Why We Don't Come: Patient Perceptions on No-Shows. *The Annals of Family Medicine* 2004;2(6):541-45.
10. Owsley C, McGwin G, Scilley K, Girkin CA, Phillips JM, Searcey K. Perceived Barriers to Care and Attitudes about Vision and Eye Care: Focus Groups with Older African Americans and Eye Care Providers. *Investigative Ophthalmology & Visual Science* 2006;47(7):2797-802.
11. Laine C, Davidoff F, Lewis CE, Nelson EC, Nelson E, Kessler RC, et al. Important Elements of Outpatient Care: A Comparison of Patients' and Physicians' Opinions. *Annals of Internal Medicine* 1996;125(8):640-45.
12. Brown GC, Brown MM, Sharma S. Difference between ophthalmologists' and patients' perceptions of quality of life associated with age-related macular degeneration. *Can J Ophthalmol* 2000;35(3):127-33.
13. Glen FC, Crabb DP, Garway-Heath DF. The direction of research into visual disability and quality of life in glaucoma. *BMC Ophthalmology* 2011;11(1):19.
14. Ormel J, Kempen GI, Penninx BW, Brilman EI, Beekman AT, van Sonderen E. Chronic medical conditions and mental health in older people: disability and psychosocial resources mediate specific mental health effects. *Psychol Med* 1997;27(5):1065-77.
15. Friedman SM, Munoz B, Rubin GS, West SK, Bandeen-Roche K, Fried LP. Characteristics of discrepancies between self-reported visual function and measured reading speed. Salisbury Eye Evaluation Project Team. *Invest Ophthalmol Vis Sci* 1999;40(5):858-64.

- 1
2
3 815 16. Kitzinger J. Qualitative Research: Introducing focus groups. *Bmj* 1995;311(7000):299-
4 816 302.
- 5 817 17. Lacey J, Cate H, Broadway D. Barriers to adherence with glaucoma medications: a
6 818 qualitative research study. *Eye* 2008;23(4):924-32.
- 7 819 18. Green J, Siddall H, Murdoch I. Learning to live with glaucoma: a qualitative study of
8 820 diagnosis and the impact of sight loss. *Soc Sci Med* 2002;55(2):257-67.
- 9 821 19. Prior M, Francis JJ, Azuara-Blanco A, Anand N, Burr JM. Why do people present late
10 822 with advanced glaucoma? A qualitative interview study. *British Journal of*
11 823 *Ophthalmology* 2013;bjophthalmol-2013-303813.
- 12 824 20. Gardiner SK, Demirel S. Assessment of Patient Opinions of Different Clinical Tests Used
13 825 in the Management of Glaucoma. *Ophthalmology* 2008;115(12):2127-31.
- 14 826 21. Patel D, Baker H, Murdoch I. Barriers to uptake of eye care services by the Indian
15 827 population living in Ealing, west London. *Health Education Journal* 2006;65(3):267-
16 828 76.
- 17 829 22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
18 830 (COREQ): a 32-item checklist for interviews and focus groups. *International Journal*
19 831 *for Quality in Health Care* 2007;19(6):349-57.
- 20 832 23. Pope C, Ziebland S, Mays N. Qualitative research in health care: Analysing qualitative
21 833 data. *BMJ: British Medical Journal* 2000;320(7227):114.
- 22 834 24. European Glaucoma Society. *Terminology and guidelines for glaucoma*. 3rd edition ed:
23 835 Savona, Italy Editrice Dogma 2008, 2008.
- 24 836 25. Wild JM, Searle AET, Dengler-Harles M, O'Neill EC. Long-term follow-up of baseline
25 837 learning and fatigue effects in the automated perimetry of glaucoma and ocular
26 838 hypertensive patients. *Acta Ophthalmologica* 1991;69(2):210-16.
- 27 839 26. Junoy Montolio FG, Wesselink C, Gordijn M, Jansonius NM. Factors that influence
28 840 standard automated perimetry test results in glaucoma: test reliability, technician
29 841 experience, time of day, and season. *Investigative ophthalmology & visual science*
30 842 2012;53(11):7010-7.
- 31 843 27. Henson DB, Emuh T. Monitoring Vigilance during Perimetry by Using Pupillography.
32 844 *Investigative Ophthalmology & Visual Science* 2010;51(7):3540-43.
- 33 845 28. Kutzko KE, Brito CF, Wall M. Effect of instructions on conventional automated
34 846 perimetry. *Invest Ophthalmol Vis Sci* 2000;41(7):2006-13.
- 35 847 29. Sherafat H, Spry PGD, Waldock A, Sparrow JM, Diamond JP. Effect of a patient training
36 848 video on visual field test reliability. *British Journal of Ophthalmology*
37 849 2003;87(2):153-56.
- 38 850 30. Heijl A, Asman P. Pitfalls of automated perimetry in glaucoma diagnosis. *Curr Opin*
39 851 *Ophthalmol* 1995;6(2):46-51.
- 40 852 31. Van Coevorden RE, Mills RP, Chen YY, Barnebey HS. Continuous visual field test
41 853 supervision may not always be necessary. *Ophthalmology* 1999;106(1):178-81.
- 42 854 32. Friedman DS, Hahn SR, Quigley HA, Kotak S, Kim E, Onofrey M, et al. Doctor-patient
43 855 communication in glaucoma care: analysis of videotaped encounters in community-
44 856 based office practice. *Ophthalmology* 2009;116(12):2277-85 e1-3.
- 45 857 33. Dawn AG, Santiago-Turla C, Lee PP. Patient expectations regarding eye care: Focus
46 858 group results. *Archives of ophthalmology* 2003;121(6):762-68.
- 47 859 34. Tatham A, Murdoch I. The effect of appointment rescheduling on monitoring interval and
48 860 patient attendance in the glaucoma outpatient clinic. *Eye (Lond)* 2012;26(5):729-33.
- 49 861 35. Agency NPS. Preventing delay to follow-up for patients with glaucoma. Rapid Response
50 862 Report, 2009.
- 51 863 36. Sharma A, Jofre-Bonet M, Panca M, Lawrenson J, Murdoch I. Hospital-based glaucoma
52 864 clinics: what are the costs to patients? *Eye* 2009;24(6):999-1005.

- 1
2
3 865 37. Wilson PM, Kendall S, Brooks F. The Expert Patients Programme: a paradox of patient
4 866 empowerment and medical dominance. *Health & social care in the community*
5 867 2007;15(5):426-38.
6 868 38. Holman H, Lorig K. Patients as partners in managing chronic disease: partnership is a
7 869 prerequisite for effective and efficient health care. *BMJ: British Medical Journal*
8 870 2000;320(7234):526.
9 871 39. Holman H, Lorig K. Patient self-management: a key to effectiveness and efficiency in
10 872 care of chronic disease. *Public health reports* 2004;119(3):239.
11 873 40. Dahlin-Ivanoff S, Klepp K, Sjöstrand J. Development of a health education programme
12 874 for elderly with age-related macular degeneration: a focus group study. *Patient*
13 875 *Education and Counseling* 1998;34(1):63-73.
14 876 41. McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, et al. Patient-Centered
15 877 Approaches to Health Care: A Systematic Review of Randomized Controlled Trials.
16 878 *Medical Care Research and Review* 2013;70(6):567-96.
17 879 42. Carlsen B, Glenton C. What about N? A methodological study of sample-size reporting in
18 880 focus group studies. *BMC medical research methodology* 2011;11(1):26.
19 881
20 882
21
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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)

review only