

ORIGINAL ARTICLE

Autism-friendly eyecare: Developing recommendations for service providers based on the experiences of autistic adults

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Funding information

This work was supported by the Wellcome Trust [209741/Z/17/Z]. The publication of this article was funded by The University of Manchester.

Abstract

Purpose: Autistic people face significant barriers when accessing healthcare services. Eye examinations present unique challenges. Accessibility of this healthcare sector for autistic people has not been investigated previously. The aim of this research was to investigate eye examination accessibility for autistic adults and produce recommendations for autism-friendly eyecare.

Methods: Two qualitative studies were conducted. In Study 1, 18 autistic adults took part in focus groups to elicit their eye examination experiences. Transcripts of the recorded discussions were thematically analysed. Study 1 findings were used to design autism-friendly eye examinations for autistic adults. These were conducted in Study 2. Twenty-four autistic adults participated in these examinations, during which they were interviewed about their experience and how it might be improved by reasonable modifications. Audio recordings of the interviews were content analysed.

Results: Knowledge of what to expect, in advance of the eye examination, could greatly reduce anxiety. Participants liked the logical structure of the examination, and the interesting instrumentation used. However, the examination and practice environment did include sensory challenges, due to lights, sound and touch. Changes in practice layout, and interacting with multiple staff members, was anxiety provoking. Participants expressed a need for thorough explanations from the optometrist that outlined the significance of each test, and what the patient was expected to do.

Conclusion: A number of accessibility barriers were identified. These suggested that UK eye examinations are not very accessible for autistic adults. Barriers began at the point of booking the appointment and continued through to the dispensing of spectacles. These caused anxiety and stress for this population, but could be reduced with easy-to-implement adaptations. Based on the findings, recommendations are presented here for the whole eyecare team which suggest how more autism-friendly eye examinations can be provided.

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INTRODUCTION

Autism is a lifelong neurodevelopmental condition, affecting an individual's social interaction, communication and behaviour. The majority of autistic individuals also experience altered sensory reactivity,¹ such as a heightened (hyper-) or dampened (hypo-) sensitivity to stimuli, and exhibit sensory seeking behaviours.² These key features form part of the UK diagnostic criteria, which are laid out in the International Statistical Classification of Diseases (ICD-11)³ and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).⁴ Approximately 1.1% of adults⁵ and 1.57% of children⁶ are recorded as being autistic in the UK, although these estimates are likely to be low due to under-diagnosis in adults,⁷ females⁸ and ethnic minority groups.⁹

Multiple studies have found various physical and mental health conditions to be significantly more common amongst autistic people relative to non-autistic individuals.¹⁰⁻¹² Research has concluded that autistic children and young adults are 11 times more likely,¹³ and autistic adults five times more likely¹⁴ to develop poor health compared to the general population. Considering this, it is not surprising that autistic individuals are more likely to access healthcare services.¹⁵⁻¹⁸

Specific to vision, there is limited research reporting investigations of eye conditions in autistic individuals. A review of studies by Gowen et al.¹⁹ concluded that autistic individuals are at greater risk of developing ophthalmic abnormalities such as refractive error, strabismus and amblyopia, but noted the upper limit of age investigated in these studies was 20 years. The majority of studies included only children and adolescents. Without any relevant studies, it is only possible to speculate on the ocular health and vision status of autistic adults. Nevertheless, it would not be unreasonable to assume, based on the currently available findings, that autistic adults require greater ophthalmic attention and would be more likely to visit an optometrist.

Unfortunately, no research exists regarding accessibility of optometric services for autistic adults. On the other hand, research has investigated the eye testability of autistic children.²⁰ Resources are available to improve the accessibility of eyecare for autistic children and autistic people with learning disabilities.^{21,22} Furthermore, The College of Optometrists²³ has recently provided guidance for optometrists when seeing patients with autism. However, these largely focus on what would take place in the testing room and are mostly based on reports of vision care provided to autistic children.

Studies have been conducted concerning general accessibility of healthcare for autistic adults,^{15,24,25} although few of these have involved UK participants. Using a community based, participatory approach, survey studies have found autistic adults report poor patient-provider communication, fear and anxiety, difficulty having a real-time conversation with healthcare professionals, cost and sensory issues as the most significant barriers to accessing healthcare, compared to non-autistic individuals.^{26,27} In

Key points

- Adults with autism face challenges when accessing healthcare services. The current work identifies a number of barriers when attending an eye examination.
- All aspects of an eye examination - from booking the appointment, to encountering multiple practice staff and eye tests and finally the spectacle dispensing - can present difficulties for adults with autism.
- Based on the experiences and feedback of adults with autism, a set of recommendations for eyecare providers on how they can deliver autism-friendly eyecare are presented.

a longitudinal survey study conducted by Vogan et al.,²⁸ autistic adults reported not knowing where to find help, feeling overwhelmed with the steps to seek help, having difficulties describing problems and needs and negative experiences with professional help as the top four barriers to accessing healthcare.

Few studies have qualitatively investigated the barriers to healthcare that autistic individuals experience. Those reported have not focused on any specific healthcare specialty. Nicolaidis et al.²⁹ conducted semi-structured interviews, in person and online, with autistic adults and individuals who support autistic people. Factors which differentiated a positive or negative healthcare experience included the design of the healthcare system and its impact on accessibility, autism-related difficulties faced by the patient and autism-awareness and adaptability of the provider. Dern and Sappok³⁰ reported the outcomes of face-to-face and online discussions between autistic adults and autism professionals. These highlighted difficulties in a number of key areas: making appointments, the waiting area, undergoing the examination, communication, hospital visits and sensory experiences. Examples included feeling stressed due to the uncertainty of what may happen during the appointment, feeling overwhelmed due to sensory over stimulation from bright lights or noises, having a lack of time to think and respond to questions and feeling anxious when meeting unfamiliar staff. Finally, as part of a study to address medical needs of autistic adults, Saqr et al.³¹ conducted a focus group with autistic adults. The overall aspects which caused stress for an autistic adult during a clinical appointment were sensory sensitivities, anxiety from waiting and a lack of mutual understanding, communication and trust between the practitioner and patient. Although participants reported stress-causing issues beginning at home and continuing during their journey to and from the clinic, the greatest stress was experienced at the clinic itself.

Whilst some of these findings could be expected to apply to optometry services, there are certain key differences between optometric practice and other healthcare specialities. For example, the retail environment of many practices and the multitude of tests conducted during an eye examination may create unique challenges. The research team in the current studies aimed to provide a detailed description of the barriers and facilitators to accessing optometry services for autistic adults without learning disabilities, who make up approximately two-thirds of autistic individuals.³² In the first study, focus groups were conducted with autistic adults to gain an understanding of their experiences of an eye examination. This included the full journey from booking the appointment, travelling to the practice, undergoing the examination and being dispensed new spectacles. For the second study, thorough eye examinations were provided to autistic adults without learning disabilities at The University of Manchester. Building on the focus group learnings of Study 1, one-to-one interviews were conducted with the participants during the eye examinations. These explored the positive and negative experiences associated with the different tests as well as what improvements could create a more positive experience. The combined aim of these studies was to gather a wealth of first-hand information so that recommendations could be created for optometric service providers on how to provide 'autism-friendly' services (see section: 'Providing autism-friendly eyecare: Recommendations for eyecare providers').

The research team was comprised of KRP, a PhD student with training in qualitative methods and practicing optometrist by profession; EG, a researcher in the field of sensory perception and motor control in autism; CMD, a professor of clinical optometry with a specialist interest in helping those with uncorrectable visual impairment; and CSP, a senior lecturer in optometry as well as practicing optometrist with a specialist interest in binocular vision. The design and procedure of these studies were developed in collaboration with the Autism@Manchester Expert by Experience Advisory Group (autism.manchester.ac.uk). The research team worked closely with two adult autistic advisors (PB and JP) who ensured that an appropriate, autism-friendly protocol would be created for these studies.

STUDY 1: METHODS

Recruitment and participants

An advertisement was publicised by email and social media using the Autism@Manchester network, local autism groups and the university platforms. Flyers were displayed around the university campus and handed out at autism events. Inclusion criteria were: formal diagnosis of autism (confirmed with visual inspection of diagnosis letter), absence of a learning disability, being 18 years or older

(no upper age limit), being able to travel to the university and being available to attend one of the specified focus group sessions.

An opportunity sample was recruited for this study. Although 27 participants signed up to a focus group session, nine did not attend. A total of 18 autistic adults took part, aged 25–67 years (mean age 47.1 years), of which six were female. All had a formal diagnosis of an autism spectrum condition (autism/Asperger's syndrome/autism spectrum condition [ASC]), were from the north of England and had previously visited an optometrist.

This study received ethical approval from The University of Manchester's Research Ethics Committee (2019-6025-9932) and participants provided written informed consent.

Study procedure

Four focus groups were held, each with four to six participants. Prior to attending, participants were sent a 'what to expect during the study' document ([Supporting Information 1](#)) to help them prepare for their visit. Upon arrival, they were taken to the focus group room and offered refreshments whilst written consent was taken. They then completed a questionnaire which collected basic demographic information. Focus groups were facilitated by KRP who followed a schedule ([Supporting Information 2](#)). Another member of the research team (EG or CMD) assisted with the sessions. Sessions ran for one to two hours, excluding a short break midway.

In line with recommendations from Durand and Chantler,³³ four key questions were presented to the groups. The final question is explored in this paper: "What are your experiences of an eye examination?" Participants were prompted to think about both positive and negative experiences at each individual stage of an eye examination.

The remaining questions, (Q1) "Does anybody feel they experience any visual issues or unusual visual symptoms?"; (Q2) "Do you feel you can do anything to improve these symptoms" and (Q3) "How do your visual issues impact your daily routine?", are discussed in another article about autistic visual sensory experiences.³⁴

Data analysis

The focus groups were audio recorded and transcribed, with participants pseudonymised, by an external university approved service for intelligent verbatim transcription. Transcripts were thematically analysed to collate the broad range of data into meaningful themes. Compared to other qualitative analysis methods, thematic analysis allows data sets to be richly described as a whole, providing more depth than just summarising data.^{35,36} The analysis was exploratory. The research student (KRP) took an inductive, semantic and realist approach from the perspective of a non-autistic optometrist.

The Braun and Clarke six-step technique³⁵ was followed. This framework is flexible and can easily be applied to a variety of research questions. Firstly, the accuracy of each transcript was checked against the original recordings. The research student familiarised himself with the data by re-reading through the transcripts whilst making notes of key ideas. The second phase involved re-reading and line-by-line coding of the transcripts to identify data features (words, sentences or paragraphs) related to the scope of the study. This was done by hand and codes were written on sticky notes.

In the third phase, codes were grouped to form initial themes. As per the recommendations of Braun and Clarke,³⁵ a thematic map was created by arranging the sticky notes according to similarity in content or ideas. This allowed the research student to visualise the formation of higher-level themes. These three stages were followed for each transcript. Moderate alterations were made to the thematic map as more transcripts were analysed.

The fourth phase reviewed the themes against the dataset as a whole. The themes and codes were discussed amongst the research team (KRP, CMD, CSP and EG). This enhanced the rigour of the analysis and ensured valid interpretation of data. The team agreed that the codes summarised relevant aspects of the data; however, some themes could be grouped together as they were (a) very small and (b) closely related. The thematic map was reorganised according to these modifications (Table 1).

Themes were appropriately named and given a short definition in the fifth phase. A detailed analysis of each theme showed many were complex or large. This led to the allocation of sub-themes. The final phase connected themes to supporting data in a report. Appropriate quotes were chosen from the dataset to justify the research findings (Study 1 results).

TABLE 1 The four allocated themes and their respective sub-themes

Theme	Sub-themes
1. Practice operation	Practice accessibility Problems with the patient journey Limited methods to book appointments
2. Eye examination-specific considerations	Inadequate communication Test-specific concerns
3. Patient-practitioner relationship	The importance of establishing a good rapport Maintaining practitioner continuity across visits
4. Preparing the patient for their visit	

STUDY 1: RESULTS

Four themes were allocated to the data arising from Q4. These are listed in Table 1 together with corresponding sub-themes.

These themes are now described in further detail. Participants are referred to by a number (P1-18). It should be noted that optometrists are commonly referred to as 'opticians' in the UK. Some participant quotes may use this lay term.

Theme 1: Practice operation

Practice accessibility

All focus groups expressed an anxiety associated with visiting optometric practices and undergoing an eye examination. In fact, "...to even approach the building, the stress of that, 110% outweighs the stress of where I have to go, what I have to do" (P12). Enquiring about accessibility requirements was important to our participants. Most participants found that "...there's never any mention of accessibility... They don't ask if you have any needs or anything" (P3).

Participants recognised that optometric practices each "...have different ideas of how to lay out their spaces" (P18), but advocated that practice layout was important when considering accessibility for autistic patients. Generally, changes to layout were noted as "unsettling" (P13) and anxiety-inducing, due to unfamiliarity. Altered sensory reactivity meant lighting and reflections from displayed spectacles made it difficult for some participants to even enter practices because "the display area for the glasses is usually at the front" (P8).

Accessibility was likewise influenced by the practice environment; participants pointed out that smaller and less busy practices were preferred:

...I'm going to a private optician, a very small one, and it was brilliant because I was the only person in the shop. They looked after me and it was a much more pleasant experience.

(P4)

Many participants indicated that this preference was because they received a more personal service and it was audibly quieter; "...it's one-to-one. But there's not the lots of people babbling...it's not the same sound issues as you would [face] in say, well, any other kind of medical [setting]..." (P8). Other participants expressed that less people present in the practice was encouraging as opposed to larger, busier practices which are "...always packed out with people" (P4).

The retail environment created around optometry practice, specifically "pressure selling" (P6) and the offer of too many optional extras, was stress-inducing for our participants; "...it's the choices that drive me mad..."

Absolutely hate it" (P5). Participants expressed that staff members should be sensitive to the fact that autistic individuals can become easily overwhelmed. They noted staff should not constantly 'attend' to them as expressed by P12:

... The woman is standing there staring at me while I'm trying to choose these specs. Well, anything that overloads my head, my brain just shuts down then ... I have to take my wife everywhere and she has to tell them to go away.

Such experiences as well as the anxiety caused by having to "interact with people" (P2) led some participants to order their spectacles online.

Problems with the patient journey

Participants expressed discomfort with having to encounter multiple staff members. This was because it took time for their anxiety to reduce around 'strangers' and "...just as you get used to someone, you think they seem alright, they just disappear...then someone else comes in" (P6). P11 said,

... You talk to someone and then you talk to someone else, and then you go and have like the pre-exam... And then you go and see the optician who's someone else. And then you speak to the salesperson. So yeah, I find that very difficult. And I knew it was going to be like that, so I did put it off as long as I could.

This type of patient journey is typical of many optometric practices. Participants expressed negative views on this system, feeling that "...it's like a conveyor belt..." (P18). This could result in them avoiding regular eye examinations. P18 described this experience as similar to "...a pinball...bouncing around from one to the other" and P6 said, "...you're part of some cattle production line. I find it very dehumanising."

Additionally, participants suggested that continuity of the room was important. Changing rooms during the eye examination was anxiety-provoking. P3 said that having to visit multiple rooms during a visit to an optometric practice "...would be an absolute nightmare."

Limited methods to book appointments

Participants understood that the most common method to booking appointments was over the phone, but emphasised that they were "...really uncomfortable on the phone..." (P16). P14's explanation captured the groups' thoughts, "...I don't phone people I don't know and I can't

predict..." explaining why some participants put off booking important appointments until it was unavoidable or they could "...get somebody else to do it" (P14). This also impacted participants' family members:

My children have had optician reminders for months. One of my children's been nagging me non-stop to get hers done. ...I won't phone ... It would have to be some kind of emergency for me to do that.

(P14)

P18 booked appointments in person, and shared "...I write down what days I'm available, what times I'm available, and I say, I need an eye appointment, there's the information, fit me in somewhere around that." This ensured the conversation with a 'stranger' was kept short, minimising stress.

The availability of an online 'self-service' system through which individuals can manage their appointment booking themselves was preferred by the participants. P5 described such a service as "...absolutely brilliant" and P10 said, "if I can book online then I don't avoid making appointments for four months..."

Booking appointments by email enabled participants to refer back to communication trails. This was "...reassuring, and settling" (P16). Participants preferred appointment reminders in the form of letters, text messages or emails, as opposed to phone calls.

Theme 2: Eye examination specific considerations

Inadequate communication

Participants overwhelmingly agreed that communication on the part of the optometrist should be improved. Generally, participants said that optometrists needed to speak slowly so that they "...can understand what they're saying" (P12). They should also be careful not to be patronising. P12 said, "...if they speak quickly, they might as well not bother."

During the eye examination, participants wanted to be well-informed about each step. P3 said, "...not telling someone what's going to happen is the thing that I haven't liked." Some participants did not understand the importance of certain tests. They questioned why they should be conducted if a "...machine's already done it" (P6). Participants expressed that it was "essential" (P15) for optometrists to tell them explicitly what test was going to be conducted, why it was being conducted and what it would involve. They agreed that this would reduce anxiety associated with not knowing what will happen next. P15 clarified that the issue was "...the actual suddenness that makes me shake, physically shake", not the tests themselves. More than reassurance, participants wanted information and "...

as much as possible" (P14). In addition, an estimate of how much time was required for an eye examination was appreciated by the participants; "...a bit of a countdown would be something that would be quite handy" (P18) and reduce anxiety.

Participants explained that optometrists' questioning techniques needed to be "more specific" (P10). Optometrists should be aware of whether their questions have been fully understood by the patient. P10 said, "I don't want to anticipate, but I wish the language was more concrete....don't ask me what's better, ask me is it supposed to be sharper or brighter or something." Optometrists should tell patients exactly what they should be judging during subjective tests, particularly when they might expect to notice no improvement/ difference. Not having this clarity made P13 feel, "I'm obviously doing something wrong because I can't see the difference."

Some participants commented on coming away from an eye examination feeling doubtful. This was the result of an insufficient explanation of the examination outcomes. P9 described this as "frustrating". On the other hand, P10, who had their queries thoroughly investigated followed by a detailed explanation, said, "now I've got the information, I'm not anxious about it anymore...And it's a tiny little adjustment from their end, but it lowers my anxiety on a day-to-day basis."

Test-specific concerns

Many participants reported that "in a lot of ways an eye test is a nice experience to go through" (P10) because of the gadgets and equipment used, and the examination's uniform structure. Some participants described eye examinations as a very distressing experience; P13 expressed, "I actually feel like I want to cry sometimes because I've had to work so hard."

Certain tests or test conditions were frequently described as extremely unpleasant. As mentioned in the previous sub-theme, tests which involved a sudden occurrence caused great anxiety. In particular, non-contact tonometry, or the 'air-puff test,' was very unpopular. Some tests provoked sensory experiences, such as those involving a bright flash of light. P8 described difficulty with practitioners instilling drops into their eyes and said, "...because of touch sensitivity I can't stand someone else doing it." Strong scents, such as practitioners wearing strong perfumes, caused difficulty for some participants. They had to work really hard to overcome the smell to attend to the tests. Tests requiring close proximity, such as direct ophthalmoscopy, made participants feel uncomfortable, for some "...beyond uncomfortable..." (P16). P11 added that they feel "...trapped behind equipment."

Greater concerns were linked to subjective tests. Participants described these as "...the hardest part of the

examination..." (P17) and that they "...get mentally tired with all the questions" (P11). Participants expressed feeling under pressure when answering questions. P6 said, "...I feel like I'm making the prescription worse" by answering questions incorrectly. P1 said, "...I'm always giving them the wrong answer probably", because they could not remember what was being compared. Making choices between lenses was particularly difficult. P11 explained that autistic people can become very overwhelmed if they have to answer too many questions. They will reach a point where they cannot answer anymore.

Participants suggested allowing more time for their examinations. This would allow them to take their time answering questions and not feel rushed. Additionally, allowing them to partly dictate the pace of the examination would improve the productivity. P4 said, "I have to say to them, slow down a bit. Or I'll say can you show me that again?...Sometimes you've just got to take control of the situation."

Theme 3: Patient-practitioner relationship

The importance of establishing a good rapport

For participants, the relationship that they established with the practitioner strongly influenced the accessibility of the eye examination and how comfortable they felt. This was well summarised by P12, who said, "...the interpersonal interaction greatly outweighs anything I have to do inside..." P8 felt that optometrists "...are a lot more accommodating in terms of practicality." Others felt optometrists need to adapt to make the eye examination a good experience.

Participants suggested simple steps to enable optometrists to develop a good rapport. P3 advised that practitioners should at least introduce themselves and P6 explained, "...if the optician straight away has been quite friendly to start with, I feel more comfortable. So, they can come into my space more..." When asked what builds their trust in the optometrist, P3 said, "They're friendly and they listen and they understand that I can find it difficult. And they reassure me a lot as well."

Maintaining practitioner continuity across visits

Having established that it took time to get used to new people, participants highlighted the importance of seeing the same optometrist for their regular eye examinations. This affected the rapport with the practitioner as explained by P15, "If it was the same one [optometrist]...for many years...they know you, they're used to you, and you're very confident in them."

Having to see a different practitioner was anxiety provoking for participants. When P13 saw a different optometrist they said, "I had to prepare myself for the fact

that I'd have to sort of build new relationships..." They further clarified, offering an opinion shared by other participants, "...even though I trust them in terms of I think they'll give me the right advice, it's just because I don't really know them."

Theme 4: Preparing the patient for their visit

Knowing what to expect during a visit to the optometrist was helpful for participants and would result in them being less anxious, "...less surprised about it" and having "...a bit more capacity" (P10). As highlighted by P15, "I think I'm so used to going to the opticians, it's not an issue for me". A few participants, who had received eye examinations for many years, already had a good idea of what to expect and did not have the same level of anxiety as others. Since this varies, one should not presume familiarity with the process. Staff should explain to the patient what will happen; "Because we already have glasses, they probably assume that we know what's going to happen" (P3).

Some participants suggested it would be useful for a staff member to explain to them, on arrival, what to expect during the appointment. P17 described their experience:

...they'd [staff at the optometric practice] tell me exactly, right from the onset, right, that's the waiting room, you're going to go through this, then that, then this...that's generally good anyway, but I don't need that anymore.

In regard to receiving the 'what to expect' information sheet for this study ([Supporting Information 1](#)), P1 said, "...I cried because I was pathetically grateful that someone had done this. And I didn't know I needed it until I first saw one." P9 explained, "...if I'm stressed about going to somewhere new I can't process written instructions. My brain just can't work it out. So a picture is miles better..." Including a map on the 'what to expect' document was useful for our participants, but P10 added that directions, information on bus routes and trains, and how to get from the bus stop/ train station to the destination would reduce travel anxiety further.

Some participants also suggested that a 'what to expect' video would be "especially helpful" (P10) to understand the experience more fully. P15 described what they thought would be an ideal video:

...have a friendly optician saying, this is what we do here, and this is where we do it. That would be amazing...and then, this is where you sit while you're waiting for the next test, and the next test is this.

A final suggestion was to offer autistic patients the opportunity to physically visit the practice in advance of their appointment.

PUTTING THE KEY LEARNINGS OF STUDY 1 INTO PRACTICE

Our Study 1 findings suggest that UK eye examinations at present are not very accessible for autistic adults who do not have learning disabilities. To improve this, the eye examination visit should be considered as a whole, rather than confining adaptations to the testing room only. These include alternative methods to book appointments, adaptations to the patient journey, being mindful of the sensory and emotional difficulties an autistic person may face and improving communication and continuity.

To put these findings into practice, a second study was designed³⁷ in which autistic adults without learning disabilities were provided thorough eye examinations. The structure of these implemented the learnings from Study 1, as detailed in the following paragraphs.

Communication with participants took place via email only. Prior to attendance, participants were sent a 'what to expect during the study' document ([Supporting Information 3](#)), which contained images, descriptions and video links of the different tests involved in the eye examination. This allowed them to prepare for the visit by understanding what the examination room looked like, what equipment would be used and how the tests would be conducted. Upon arrival, participants were taken to the eye examination room and had the opportunity to look around. Thereafter, each participant underwent a thorough and full eye examination conducted by KRP. He informed participants of what each test did before conducting it, what the test would involve and if the participant was required to do anything. For example, for pupil assessment KRP would say, "in the next test I will be checking your eyes' reaction to light and I will need to lower the room lights for this. This involves me shining this bright light into your eyes [showing participant pen torch] and your job is to keep looking straight into the distance."

Participants were offered three optional breaks during the examination, with the option to request more. They were also reassured to ask any questions they had at any time during the examination. Concluding the examination, KRP provided a summary of the test findings, and related these to the participants' presenting concerns. Finally, KRP dispensed any spectacles or treatment that was required, in the examination room. Participants were sent away with an information pack, containing their spectacle prescription and any leaflets relevant to their eye health or vision.

Using structured interviews, Study 2 aimed to understand the impact of making these adaptations for autistic adults, and gain further detailed information on what

optometrists should keep in mind when examining an autistic patient.

STUDY 2: METHODS

Recruitment and participants

An advertisement was publicised using the same platforms as Study 1, inviting autistic adults for a full eye examination at The University of Manchester, during which interviews would be conducted. Inclusion criteria were: formal diagnosis of autism (confirmed with visual inspection of a diagnosis letter), absence of a learning disability, being aged 18 years or above (no upper age limit) and being able to travel to The University of Manchester.

An opportunity sample was also recruited for this study. Although 38 participants had signed up to take part, 11 did not progress to arranging a visit, and three were unable to attend on their scheduled visit date. It is important to highlight that participation in this study is likely to have been impacted by the COVID-19 pandemic; the study began pre-pandemic but was halted for approximately 11 months (March 2020–February 2021), before resuming. Finally, a total of 24 autistic adults took part in this study, aged 19–67 years (mean age 43.3 years), of which 14 identified as male, nine as female and one as non-binary. All had a formal diagnosis of an autism spectrum condition (autism/ Asperger's syndrome/ ASC/ autism spectrum disorder [ASD]) and were from north or southeast England.

This study received ethical approval from the NHS Research Ethics Committee (271545) and participants provided written informed consent.

Study procedure

Table 2 presents a list of the tests conducted during the eye examination, in the order they were carried out. Tests were arranged into blocks (Table 2). Participants underwent a structured interview, led by KRP, after each test block in which they were asked three questions using the 'stop, start, continue' feedback approach:

- Q1. Are there any tests that you did not like? Why? (STOP).
- Q2. Was there anything you liked about the way in which these tests were carried out? (CONTINUE).
- Q3. What could have been improved about the ways these tests were conducted? (START).

At the end of the examination, participants were asked if they had accessed the 'what to expect during the study' resources and if/ how they had been helpful. Each

participant underwent up to seven interviews during the examination. In total, this required between 5 and 20 minutes.

Data analysis

The interviews were audio recorded. These were carefully listened to by KRP, who made detailed notes of each conversation with participants pseudonymised. Thereafter, the notes were content analysed, in an exploratory manner, to summarise data into meaningful categories. This technique is a useful descriptive tool,³⁸ supporting analysis for the study's aims and questions which did not require in-depth interpretation of data. This is also why we did not feel transcription was necessary; key points from each participant were manifest in what they said.

The inductive category formation approach³⁹ was used to analyse data. This was appropriate, as it focused only on data relevant to the research question, supported the development of summarising categories and provided a true description of the dataset without being biased.³⁹ To answer the research question – What factors influence eye examination accessibility for autistic adults? – the next step was to formulate a selection criterion to establish what material was relevant from the data: comments associated with the tests/ eye examination process/ optometrist, on what was liked or pleasant, was disliked or unpleasant and could be improved. Additionally, the level of abstraction (that is, how general or specific the categories had to be formulated) was concrete positive and negative experiences and feedback from the participants, related to the examination process.

The next phase involved reading through and coding the detailed notes line-by-line, by hand. Material which fit the selection criterion was either classified into a new category or subsumed under an existing category. After 50% of the data had been analysed, the coding, category system and level of abstraction were checked to ensure they addressed the research question.

Thereafter, the full dataset was analysed and categories were formulated. To improve rigour, KRP discussed these with the research team (EG, CSP and CMD). They critically reviewed the analysis and agreed that the categories were an accurate representation of the participants' feedback.

Categories were appropriately named to reflect the content they represented. Relevant quotes were selected from the dataset to evidence these (see Study 2 Results). As per Mayring,³⁹ it can be appropriate to conduct a frequency analysis of participant responses. The proportion of participants, who made no comments in response to the interview questions (not represented by any category), was calculated (Table 3).

TABLE 2 A list of the tests carried out during the eye examination (in order). These have been grouped into blocks. Participants were presented with the three interview questions after each block

Block	Tests/assessments
1 Preliminary examinations	a. History and symptoms b. Distance and near unaided vision c. Distance and near unaided cover test d. Ocular motility e. Pupil assessment f. Intraocular pressure using iCare
2 Distance vision tests	g. Distance objective and subjective refraction, and visual acuity h. Distance dissociated heterophoria measurement i. Distance associated heterophoria measurement j. Distance prism fusional reserves
3 Near vision tests	k. Amplitude of accommodation l. Nott dynamic retinoscopy (if pre-presbyopic) m. Accommodative facility (if pre-presbyopic) n. Near addition (if presbyopic) and visual acuity o. Near dissociated heterophoria measurement p. Near associated heterophoria measurement q. Stereoacuity r. Near prism fusional reserves s. Near point of convergence
4 Supplementary tests	s. Pattern glare test t. Colour vision assessment using the City University test (Mark 2)
5 Ocular health checks	u. Ocular health assessment v. Visual fields w. Ocular imaging
6 Colorimetry	x. Colorimetry assessment (if required)

TABLE 3 The proportion of participants who made no comments in response to the interview questions, per test block and across all tests (final row)

Test block	% of participants who		
	Did not express any dislikes for the tests (Q1)	Did not identify any likes for the tests (Q2)	Suggested no improvements (Q3)
1	16.7	20.8	83.3
2	54.2	33.3	58.3
3	62.5	37.5	54.2
4	33.3	45.8	66.7
5	54.2	20.8	58.3
6	100.0	75.0	100.0
All tests	0.0	4.2	29.2

STUDY 2: RESULTS

Participants underwent all the tests apart from colorimetry, which was only conducted with four participants. [Table 3](#) reports the proportion of participants who made no comments in response to the interview questions for each test block; the final row shows the proportion

of participants who made no comments across all test blocks.

Nine inductive categories were allocated to the remaining data and are listed in [Table 4](#), according to the question from which they arose.

The remainder of this section describes these indicative categories in further detail, evidenced with participants' quotes. Participants are referred to by a number (A1-24).

TABLE 4 The nine allocated inductive categories, each listed beside the interview question from which they arose

Interview question	Inductive categories
Q1. Are there any tests that you did not like? Why?	1. Provoked sensory experiences 2. Tested concentration 3. Issues with close proximity
Q2. Was there anything you liked about the way in which these tests were carried out?	4. Good communication 5. An interesting process 6. Being aware of patient comfort
Q3. What could have been improved about the ways these tests were conducted?	7. Tips to enhance communication 8. Routine adaptations
Q4. Were the 'what to expect during the study' resources useful?	9. It's useful knowing what to expect

Some participant quotes use the lay term 'optician' to refer to optometrists.

Category 1: Provoked sensory experiences

Many tests induced sensory experiences for participants. These began with those involving bright lights, such as pupil assessment, ocular motility, slit lamp and Maddox Rod. A22 said that the bright pen torch "...made my eyes hurt quite a bit", and A9 described,

I didn't like the ones where you've got bright lights in your eyes like the flash and this machine here [slit lamp]. I sort of had to tense myself to cope with it...it was at the edges of what I could tolerate.

Assessing pattern sensitivity was unpopular amongst the participants as it was "...very unpleasant to look at things like that" (A1) because the test "...gave some effects which were unexpected" (A7). Furthermore, A5 added, "it just made me physically uncomfortable."

Tests which required instruments to physically touch participants, for example the RAF rule or holding the Volk lens close to the eye, were uncomfortable. A13 did not like the sensation of the cold metal bar touching their forehead whilst using the pupilometer, and regarding the Notts rule A6 stated, "because it's a narrower contact area it felt more intrusive." Some participants would have preferred use of a non-contact tonometer over the iCare "...because there isn't a physical thing touching [the eye]" (A6) and it is an obvious rather than irritating sensation. A12 said the iCare felt "...like a little dart that was going into my eye...maybe like a little feather which was about to fly and I had to blink it away."

Category 2: Tested concentration

Participants struggled to avoid distraction and felt "...it was hard concentrating" (A21) for tests which had other targets

around the fixation point. For example, when measuring amplitude of accommodation using the RAF rule, A21 mentioned "...I found the words underneath [the N5 print line] too distracting 'cos my eye is generally drawn elsewhere." Also, for accommodative facility, A13 commented "...I wanted to keep reading ahead when I could see all of them at once."

Category 3: Issues with close proximity

Tests requiring close proximity of the practitioner or instruments to the patient were not popular among participants. While the iCare tonometer was deemed more comfortable, A18 said, "something coming that close to my eyes isn't that pleasant." Although they received a clear explanation of the tests and knew that lenses would be placed in front of the eyes, A10 would have preferred to "...have seen what was going to be held in front of my eyes first of all" such as the cross-cylinder or $\pm 0.25DS$ flippers. On the other hand, when measuring amplitude of accommodation, although A20 could see the instrument, they felt that the target being brought steadily closer was "quite intrusive".

Category 4: Good communication

Overwhelmingly, participants appreciated the communication received during the eye examination. A5 said, "...you explained everything which for an autistic person is a really good thing" and A17 commented, "I understood what was happening, I understood the purpose for it so that put me at ease and I could understand the reasoning for it." For example, participants liked being told that a bright light would be used in some tests, that their eyelids would be touched during ocular health checks or that an instrument would be held close to them. Regarding cross-cylinder assessment, A9 described,

One thing that definitely made a big difference was actually telling me that I should be aiming for no difference, because normally

(a)

Preparing the practice for autistic patients

Advice	How could you implement this?	Applicability
Develop your understanding and awareness around autism	<ul style="list-style-type: none"> Autistic patients can be hypersensitive to lights and touch. Consider alternative tests which don't require a bright light or skin contact. If sensory experiences can't be avoided, minimise these and give the patient advance warning of them. Autistic patients may be anxious or stressed about their appointment, so think about ways in which you could make them feel calm and comfortable. This can be achieved by staff introducing themselves, explaining and not rushing procedures, and not overwhelming the patient with lots of choices. Undergo autism awareness training to develop a basic understanding of the condition. Have an in-practice autism champion who has an advanced understanding of autism. They can be the point of contact for autistic patients, and can advise practice staff on what considerations and adaptations to make. They could also set-up autism awareness training for practice staff. 	All staff
Consider what adaptations you could make to your practice operation	<ul style="list-style-type: none"> Identify quieter times of day in the practice. Appointments at these times can be offered to autistic patients who are hypersensitive to sound or lots of movement, or feel anxious around too many people. If extra time is required, is it possible to spread the examination across two visits? If the autistic patient is hypersensitive to the lighting in the practice main entrance, could they come in through another entrance? Is there a 'quiet area' in the practice where autistic patients could wait as opposed to a busy waiting area? 	All staff
Aim for practitioner continuity across visits	<ul style="list-style-type: none"> Try to have autistic patients managed by the same optometrist and dispensing optician at each of their visits. It may not be possible to have every staff member as a constant for every visit, but a familiar face can make an autistic person feel less anxious. 	Optometrists, dispensing opticians

(b)

Booking the appointment

Advice	How could you implement this?	Applicability
Provide electronic methods to book appointments	<ul style="list-style-type: none"> Incorporate online appointment scheduling into your practice website, where autistic patients can choose a date and time slot to attend. Incorporate an appointment request form into your practice website, where autistic patients can provide their preferred contact details to be contacted back by you. Provide your practice email address to patients as a means to book appointments and communicate with you. 	Practice manager/ administrator
Ask about accessibility or special requirements	<ul style="list-style-type: none"> Do this at the appointment booking stage. This will help you understand any factors which could influence the eye examination for patients. Add a free-text space to your online appointment scheduling or request page, asking about accessibility or special requirements. Provide examples of adaptations you could offer (e.g. a separate waiting area, extended/split appointment). If appointments are booked by email, clearly request any accessibility or special requirements information as part of the communication exchange. 	Practice manager/ administrator/ reception staff
Prepare your autistic patients for their visit	<ul style="list-style-type: none"> Send autistic patients "what to expect" information in advance of their appointment. E.g.: <ul style="list-style-type: none"> An information document containing descriptions and pictures of the practice location, the various rooms in the practice, individual tests procedures, and the staff members involved. See our patient resources webpage: sites.manchester.ac.uk/autism-and-vision/patient_resources/ Videos which walk the autistic patient through the course of the appointment. See our 'What to expect during your eye examination' videos: bit.ly/3H8uvh7 You could add these links and resources into your practice website. 	Practice manager/ administrator

FIGURE 1 (a)–(e) Recommendations for eyecare providers on delivering autism-friendly eye examinations, considered stage-by-stage. For each, the first column gives the individual advice and the second column elaborates on how these can be implemented. In (a), (b) and (c), the final column indicates which practice staff members the advice applies to. Advice specific to optometrists is provided in (d) and advice specific to dispensing staff is provided in (e)

(c) Attending the appointment

Advice	How could you implement this?	Applicability
Be aware of patient requirements	<ul style="list-style-type: none"> Make sure you have seen the special requirements information which the patient provided when booking the appointment. Think about how the patient's special requirements may impact the different stages of the eye examination. 	All staff
Minimise the number of staff/ practitioners involved in an autistic patient's visit	<ul style="list-style-type: none"> Try and manage most of the tests and procedures between the optometrist and dispensing optician/ an optical assistant. E.g.: <ul style="list-style-type: none"> The optometrist could conduct the eye examination, visual field assessment, fundus photography and intraocular pressure measurements. The dispensing optician/ optical assistant can manage the full dispensing procedure. 	All staff
Minimise the number of rooms which need visiting in the practice	<ul style="list-style-type: none"> Complete as many of the tests (as is practically possible) in the eye examination room. 	Optometrists
Preparing the patient	<ul style="list-style-type: none"> When the autistic patient arrives for their appointment, sit down with them in a quiet space and explain what will happen during the visit. Be sure to include details on having to go to different rooms or meeting different members of staff. 	Practice manager/ Reception staff
Establish a good rapport	<ul style="list-style-type: none"> Introduce yourself and what you will be doing. E.g., "my name is Ketan Parmar and I will be looking after your eyes today". Be kind and friendly in the way you speak and act. Be aware of the autistic patient being anxious, stressed or overwhelmed. Be reassuring and speak with a calm tone. Be patient and avoid rushing procedures. 	All staff

(d) The eye examination: Recommendations for the optometrist

Advice	How could you implement this?
Clearly communicate the tests	<ul style="list-style-type: none"> Before conducting each test, communicate to the autistic patient what you will be doing: <ul style="list-style-type: none"> Briefly explain the purpose of the test. Clearly explain what they will be required to do without making assumptions. E.g., "I am now going to show you two lenses. Tell me which of these lenses makes the circle appear clearest and roundest. If you can't choose between the two that is fine, just let me know". Show the autistic patient what equipment you will be using for the test and how it will be used. Tell them if you or the equipment will touch their face. Show and describe any retinal photos or scans to the autistic patient. Report the outcomes of the tests as you go through the examination. If this isn't immediately possible because you need to do further tests to confirm your findings, clearly inform the patient about this.
Adapt your routine by being aware of the autistic patient's sensory difficulties and comfort levels	<ul style="list-style-type: none"> Conduct more demanding tests earlier in the eye examination. If the autistic patient is struggling with subjective tests, employ and rely more on objective tests. These include retinoscopy and cover test. Minimise exposure to stimuli which could provoke sensory experiences for the patient, but cannot be eliminated. E.g., check pupil reactions during direct ophthalmoscopy or slit lamp examination rather than separately at a different point in the eye examination. Substitute tests which provoke sensory experiences where possible. E.g., measuring NPC remotely rather than with an RAF rule which can cause touch sensitivity. Offer the autistic patient optional breaks during the examination. Reassure the autistic patient that they can ask questions at any point during the examination. Consider spreading the examination over two visits if the patient is becoming overwhelmed or feels stressed.
Ensure all the autistic patient's presenting queries/ concerns are addressed in conclusion	<ul style="list-style-type: none"> Refer back to the patient's presenting complaints. Respond to them one-by-one with your findings or management. Write down, or provide a written report of your findings so that the autistic patient can digest the information in their own time. Reassure the patient that they can contact you again if they have any further questions.

(e) Dispensing spectacles: Recommendations for dispensing staff (dispensing opticians, optometrists and optical assistants)

Advice	How could you implement this?
Allow autistic patients to have their own space and time to choose spectacle frame and lenses	<ul style="list-style-type: none"> Don't constantly watch autistic patients whilst they are choosing spectacle frames unless they ask for assistance. Reassure autistic patients that they can come back another day to have their spectacles dispensed.
Deal with each part of the dispensing process in turn	<ul style="list-style-type: none"> Don't overwhelm autistic patients with too much information at once. Conduct the spectacle dispense in a logical and step-by-step manner: <ol style="list-style-type: none"> Discuss lens choices Discuss spectacle frames Discuss tints and coatings

FIGURE 1 (Continued)

opticians don't tell you that. They just say 'can you see a difference' but they don't tell you that you are supposed to be aiming for a point when there is no difference...it is very stressful for the autistic person because you are looking for a difference that isn't there...

Next, participants valued the opportunity to ask for clarification if they had difficulty understanding explanations; A4 highlighted, *"I like that I've been able to ask questions without feeling that I'm wasting your time too much."* Using visual aids to explain some tests was beneficial for participants, *"it was helpful when you had the light shine on the corner of the top right of the mirror sort of making me feel I knew where I was supposed to be looking, not just assuming I'm looking in the right place"* (A11). For others, receiving a demonstration of a test, for example prism fusional reserves, improved their understanding of what to expect *"...rather than just being thrown into it"* (A22).

Finally, participants liked knowing what the results were as the examination progressed. When checking ocular health, A4 said, *"I liked seeing the results from scans and you describing what the retinal scans...and the layers at the back of the eye were"* which was an opinion shared by many of our participants.

Category 5: An interesting process

Participants enjoyed the eye examination because they had to do *"...different kinds of tasks"* (A13) and there were different 'gadgets' involved. A5 said, *"I'm quite fascinated by what's going on."* As a result, participants did not find the examination monotonous and *"...didn't get bored"* (A8). Some of the tests participants specifically liked were prism fusional reserves, stereoacuity and assessing near vision/ visual acuity, because of the challenge involved.

Category 6: Being aware of patient comfort

Many participants noted the steps taken by KRP to ensure a comfortable experience. They highlighted that the examination *"...felt very relaxing"* (A12). When asked what they liked about the examination, A15 said, *"your patience in that I didn't feel that I had to rush...to explain in detail what's happening and to take it really slowly, and not to make me feel as if I should have done it ultra-quickly."* A12 appreciated that there *"...was plenty of time to take a break."*

Some participants valued the way in which they were spoken to. A10 commented, *"...you have a nice tone and pace to your voice"* ensuring they could process the explanations. A21 fed back, *"you've got a really reassuring voice which makes all the difference...if you have a clinician who speaks to you quite abruptly it's very, very difficult to feel comfortable."*

Participants suggested that they preferred holding instruments where possible. This included when checking near vision or assessing near associated heterophoria. A12 reasoned, *"I feel a lot more comfortable when I'm holding something and looking at it myself."*

Category 7: Tips to enhance communication

Participants provided some guidance on how communication could be further improved. They suggested *"...it would be better if there was some more specificity in the questions"* (A4). A4 felt anxious, *"...what if I'm paying attention to the wrong dynamic in this visual thing, and so I'm giving you wrong information so you get the wrong prescription?"*

A15, as did many others, recommended giving clearer instructions during prism fusional reserves assessment. A2 proposed showing the patient printed examples of what may be experienced during subjective tests. For example, the possible presentations when assessing associated heterophoria. A4 said, *"it would have been interesting to see some examples of what other people experience with the [pattern glare test]...and say 'is it anything like this?'"*

Otherwise, participants advised providing more information during the eye examination. This included informing patients if equipment is not working, how long each test would approximately take and allowing them to handle equipment before it was used. Furthermore, A3 said,

there will be lots of concerns [amongst autistic patients] about what you're doing and your 'erms' and 'yes' and 'that's fine,' and I'm thinking 'well have I got it right or haven't I got it right?' Maybe a little bit more reassurance 'yeh that's fine, that's normal'.

Category 8: Routine adaptations

Participants recommended re-arranging the order of tests, with more difficult tests occurring earlier in the examination. Regarding prism fusional reserves, A21 commented,

I think that test is quite hard to do at the end of all these other tests, is it possible to do it earlier on? Anything that requires quite a lot of explanation about what you're doing I think is easier to do when you're less tired.

In terms of sensory sensitivities, a few participants proposed handling their own eyelids as opposed to the practitioner doing this. Another suggested, *"...being able to close my eye for a bit..."* (A1) during slit lamp would have been useful, as a break from the bright light. Some participants highlighted that bursts of background noise were distracting, because they can be *"...a cause for sensory stimulation"* (A16).

To overcome this, A3 suggested, “it would be nice to have some constant [white] background noise, whether it was sort of waves of a sea...just something to amalgamate all the sounds together.”

Category 9: It's useful knowing what to expect

Most participants accessed the ‘what to expect during the study’ resources before attending their eye examination. They unanimously agreed that these resources were “... very helpful, very thorough and really very comprehensive and excellently explained...” (A7). A4, who also appreciated seeing the photo of the testing room, described,

I never would have thought, prior to finding out about my autism and everything, that this sort of stuff would be helpful for me...I'm surprised how much less anxious I feel...it just takes a little bit of the load off.

A17 commented, “...It was quite nice just to see like where the building was going to be”, and A4 added, “...it allayed any fears there might have been.” Some participants, who routinely attended eye examinations, felt the resources served as a useful reminder. All participants agreed that using photos and videos to explain the tests was advantageous so that they “...didn't have to guess what the tests or equipment may be like” (A19).

DISCUSSION

The aim of these studies was to explore the barriers and facilitators to accessing eyecare services in the UK for autistic adults without learning disabilities. The research team's objective was to formulate recommendations for eyecare providers, to equip them with the tools and knowledge needed to provide autism-friendly services. To the research team's knowledge, this was the first formal investigation in this area.

Our studies have built on findings from previous research focusing on general barriers to accessing healthcare services for autistic patients.^{26–28,30,31} Of course, this research has provided detailed descriptions of the multidimensional barriers that autistic adults face accessing healthcare. However, there are certain key differences between optometric practice and other healthcare specialities which result in distinctive barriers. These differences include:

- many high street optometric practices structure patient visits so that patients interact with multiple staff members in different parts of the practice for different portions of the ‘patient journey’;
- community optometric practices commonly house a retail environment;

- the practice waiting area is usually integrated with the dispensing area, where there is a large display of spectacle frames;
- the eye examination involves a variety of tests that require close proximity, subjective responses and uncomfortable stimuli.

We now discuss these findings, in the context of previous literature, under three key headings.

Healthcare provision: A well-known problem for autistic people

Significant issues surround healthcare provision to the autistic population,^{26,30} especially as they transition from childhood to adulthood. Autism services and community support sharply decline for autistic adults.⁴⁰ Results of a survey conducted by the Westminster Commission on Autism⁴¹ showed 74% of autistic, parent-advocate and professional respondents felt that the autistic population receives poorer healthcare than the non-autistic population. Additionally, autistic adults are significantly more likely to report unmet medical needs and lower satisfaction with healthcare self-efficacy.²⁶

Our findings suggest that these issues with healthcare provision for autistic adults extend to optometric services. Our participants reported challenges accessing eye examinations due to difficulties with communication, interaction with multiple strangers and sensory experiences. These difficulties are common for autistic people, and occur across many settings, suggesting eyecare providers lack a basic understanding of autism. This is not unusual as systematic reviews^{15,24,42} have highlighted that healthcare providers lack knowledge about autism, and that autism-related resources for providing autism-friendly services are limited. The National Institute for Health and Care Excellence (NICE) clinical guideline 170⁴³ recommends all professionals working with autistic children and young people receive training in autism awareness and management; although this is encouraging, it omits autistic adults without learning disabilities.

Multiple factors impact eye examination accessibility; these are similar to findings of the existing literature.^{27,30,31} Challenges associated with anxiety are not surprising. Recent systematic reviews and meta-analysis have found approximately 42% of autistic adults⁴⁴ and 40% of autistic youth⁴⁵ suffer an anxiety disorder in their lifetime, compared to 5% in the general population.⁴⁶ These include specific phobias, generalised anxiety, panic and social anxiety. Despite this, our participants enjoyed the organised structure, variety of tests and gadgets involved in an eye examination. The current work suggests that a small number of changes adopted by the optometrist can reduce eye examination related anxiety for autistic individuals.

Challenges of the unknown

Social difficulties linked with autism³ make physical interactions with 'strangers' challenging. In Study 1, participants emphasised that they needed time to become comfortable with someone whom they had not met before. This applied to several stages of the eye examination: booking appointments over the phone, booking in when arriving for an appointment, undergoing pre-screening assessments with optical assistants, undergoing the eye examination with the optometrist and having spectacles dispensed by the dispensing optician. It is common for a patient episode to be arranged into a 'journey' with different portions of the visit being looked after by different staff members. This lack of continuity has been commonly identified as a barrier to accessing healthcare for autistic people^{29,30,47} and was strongly echoed by our participants. Participants who attended practices that had more continuity with staff and location experienced less anxiety. Continuity of staff members is not only important during a visit but also across visits, particularly continuity of the practitioner,⁴⁸ which allowed our participants to feel more comfortable and reassured.

The concept of continuity also applied to unexpected changes in practice environment. A scoping review found unfamiliar settings to be intimidating or overwhelming for autistic adolescents and hindered their attendance.⁴⁹ Visiting a new room in the optometric practice, seasonal changes in floor layout or refurbishments can be disconcerting and disorientating. Most autistic individuals experience altered sensory reactivity,¹ causing great distress and anxiety.⁵⁰ Some participants in Study 1 preferred quieter and less crowded practices, and were affected by the glaring reflections from spectacle stands. It is important to consider if any aspect of an optometric practice may induce sensory symptoms. In a randomised control study, adapting the sensory environment of dental practices reduced anxiety, pain and discomfort experienced by autistic children.⁵¹ A checklist for autism-friendly environments, produced by the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE),⁵² highlights sensory factors which should be considered for the accessibility of an autistic person. This reinforces the importance of asking autistic patients, before their appointment, about any accessibility needs they have. This is a legal requirement in the Accessible Information Standard.⁵³ Mirsky and Gurenlian⁵⁴ further recommended blocking out other appointments during the time that autistic patients are scheduled, to reduce additional stimuli.

Regarding booking appointments, consistent with the existing literature,^{30,55} participants in Study 1 preferred electronic methods such as email, text or an online self-service system. Some practices already offer these alternatives. Participants who used these said they increased accessibility and allowed them to have control. The positive impact of an online booking portal for patients booking

hospital outpatient appointments has been observed in a general population by Dusheiko and Gravelle.⁵⁶ They estimated appointment non-attendance was reduced by 72, 160 (8.7%). This suggests benefits of an electronic appointment booking system are not confined to autistic people. However, our participants suggested that such alternatives were a necessity to provide accessibility for autistic patients.

It is impossible to eliminate all anxiety-provoking or stress-inducing situations. Preparing an autistic person for who they will meet, what the practice environment may look like and what tests they will undergo may reduce barriers. This can be done by an information sheet presenting a detailed description including pictures of how the patient can reach the practice, the practice building and layout, the staff members they will meet, the test procedures they will undergo during assessment and how they may feel.^{19,20} This may also be done by a social story or videos with similar content. We have developed a resource for optometrists; see the "Providing autism-friendly eyecare: recommendations for eyecare providers" section. Across both the current studies, most participants agreed that being provided such 'what to expect' information in advance of their eye examination would be very beneficial. In Study 2, participants highly appreciated receiving this ([Supporting Information 3](#)). It allowed them to come to their appointment with a pre-built level of familiarity and predictability. This reduced stress and fear of the unknown. Additionally, in agreement with The College of Optometrists' guidance,²³ some participants in Study 1 suggested visiting the practice in advance or being given time to familiarise themselves with the practice on the appointment day would be helpful.

Communication, rapport and reassurance

Poor mutual understanding, communication challenges and lack of trust have been reported to cause stress for autistic adults during clinical appointments.³¹ Study participants spoke largely about the importance of clear communication. Autistic adults have previously described low satisfaction with patient-practitioner communication.^{26,27} The optometrist's communication influenced our participants' comfort and anxiety levels, and their confidence in completing clinical tests.

Good communication is likely to impact all optometry patients positively: Kim et al.⁵⁷ investigated the influence of good optometrist communication on patient satisfaction in a general Korean population. They concluded "the better the former, the better the latter." Variables such as sincere listening and use of a kind tone and language influenced how a patient felt during an eye examination.⁵⁷ In the current studies, participants additionally valued optometrists simply introducing themselves, being friendly and attentive, and aware of how an autistic patient may be feeling. Evident in Study 2, this established a good rapport which made the participants feel relaxed.

It was extremely important for our participants to be given a description of each clinical test before it was conducted, preventing sudden spikes in anxiety. Autistic adults have reported difficulties with decision-making.⁵⁸ They may only provide relevant information if specifically asked³⁰ and may think very literally.¹⁵ Difficulties encountered by our participants during subjective tests are not unexpected. To overcome this, optometrists need to provide clear and specific instructions regarding what the patient is required to do. This is reinforced by the positive comments received from participants in Study 2. The suggestions of Luke et al.⁵⁸ can reduce the stress and anxiety that autistic patients experience during decision making: providing extra time during decision making tasks, asking more closed questions, giving autistic patients reassurance and understanding the autistic patient's strengths in decision-making.

Reassurance is particularly important in an optometric setting. Participants in Study 1 felt that responses to subjective tests were the sole means of an optometrist determining a spectacle prescription. This led them to feeling overly responsible for the outcomes of the examination, increasing their levels of stress and fear. This could be easily managed by optometrists assuring autistic patients that the majority of subjective tests also have an objective component. For example, subjective refraction is accompanied by retinoscopy. Using an alternative testing technique could also be the solution for tests which participants found stressful due to proximity or which provoked sensory experiences in Study 2. For instance, near point of convergence could be assessed remotely rather than using the RAF rule. In summary, optometrists should be resourceful and adaptable to ensure a thorough eye examination is achieved when seeing autistic patients.²³

Limitations and recommendations

To our knowledge, these are the first qualitative studies exploring the accessibility of eye examinations for autistic adults. Although results are only relevant for autistic adults without learning disabilities, these complement the resources and guidance currently available to provide accessible services to autistic children and autistic individuals with learning disabilities.²¹⁻²³ Participants were limited to those who could communicate verbally in a physical focus group and one-to-one interview setting. A further study conducted virtually or using text chat may have yielded additional insights.

Regarding Study 1, participants' experiences were influenced by the type of practice they attended (e.g., multiple or independent). A similar study focusing on the characteristics of the practice the participants attend would identify specific barriers linked to a particular practice type. Specific to Study 2, the research student collected data about his own performance. It is likely

that feedback received from participants influenced how he conducted eye examinations for subsequent participants. However, as we took a qualitative approach, giving equal importance to all participant feedback, this would not bias results. Next, only four participants underwent a colorimetry assessment. The decision to test was based on the pattern glare test result and the presence of any other optometric/ orthoptic anomaly. As a result, it is likely that we did not capture the full range of participant feedback specific to this test. Finally, it is important to acknowledge that eyecare services vary across different countries. Although this study was based in the UK and modelled on UK eye examinations, the majority of our test procedures were not unique to UK optometry.

Sample size determination is difficult in qualitative research. There are alternative approaches suggested for this. A recent article by Braun and Clarke⁵⁹ discussed data saturation in the context of thematic analysis. It points out that it is difficult to justify sample size with data saturation for studies that are exploratory, inductive and which do not ask the same questions during every focus group/ interview. In Study 1, recommendations regarding number of focus groups by Guest et al.⁶⁰ and data saturation, during the planning and data analysis phases respectively, were used to confirm a suitable sample size. However, in line with Braun and Clarke's⁵⁹ rationales, our focus groups were on a very select topic and all our participants were autistic and had experience of an eye examination; therefore each was likely to have more 'information power',⁶¹ meaning our modest sample size was acceptable.

Due to the impact of the COVID-19 pandemic on Study 2, a pragmatic approach had to be taken, in which as many participants as was feasible were interviewed in the given timeframe. This resulted in fewer interviews than originally envisaged. However, since participants carried high 'information power' as per Multerud et al.,⁶¹ and questions to all participants were identical, this supported the small sample size.

CONCLUSION

These are the first studies to investigate the eye examination experiences of autistic adults without learning disabilities, and the adaptations which can be made to make eyecare services more autism-friendly. Focus group discussions and structured interviews with autistic adults revealed UK eye examinations are not very accessible for this population. However, reasonable adaptations can be made to overcome this. To achieve an autism-friendly service, an autistic person's visit to an optometry practice needs to be considered as a whole, not just within the testing room. Methods to book appointments, adaptations to the patient journey, improved communication and continuity are the areas to be deliberated. Furthermore, practitioners need to develop their understanding of autism. Then they can

appreciate the disparities that an autistic person may face during an eye examination, and confidently make adaptations to their testing technique.

PROVIDING AUTISM-FRIENDLY EYECARE: RECOMMENDATIONS FOR EYECARE PROVIDERS

Bringing together the findings of our focus group and interview studies, we outline the following recommendations (Figures 1a–e) for the provision of autism-friendly optometric care. These are presented according to the different stages of an eye examination. Of course, this is not an exhaustive list, and some recommendations may need to be adapted according to the needs of a specific autistic patient.

ACKNOWLEDGEMENTS

We thank the Autism@Manchester Expert by Experience Advisory Group for their advice and guidance. Many thanks to Mehtab Uddin and Tony Payton for helping us create the patient resource videos. We appreciate the work of the Web Content team at The University of Manchester in creating our project website, which is now a repository for patient and practitioner resources. Finally, we extend our gratitude to all our study participants who shared their experiences and provided feedback, making this work possible.

AUTHOR CONTRIBUTIONS

Ketan R. Parmar: Conceptualization (equal); data curation (lead); formal analysis (lead); investigation (lead); methodology (lead); project administration (lead); resources (lead); writing – original draft (lead); writing – review and editing (lead). **Catherine S. Porter:** Conceptualization (equal); data curation (supporting); formal analysis (supporting); investigation (supporting); methodology (supporting); project administration (supporting); resources (supporting); supervision (equal); writing – original draft (supporting); writing – review and editing (supporting). **Christine M. Dickinson:** Conceptualization (equal); data curation (supporting); formal analysis (supporting); investigation (supporting); methodology (supporting); project administration (supporting); resources (supporting); supervision (equal); writing – original draft (supporting); writing – review and editing (supporting). **Peter Baimbridge:** Conceptualization (supporting); methodology (supporting); resources (supporting); writing – original draft (supporting). **James Pelham:** Conceptualization (supporting); methodology (supporting); resources (supporting). **Emma Gowen:** Conceptualization (equal); data curation (supporting); formal analysis (supporting); investigation (supporting); methodology (supporting); project administration (supporting); resources (supporting); supervision (equal); writing – original draft (supporting); writing – review and editing (supporting).

CONFLICT OF INTEREST

None.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: Parmar KR, Porter CS, Dickinson CM, Baimbridge P, Pelham J, Gowen E. Autism-friendly eyecare: Developing recommendations for service providers based on the experiences of autistic adults. *Ophthalmic Physiol Opt.* 2022;42:675–693. <https://doi.org/10.1111/opo.12975>