Introduction by Keith Barton

The first of our speakers this afternoon is our keynote speaker Professor David Crabb who is a Professor of Statistics and Vision Research at City University London. He gained degrees in mathematics and statistics at Oxford and Sheffield before completing a PhD in Visual Science in 1996. Following a post doctorate position at UCL and lectureship at Nottingham, David took up his position at City in 2005. Professor Crabb is a Fellow of the Royal Statistical Society, Honorary Consultant of Visual Sciences at Moorfields Eye Hospital and the leader of the Applied Vision Research Group at City University London. Professor Crabb’s research laboratory contains a lively mixture of vision scientists, ophthalmologists, psychologists, mathematicians and computer scientists. This laboratory focuses on measurement of vision, visual fields, imaging, function, eye movements, quality of life measurements and medical statistics. One of the main themes of his work in glaucoma is relating the different stages in the condition process to a patient’s visual disability. Today, Professor Crabb is going to talk to us about glaucoma through the eyes of the patient. Ladies and gentleman: Professor David Crabb.

David Crabb

Thank you for inviting me to give this Janice Krushner Memorial Lecture. When I look at the long list of names of people who have given this talk in the past, it’s a real privilege that I’ve been asked to present. It’s also a privilege to be able to share some of my research with the real experts: you, the patients. Hopefully you’ll find this tour of some of our research interesting.

Visual fields

One of the key measurements in glaucoma management is eye pressure, which is the only modifiable risk factor for the condition. Since glaucoma is a condition of the optic nerve head - a tiny structure at the back of the eye - a good assessment of this structure using imaging is also crucial. However, both of these measurements are indirect measures of vision. In order to get a more direct idea as to what a person actually can and cannot see as a result of their glaucoma, the visual field test is
used (figure 1). Many patients will be highly experienced at this task, which involves sitting in a darkened room with one eye covered and clicking a button whenever a white light appears.

Our group has a particular interest in measuring visual fields, and our researchers have looked to try to design better types of test, and to develop improved methods of analysing the results from those tests, in order to help improve the management of patients. We are also keen to involve patients directly in this process, and so, in a recent study, we set up a number of focus groups in different hospitals around the country, to try and ascertain how patients actually feel about visual field testing. Our results suggested that although patients find the visual field test challenging to perform, they acknowledge it is important to their overall care and management. However, one interesting finding was that many patients had never had the visual field assessment explained to them in detail. Those people reporting positive experiences with visual field testing also talked about the importance of being supervised throughout the test - especially when they did their first visual field test - and of a quiet, comfortable test environment. These are all areas that could be addressed by clinicians and hospital managers to help improve the quality of visual field testing.

We asked patients about their views of visual field testing in several focus groups in hospitals across England (figure 2). The results of this work can be found in a freely available article on the web1.

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Figures:

Figure 1: The visual field test

Figure 2
Measuring condition severity
There are a variety of different ways in which we can summarise the severity of visual field loss as measured by the visual field test. However, generally, a lot of importance is placed on single numbers provided on the test printout, such as a summary index called the Mean Deviation (MD). These values can be easily tracked by the clinician over time to establish whether your vision is deteriorating or not. However, relying too much on these numbers may overlook other key information.

Figure 3 shows greyscale representations of a number of visual fields: the darker areas show those regions of the field of view where the patient struggled to detect the light presented there during the test. It can be seen that all of the visual fields look different, in terms of their scotomas or the location of the visual field damage. Certainly, some of these patients would be more affected by the location of their vision loss than others. Yet the vision loss of all these patients is summarised by the same “MD” value: -5dB. We believe that it is important to acknowledge that although these patients have the same value ascribed to them, the different types of visual field defects, because of their location, could have varying degrees of impact on the different activities these patients want to achieve.

Patients have two eyes!
In the clinic, visual field measurements are typically taken monocularly - one eye at a time - and it is unusual to be
asked to complete the visual field test with both eyes open. Yet, of course, in real life both eyes work together as we go about our everyday tasks. It would therefore also make sense to consider a measure of binocular vision in order to better understand how visual field loss might affect a person’s functioning.

Some years ago we came up with a simple concept called the ‘integrated visual field’. This isn’t an extra test: it simply uses software to combine the two monocular visual fields that were initially measured. The idea is to get a representation of what the patient can see with both eyes together by merging the results for the left and right eye that were acquired in the clinic. Figure 4 shows examples of three patients’ left (L) and right (R) visual fields respectively. It would be reasonable to deduce from this information that these patients have moderate to severe vision loss. Yet, if we calculate each person’s integrated visual field (shown underneath the L and R visual fields), the picture is suddenly very different. Considering the visual field in this way may help to explain why some patients with quite severe vision loss in each eye separately can still have good functional vision when the two eyes work together.

Figure 4: Example integrated visual fields. The left eye and right eye visual fields are combined using software to produce a representation of binocular vision (referred to as the ‘integrated visual field’). This may give a better idea of how a person might function using both eyes together.
Real world vision
Results from a series of visual field tests taken by a patient with glaucoma in the clinic might show that their visual field loss is worsening over time. However, this does not really tell us anything meaningful about how this loss will actually impact the person’s day-to-day lifestyle. For instance, a patient may wish to know at what point the visual field worsening will affect their ability to read. Will the level of visual field loss put them at risk of falling? At what stage of condition will their driving performance and their legal fitness to drive be impacted?

One of the main interests of our group is relating the visual field measurements taken in the clinic to the patient’s visual ability in tasks that are more relevant to their real life. Instead of asking patients about problems they may have, many of our studies involve actually measuring a person’s performance during different types of tasks. We can only really scratch the surface with these kinds of projects, but what we are really trying to do as a group is to illuminate the problems faced by glaucoma patients so that these can be addressed in management of the condition.

Reaching and grasping
In one study, we examined whether patients have deficits in the visually guided task of reaching and grasping for an object. The participants were asked to reach and grasp a selected object on the table-top while cameras above their
head and markers placed on their hands and wrists tracked their movements. By doing an experiment such as this, we could take a lot of measurements in a short space of time and get a very accurate reading about how well a person would actually perform this task. We then compared the performance of a group of patients on the task with another group of people of a similar age with normal vision.

We found that patients were slower on average in terms of reaching out for objects, but also that the way in which they reached towards an object - which is known as prehension - varied enormously in the patients compared to the controls. Interestingly, the way in which patients performed this task was also very dependent on their type of visual field (VF) loss. So, a person with a superior visual field defect (loss of vision in the upper part of their field of view) is likely to perform better than people with inferior visual field loss (loss in their lower field of view). Yet in the clinics, these two VFs would be quantified as being the same (they would be given the same MD value to summarise the level of vision loss). This task therefore shows the importance of considering the location of the visual field defect.

**Driving hazard perception**

We have also carried out some work relating to driving performance. Young people learning to drive nowadays have to do a whole battery of different theoretical tests including multiple choice questions and an assessment called the hazard perception test. The hazard perception test consists of a series of driving films that have been shot from the perspective of the driver. In each film, some sort of hazardous event occurs that eventually causes the driver in the video to take an action, like changing direction or stopping the vehicle. The person doing the hazard perception test is required to press a button as soon as they see these hazards occur in the film.

We thought it would be interesting to show these films to visually impaired patients and to compare them with
age-matched controls to see if there were any differences in performance, or particularly, with regard to things they tended to look at in these driving scenes. So, we set up an experiment where we tried to work out exactly where the participant was looking when they viewed the films.

To achieve this we used an **eye tracker** (figure 7) which was placed on the participant’s head as they carried out the task. Using two cameras that sit in front of the eyes and another camera looking at the screen, we can actually work out very precisely where the person is looking.

The eye is capable of moving three to five times a second - we actually move our eyes more times than our heart beats. As we look around visual scenes we make short linear movements called saccades. Every now and again, the eye will then dwell on something of interest, which is referred to as a fixation. The eye-tracker collected this information as the person viewed the videos and we analysed this data to gain insight into how people actually viewed the videos.

These experiments generate masses of data. The person who has done a lot of the work on eye movements in my lab is Dr. Nick Smith (figure 8) and at one stage we counted up how many data points we had in our spreadsheet and it was 13,000,000. So he’s not often smiling like in the picture to be totally honest!

When we looked at the results, we found that patients with glaucoma did appear to be moving their eyes differently on average to control...
subjects. For example, they seemed to be moving their eyes more (so they were making more saccades) than the people with normal vision. This finding was interesting to us as it suggested that glaucoma patients may perhaps compensate for their vision loss by moving their eyes differently.

This research paper was also published in an open access journal on the web and there are some links to it on the IGA website. It generated a lot of interest because I think it illustrated some of the difficulties that patients may have with driving.

Visual search
In another experiment we considered the influence of visual field defects when searching for objects in everyday scenes. In this study we showed participants some photographs on a large computer monitor and then asked them to find specific items within the photos, such as a road sign, or the price of something on a supermarket shelf. At the same time, we monitored their eye movements. Our results suggested that, on average, the patients took significantly longer to find the objects than the controls.

Some of the results for individual patients (and their visual fields) are shown in the graph (figure 10). It may look complicated, but one of the key messages to take from this is that there is wide variability in patients’ responses: in other words, the performance of one patient may be very different to another with the same severity of vision loss. We thought it would be useful to tap into this finding to help determine what exactly some patients are doing that enables them to function well in this task, in spite of their vision loss.

We found some evidence to suggest...
that some of this variability in performance could be related to the eye movement strategies being used by the patients. For instance, some people struggled to find the items in the photographs, and also seemed to have more restricted eye movements. However, other patients appeared to look around the scene much more (they increased their saccade rate) and also seemed to perform fairly well at the task compared to the people with healthy vision. So, perhaps changing aspects of their eye movement behaviour could help some patients function better in tasks like searching for objects.

Reading and face recognition
When we talk about glaucoma, we often associate it with problems with peripheral (side) vision. However, we know that patients often report difficulties with tasks such as reading, which require good central vision. Dr. Robyn Burton in our lab has investigated the performance of patients when reading; specifically, she showed that the real problem is when contrast is low. Some other work also highlighted, for the first time, the problems that patients had in finding the next line of text when reading.

Another task that requires good central vision is face recognition. We were inspired to investigate this area partly by an eloquent quote in a patient journey series in the BMJ, where a patient talks about the problems with
living with glaucoma: she says, that what’s most distressing is: ‘That I will never again be able to see up close the entirety of someone’s face’.

We thought it would be interesting to try and quantify this, and so we set up a lab-based experiment which involved measuring performance and tracking the eye movements of people with and without glaucoma as they carried out a face recognition task. In this task, the participant was introduced to a series of faces, shown from different angles, one at a time. The person was later asked to choose from a selection of three different faces the person that they had seen before. This experiment was initially developed for researching a condition called prosopagnosia, or face blindness, but is a standardised test that has also been used by other researchers for investigating other conditions: we therefore thought it would be interesting to apply it to glaucoma patients.

Dr. Fiona Glen has done some really interesting work in this area which showed that it is only really when patients have advanced loss, particularly
in more central regions of the visual field, that they start to have problems with recognising faces. We found that on average, some patients with moderate to early loss did not really have a problem with the face recognition task.

Again, what we thought was really interesting was the range in performance between the patients with similar levels of loss in terms of how well they did the task.

In this graph (figure 13), each point represents a patient with central visual field loss: those towards the top of the graph did well at the face recognition task, while those further towards the bottom were poorer at recognising faces. Fiona then extended this research to look at the eye movements the patients made while they carried out the task. An interesting finding was that those patients who made larger eye movements when recognising faces (larger average saccade amplitude), also performed better at the task. The results from this study may therefore again suggest that studying eye movements could provide an interesting window into understanding the functioning of patients during real-world tasks.

To summarise, in this programme of work, we have tried to establish a link between the measurements that the clinician takes in the clinic and what patients can and cannot do in real life. By doing this, we are trying to illuminate some of the problems that patients experience. Our own particular interest is the concept of eye movements and the fact that they might give us an idea about the functional problems experienced by people with glaucoma.

What does glaucoma look like?
The second part of this talk focuses on another study concerning the visual symptoms of glaucoma; specifically, what does a glaucomatous visual field defect actually look like to the patient?

If you type glaucoma as a search term on the internet you will often see a number of pictures depicting the world through a black tunnel. Most patients
and clinicians will know that this is not really an accurate representation of what the world looks like from the perspective of a person with glaucoma: really, the perception of vision loss in glaucoma is much more complicated. For instance, the process involves both eyes working together, as mentioned earlier, but also the brain does a magnificent job of looking at the jigsaw of the visual scene, where parts of visual information are missing, and then compiling a new image that is believable to the patient. Therefore, any visual problems might not be immediately obvious to the person.

We thought it was important to investigate this area in more detail for two main reasons. If we try to raise awareness about the symptoms of glaucoma - and this is something the IGA do brilliantly - and yet always depict glaucoma as causing tunnel vision or black areas in the field of view, then we are not really doing a very good job at emphasising the asymptomatic nature of the condition.

Secondly, glaucoma is a chronic condition, where patients are required to take medication for the rest of their lives even if they do not actually experience any symptoms. If patients do not identify with the information about glaucoma that they see in the media, perhaps believing their own vision to be less severe than these representations, then they may decide not to take their eye drop medication, which would be a
big mistake.

Therefore we thought this area was worthy of some research, and aimed to test the simple scientific hypothesis that patients with visual field loss do not actually recognise their impairment as a black tunnel effect or see black patches in their field of view. This study was generously funded by the International Glaucoma Association, and we were very pleased to publish the results in the journal *Ophthalmology*.8

In the study, we asked a number of patients, who had moderate to severe vision loss, to describe to us how glaucoma affected their vision. We were interested to know whether patients were actually aware of their visual field defect, and if so, if they could describe what it looked like and how it impacted on them.

We also showed the participants six versions of a photograph and asked them to choose the image that most closely represented their own vision (figure 15). The photographs showed examples of common representations of visual field loss caused by glaucoma: a black tunnel, black patches, a blurred tunnel, blurred patches, missing regions and no change.

The striking result was that - in contrast to the images you commonly see on posters or the internet - none of our fifty participants talked about experiencing any black areas in their field of view. The second important point was that one in four of the patients said they have absolutely no symptoms at all: remember, these were patients with visual field loss in both eyes; and yet they reported no symptoms, which was surprising. However, there was no obvious link between the severity of a patient’s visual field defect, as measured by the MD value on the visual field printout,
and the picture they chose. In other words, the patients with more advanced visual field loss, according to their MD summary value, were not necessarily more likely to pick the picture with a blurred tunnel. Perhaps the specific location of visual field defect is important here, but this is something we hope to investigate more in the future.

We then looked at the interview responses and tried to pick out the words that patients use to describe their visual symptoms.

Figure 16 shows some of the most commonly used words by patients when describing their vision: the larger the word, the more frequently that word was used as a descriptor of their visual symptoms. So, words like *blur*, *fuzzy* and *disappear* were commonly used to describe their vision. One patient was very eloquent and described their vision as being ‘similar to looking through a window that has condensation on it’, which we thought was an interesting analogy.

The patients also described a number of activities that they felt were affected by their vision loss. Many of the patients described problems with some of the tasks we investigated in our other research, such as driving, reading and
”. . . when I am reading it looks like someone has poured bleach on the page. . . . the words have been wiped away…”

“... I saw a bus coming. I thought it was a single decker and it turned out to be a double decker…”

Figure 17

mobility, in addition to other tasks such as using a computer or watching TV.

Figure 17 shows some example quotes from two patients and their visual field defect. Sometimes the location of the person’s visual field defect corresponded to the problems described by them: for instance, one person with a defect at the top of their field of view said she sometimes struggled to see the top deck of a double-decker bus.

Finally, I want to come back to the title of this talk which is trying to show what the symptoms of glaucoma really are. We are currently trying to build on this work, by developing new and innovative ways of showing people what it is like to have visual field loss caused by glaucoma.

My PhD student Vera (figure 18), who has excellent vision, is watching a film and as she does, the eye tracker, which sits just underneath the monitor, is monitoring where she is looking. As she watches the video, a distortion in the scene, representing a specific visual field defect, moves with her eyes as she looks around. The idea is that by using this system, a person with normal vision can experience what it is like to have defects in certain regions of their field of view. We think this could be a
really nice way of helping people understand what the symptoms might be like for a glaucoma patient.

We have also applied this system in a new driving study that was generously funded by the IGA. We recruited people from the University who had normal vision and asked them to search for hazards in a number of driving videos from the hazard perception test. In some versions of the hazard perception test we also included a distortion in different parts of their field of view that moved with their eyes as they carried out the task, to try to work out where it is more important to have preserved vision. From a scientific point of view this is a really nice experiment because we are comparing a person with their own normal performance.

As part of our study, we added a distortion in the superior visual field (the top part of the visual field) and looked at each person’s hazard perception performance compared to when they completed a version of the test with a distortion in the lower part of the visual field (inferior visual field defect). We found that the participants were less affected by an inferior visual field defect than by a superior visual field defect. Perhaps we did not need a scientific experiment to prove that point because most of your inferior (lower) field of view when you are driving will really be inside the car rather than being relevant to the actual driving scene. However, it is interesting to note that the Esterman Visual Field test - which some patients may recognise as being the test used by the DVLA when assessing fitness to drive - was actually designed 30 years ago to assess mobility, and places emphasis on more inferior (lower) parts of the visual field. So in other words, the test used to assess the visual field in relation to driving was never really designed for driving. So we hope that when this work is published, it may provide a step towards improving the ways in which we can quantify the visual field for driving.

Finally, I want to make the point that although some of the films and images I have shown you are a really useful experimental tool for us, we know they may still not accurately depict the way many patients perceive their visual symptoms. The effect is likely to be much more subtle than a distortion or a blur that occurs in the field of view and we are continuously trying.
to improve the ways in which we represent vision loss caused by glaucoma.

The most important conclusions for us, in terms of the work that has been sponsored by the IGA, is that we’ve provided evidence that patients do not see black areas in their field of view. It is a much more complicated process and we think that this is important for raising awareness of the condition and especially for the detection of glaucoma, which can be asymptomatic in the early stages.

**Thank you**
To finish, I would really like to thank the IGA because they’ve been incredibly supportive of our research over the years. We are also grateful to all of the people who have kindly given up their time to take part in our studies - we couldn’t have done this work without them! Thank you very much for listening.

**Future work**
There is still much to learn about glaucoma from the patient’s perspective and we have some exciting studies planned over the next year.

If you have been diagnosed with glaucoma and would like to talk to us about your experiences with vision loss, or if you would like to hear more about our research, then we would be very interested to hear from you!

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*Figure 19: Screenshots from the hazard perception test with distortions representing visual field defects in the upper visual field and lower visual field. These distortions moved with the participant’s gaze (small red dot) as they looked for hazards within the scenes. The visual field defects on which we based these distortions are also shown.*
References


