IGA Open Summer Patient Meeting 2011

The development and testing of an education programme delivered to a group of patients to improve adherence with glaucoma eye drops

Professor Heather Waterman & Jill Annis

Heather Waterman:

Thank you very much for inviting us here today. I am delighted to be here especially to talk to a group of patients. It's the first time I have actually done this and so I'd really welcome your feedback at the end. I'm going to present a joint project between the University of Manchester and Manchester Royal Eye Hospital which we carried out to develop and test an education programme delivered to groups of patients to improve adherence to glaucoma eye drops.

Before I go into the details, I just would like to tell you a little bit about myself: I am a Professor of Nursing from the University of Manchester but long ago, in the distant past, I was a ward sister at Manchester Royal Eye Hospital and so that's where my interest in this area came from and I would just like to introduce my partner here.

Jill Annis:

I am Jill, I am a community pharmacist and a glaucom patient hence why I've got an interest in this.

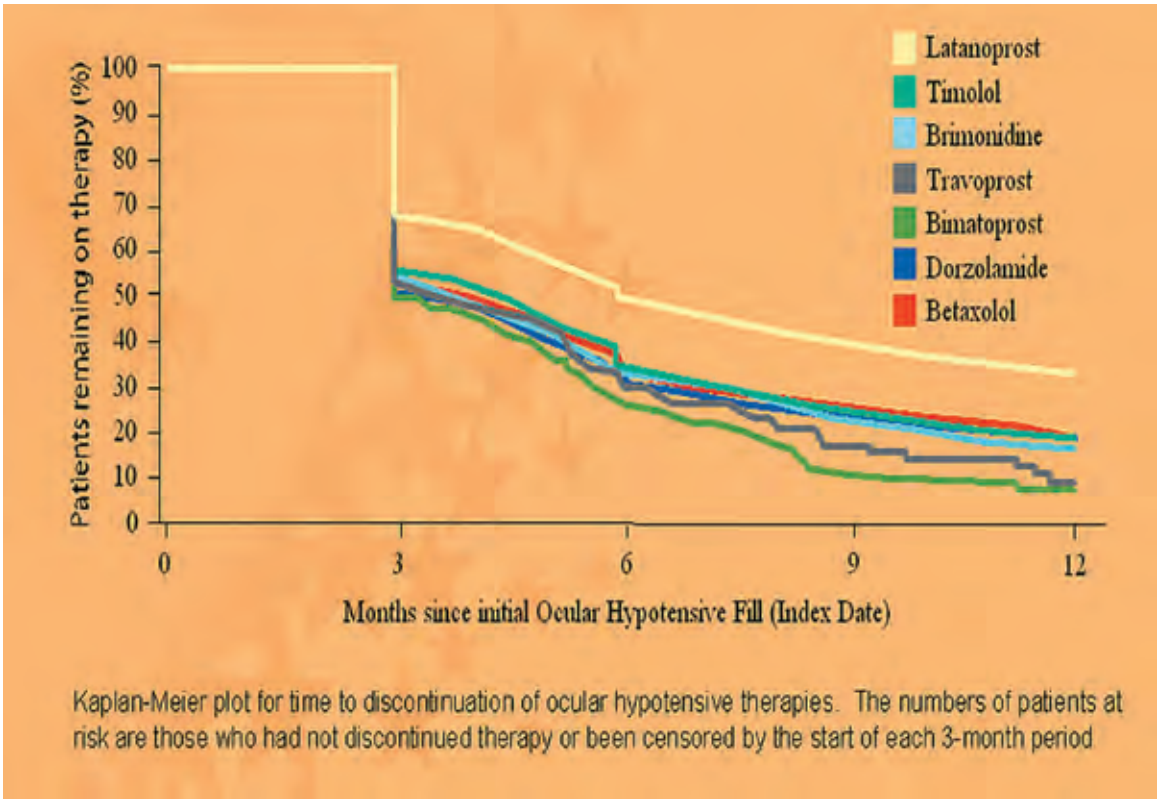
Why did we carry out this research?

Heather Waterman:

The aim of the talk is to give insight as to how we have used research to improve the nursing care of patients and to inform you on how patients may be involved in research. It's well known that some patients have a tendency to not persist with their eye medication as this graph shows (Fig 1). After twelve months only about one third of patients are still collecting their prescriptions and even those who do carry on with their eye drops have been found to have 'breaks' from their eye drops, or they may not put them in at the time advised by the doctors.

This study was carried out in America, so we wanted to see what the situation was in the UK. We observed consultations between doctors and patients and between optometrists and patients, and we interviewed them as well. We found that patients told us that they weren't putting in their eye drops and they seemed to have very poor knowledge of what glaucoma was. In addition, because of the busyness of clinics they weren't given much

Figure 1



Kaplan-Meier plot for time to discontinuation of ocular hypotensive therapies. The numbers of patients at risk are those who had not discontinued therapy or been censored by the start of each 3-month period

time to talk about any problems with putting in eye drops and nurses weren't really involved in their care either.

I've got here a poem written by an ophthalmologist and I think it illustrates some of the issues shown by the graph (Fig 1):

I am sure it's not the case in all situations, just in some, but this is sufficient perhaps to make us think we want to do things better.
Jill is now going to share with you her experience of being a patient and what it was like when she was being diagnosed.

Jill Annis:

I first learnt about the study when I was approached by Fiona Spencer (Ophthalmologist), who told me The Burdett Trust needed a pharmacist and a glaucoma patient, so I suppose I provided two for the price of one. I was interested to have the opportunity to learn more about glaucoma, how other patients were coping with it, and how their lack of knowledge could be rectified because as a pharmacist I come across a lot of it.

I was diagnosed with glaucoma about nine years ago after arguing with my optician that as my intraocular pressure was always at the upper limit of normal I should be referred. But by the time I saw an Ophthalmologist and was diagnosed with glaucoma I unfortunately had visual field defects in both eyes. I had a lot of questions to ask but the consultant kept looking at his watch, obviously not having much time to

A visit to the eye clinic

My annual check of IOP is quite a day as you will see
My hypertension amplifies come time again to check my eyes
The specialist looks far too young and comes across highly strung
I've not laid eyes on her before, they change each time I see the score
I cannot see the vision chart and she seems to think I'm not that smart
We've lost your notes so say what's wrong but to the point and don't take too long
What drops do you take, which eye or both, precisely what do you mean by growth
Now keep still you're chin goes here, don't blink so much look at my ear
These drops will sting and blur your sight, don't squeeze so tight this poke is slight
She huffs and puffs 'will I go blind, please tell the truth, please be kind'
Not apt to be malignancy, we think it best to wait and see
Just take these drops, next patient please, and don't forget to pay your fees
Oh the oath to care and heal disease forgotten oh Hippocrates

spare. I was given no information at all, just a diagnosis and 'here is your prescription, go and get the drops'. I was angry at first, then determined to learn as much as I could in order to help others. I used drops for about four years and then I had surgery on both eyes.

My role was to attend meetings and give input both as a patient and a pharmacist. I was only given a brief induction as I already had a medical background and was used to working with groups. I had to attend about six or seven meetings at the Eye Hospital where I was expected to put forward my perspective on patient education.

Next step: setting up an action research project

Heather Waterman:

We realised there were issues to do with patient support and patient education. We already had carried out some research on this subject and delivered education to some patients singly. We found it worked really well and that patients felt more educated and were putting in their eye drops more. So we thought let's try and see if delivering education to patients in groups would work as effectively, because with the NHS being cash starved at the moment we thought it might be more

attractive. This is how the idea of this study came about and we were fortunate to get funding from the Burdett Trust for Nursing on this.

The aims of the research were to find out how we should deliver the programme to groups of patients, what their learning needs would be, the content and duration of group education and then carry out a pilot study with real patients to see if it was feasible and acceptable. So to do this we felt it was really important to work closely with patients because after all they will be the recipients of care. We also wanted to work with staff because they would be delivering the programme if it was found to be any good. So we carried out what is called an 'action research project' where action researchers aim to work in partnership with patients and staff to understand and then improve an aspect of care. We formed an action research group, including patients, who kind of led the study by contributing to the design, conduct and analysis of the research. Jill was part of this group and is now going to share her experience as a member.

Jill Annis:

The group consisted of Heather, Ophthalmologists, Optometrists, GPs, Researchers, Nurses and patients. During the first year we covered our own experiences

Figure 2 Remit of the action research group

and views on patient education. Questionnaires were put to the patients, sometimes I felt the language was a bit too technical and should be made more user-friendly. I participated in the analysis of patient interviews, commented on their stories and reflected on my own and other experiences. I fed back to the group what the learning needs were and raised the importance of covering legal aspects, such as informing the DVLA and car insurance. I participated in the dummy run of the programme, which was practiced on three of us patients present at the meetings and offered advice on the use of the language. I attended the hearing of the first set of results and gave feedback on these. I have gained a lot from the experience and learnt about lifestyle issues which I didn't know, for instance I now realise I'll never go scuba diving with sharks. It was interesting to listen to other patients on the panel, some of whom were particularly well informed, and I enjoyed the interaction.

Finding out what patients want to learn

Heather Waterman:

We interviewed 27 patients from different ethnic backgrounds and with a range of glaucoma. We asked open ended questions which invited patients to talk about issues important to them, we recorded and transcribed the interviews then we examined the transcriptions to identify what patients needed to learn. The idea being that if we knew what patients needed to learn we could then build a teaching session from it. Figures 3 and 4 show you the learning needs identified. In the left hand column are quotes from patient interviews and in the right hand column are the patients learning needs that we found. There are ten altogether.

For example, for the first learning need it states that patients need to understand their diagnosis or understand the difficulties with giving our diagnosis and in the other column it shows you a quote.

Now there wasn't just one patient who said this, there were several

Figure 3

Quotes from patient interviews	Learning Needs	
'...after that I was never really officially diagnosed... nobody actually sat down and explained to me what I had and why I had it' Pt 04		To understand their diagnosis/ understand the difficulties with giving a diagnosis.
'...they didn't warn me about the dangers, they did not warn me about ...what the glaucoma...do to you or whatever...like, I've got glaucoma and that's it' Pt 15	2	To understand glaucoma
'I just said the drug was no good...I wasn't using it, but if I had enough information, I would be using that drug, even if my eyes are reddish' Pt 13	3	To understand the implications of eye drops
	4	To understand the side effects of eye drops and tablets
'I think there's also, my biggest fear was actually putting drops in my eyes' Pt 03	5	To feel confident to instil eye drops
'He said '...your pressure's 17' which didn't particularly mean a lot to me at the time. [if] you haven't a clue about the subject... you've no sensible questions' Pt11	6	To be able to ask questions of the Doctors/Nurses/Optometrists involved in their care

Figure 4

Quotes from patient interviews	Learning Needs	
'the main thing is...timescales between appointments. Quite a lot of time this concerns me...I did ring up and speak to the secretary, I wasn't given an earlier appointment because she said it didn't seem as if it was urgent. Now the consultant locally said it was urgent' Pt 06	7	To be able to challenge the system
'It was just forgetting and then thinking 'oh it'll be alright'. Erm, I think maybe for the first couple of months I'd be a bit...put it off...didn't know how to do it, erm but it did it took a while, but again, understanding the implications...implications of not doing it' Pt 03	8	To understand their own reasons for non adherence
'you read books about it and it'll scare the life out of you' Pt 10	9	To put the condition into perspective - to know how to manage their risk
'I found out more information, well that's just by looking on the internet, the International Glaucoma Association...so I got more information from them that way than anywhere else' Pt 04	10	To know where to get other sources of information and support

and this is an example of a quote. Another example of a learning need was for patients to be able to challenge the system. This happens when, for example, there might be delays to appointments which are put back. Some patients were quite worried about this but felt awkward or didn't understand how to ring up and challenge the fact that their appointment had been put back. From the quote in Figure 4, it also seems as if this patient received mixed messages as well.

Consequently, in this instance the learning need was about helping patients understand why appointments might be put back and therefore depending on circumstances how they can either accept it or if they really feel that it is the wrong thing to happen, what are the processes involved in trying to do something about it.

Note: More information about timescales between appointments can be found in the NICE Guidelines (CG85) published in 2009. Alternatively, patients are welcome to contact the IGA Sightline on 01233 64 81 70 to discuss their concerns.

Translating learning needs into a training programme

So we translated these learning needs into two sessions of two hours over two weeks. Patients were saying, they didn't want any more than two sessions, that it would be enough. Interestingly a few patients actually said they wouldn't come to a group education session and there was a lot of difference in opinion about when it should be put on, morning, afternoon or evening. This isn't a worry because if you're setting up a service in the hospital you can actually set up this programme at different times and slot in patients at the time that suits them.

Figure 5 shows the content of the first education session.

During session one, patients were first greeted, then they were put into groups of four and asked to share with one another their experiences of glaucoma and the questions they may have about their condition.

Figure 5

Session 1	Content
Patients' stories (10 mins)	Why are you here today? What do you want to know about your condition?
Getting to grips with glaucoma (30 mins)	What is glaucoma? (including eye pressure) Difficulties of giving a diagnosis Different types of diagnosis How might glaucoma effect my eye sight? What to expect at an eye clinic appointment?
Feeling confident with instilling drops (45 mins)	Practical workshops instilling eye drops and drop aids How eye drops work to control glaucoma Side effects of drops How to store eye drops Start to discuss behaviour of using drops/beliefs about drops/medicines in general
Understanding planning own adherence (35 mins)	Self management plan Filling out self assessment form on questions regarding adherence to drops
Information sources (5 mins)	IGA Website Nurse phone number
Evaluation	Verbal assessment

These were noted by Jane Ladditt, Glaucoma Nurse Specialist at Manchester Royal Eye Hospital, who ensured that during the course of the two sessions we addressed them all (if they couldn't be answered straight away, research would be done and answers given during the following session). Then we moved on to explaining what glaucoma is using the model of an eye, the difficulties of giving a diagnosis, the different types of diagnoses, how glaucoma affects your sight and so on. Then we moved into a practical workshop where we actually taught patients how to put in eye drops using artificial tears, so we made sure that everybody there who could physically do so was taught how to do it. There was an elderly gentleman who was just absolutely sure he couldn't put his own eye drops in but as a ward sister I remember teaching somebody aged 101 years old to put their eye drops in, so this gentleman left knowing how to do it. Then we talked about how eye drops work, side effects, storage and patients' beliefs about eye drops and so on. We got them to talk about their adherence and tried to get them to talk about the reasons for not being adherent and what they might do in order to be adherent. For example one of the things you can recommend is making sure that the eye drop bottle is near the lamp beside your bed so it becomes part of your routine to put the eye drop in because one patient had said: 'I keep them downstairs and sometimes I get into bed and I'd forgotten to put them in and then I'd think I can't be bothered to go back down'. Another person said: '... but I go camping and I forget to take them camping and I'm worried about it' therefore we discussed how this might be facilitated. We talked about how quite a few patients go away to Spain and places like that and don't plan ahead to get the prescriptions in advance. We were just talking through some of these problems to make sure it is in people's routine and because there was other people in the group they could hear what other people were doing as well.

Finally we talked about the IGA and we talked about Jane's phone numbers so if anybody had any questions they could talk to Jane and then we did a brief evaluation.

Figure 6 shows the content of the second education session

In session two, we reflected on the patients' action plans to improve their adherence.

We gave advice on the DVLA and we actually helped patients to rehearse the kind of questions they might like to ask doctors. At the end of the session, they had the opportunity to talk to Jane about their own glaucoma if they wished.

Figure 6

Session 2	Content
Feedback of action plans (30 mins)	Review of action plans by patients - did they help them to instil their drops?
Advice on DVLA	Information on the regulations concerning driving and glaucoma
Getting information (60 mins)	How to find out information they need in a consultation Group discussion
Individual chat with a health professional for advice (5 mins)	Opportunity to discuss treatment with specialist glaucoma nurse
Evaluation (10 mins)	Verbal evaluation

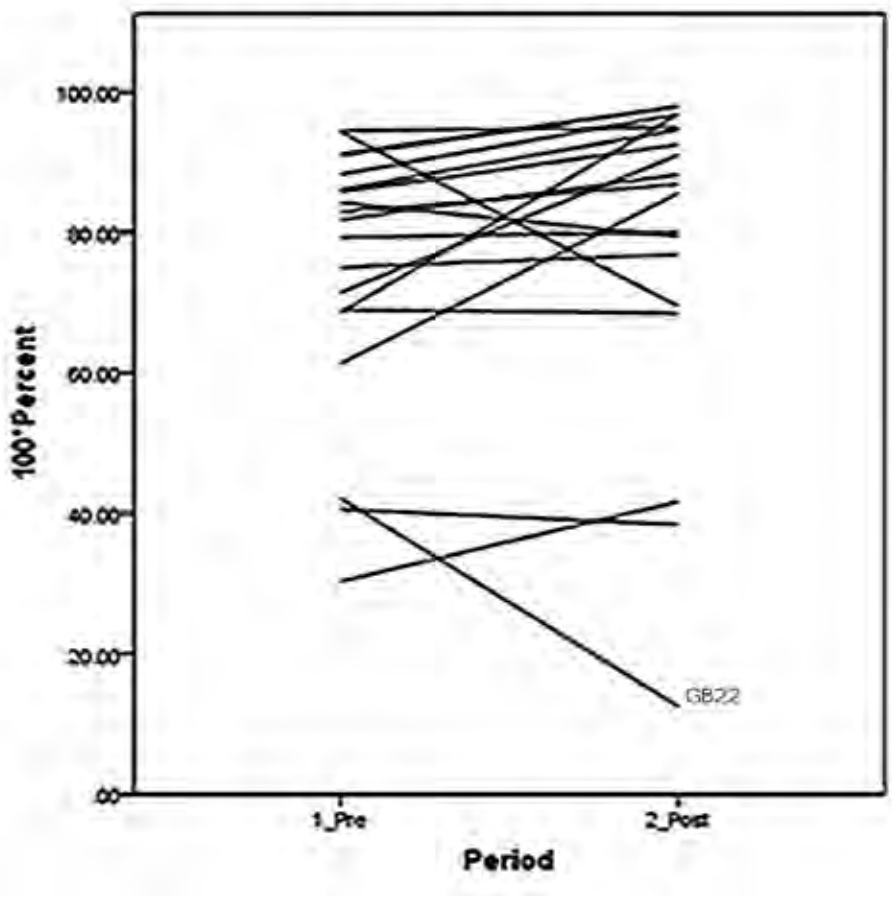
Evaluating the sessions

You will recall we wanted to see how feasible and acceptable the programme is. We did this by looking at whether patients would come to the education session, their reactions to the sessions, and whether if there would be any difference to their adherence before and afterwards.

Attendance was great. In September 13 patients came (10 for the first session and 10 for the second). In November nine came and eight for the second. Most people who came were over 70 years old and had chronic open angle glaucoma. Most of them were retired but there was a fair proportion who were still working. Initial reflections on the programme were that patients liked the eye models, to be shown how to put the eye drops in and to be reassured. Incidentally, we found out that patients don't like the Cosopt bottles, many of them were worried about the DVLA but felt reassured afterwards, and many of them voiced different reasons for non-adherence.
These are some of the quotes from the patients who evaluated the programme: 'I thought the course was fantastic', 'didn't expect to learn as much as I did', 'during the session you could interrupt and ask Jane questions which was very good', 'I liked the fact that they told us when you go to clinic don't be afraid to ask questions, so when I go next time I shall be firing all sorts of questions'.

Regarding the before and after comparison; we compared the understanding of glaucoma, whether patients felt able to look after their eyes, the quality of life, what they thought about glaucoma, their beliefs about medicines and whether

Figure 7 Per-patient line plot of adherence



they put their eye drops in. We measured these by questionnaires given out before the education sessions, immediately after and three months after. We found that their level of knowledge was improved: before the programme only two patients scored 15 out of 19 on the knowledge questionnaire but immediately after 11 patients scored 15 or more and at three months the score had dropped slightly to nine patients who scored 15 or more. In addition, they felt more able to care for themselves with regard to their eyes, their perceptions about glaucoma were more realistic, their beliefs about medicines and need of medicines were better and their quality of life, health and wellbeing immediately after went up, but went down again after three months.

During the course of the programme patients were advised to administer eye drops within a four hour window, usually around 10 o'clock.

To measure how often patients were putting in their eye drops, we asked patients to place their eye drop bottle in a small white container, keep it in there and only open it when they were putting their eye drop in. Every time they opened it, it was electronically recorded in the lid. Unfortunately, this was not fail-safe because patients could still unscrew it and not put it in but it's the best we could do. It was the first

time we used this device therefore we didn't know whether patients would take to it or not, but luckily all 25 patients used it which was good. We said patients were adherent if they put their eye drop in at the four hour window every day and if they didn't put it in using that four hour window we said they were non-adherent. The left hand side of Figure 7 shows patients level of adherence, that's what they were doing before the educational programme. The right hand side is where it was when it finished. So the graph shows that we actually maintained their level of adherence but we didn't improve it. You might think the programme hasn't worked however considering previous research has shown a decline in adherence over time it may be that having maintained adherence is actually a positive effect. This needs to be tested in a larger trial with a control group to make proper comparisons.

In conclusion patients can be closely involved with the whole process of research and gain a lot from it. Group based education shows promise. Our educational programme not only targeted knowledge but motivation and behavioural skills.

The education programme was carried out by professionals with patients and part of the programme is suitable for standardisation but strategies to improve adherence need to be individualised.

Jill Annis:

I don't think group education is for everyone. I think in some cases people will benefit more from one to one education but the group education can complement this.

One thing I feel very strongly about is that this programme should be rolled out and include all glaucoma patients not just the newly diagnosed because I come across plenty in my practice who've been diagnosed years ago and still don't know how to adhere to their eye drops, what they're for or how to use them properly.

Thank you.

We know that ease of instilling medication has a huge influence on compliance.

Many dispensers can be provided by your hospital, or alternatively, all of them can be purchased from the IGA. For more information on how to get hold of the dispensing aids please contact Sightline on 01233 64 81 70.

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Questions & Answers

Q1. When was the study actually carried out and over what period of time? How often did you see the patients?

A1. Two years but it was a pilot. We just wanted to see whether we could gain enough evidence for us to feel confident to go forward.

Q2. How many clients did you have in your pilot study?

A2. In the pilot study we had twenty five altogether.

Q3. I've had glaucoma for 10 years and I've been very happy with my Consultant but I haven't never seen a nurse at all in clinics and there have been lots of little questions I've wanted to ask, but because I'm an ex-nurse people assumed I would have known. What are the chances of maybe involving your specialist nurses in clinics?

A3. Jane Ladditt:
I've been a glaucoma nurse in Manchester for two years so it's quite a newish post really and at the moment there is only one of me because of a funding issue, so for the near future there will continue to be only one of me. While I do try and see as many patients as I can, in a clinic of 100 patients I am limited as to how many I can see.

Q4. I think the IGA is marvellous and I've recently become a member and I've been able to ring up if I've been frightened, I've been upset or worried and it's been brilliant to have somebody at the other end of the phone that's been able to help and advise me. I do appreciate the shortages with only one of you and there's hundreds and hundreds of people with glaucoma but it would be nice to be seen at some point, you know, like your people in your pilot study were.

A4. Heather
We're hoping to set the education programme up at Manchester. We're sort of going through all the procedures; we're very close to getting it off the ground.

Jane

Yes, it's almost ready and then what will happen is that any doctor in clinic will be able to refer a patient onto this course.

Heather

With the latest Research Grant that we have been attributed by the IGA, we're planning on trying to roll the programme out to about five other hospitals and see how it works somewhere else.

Q5. Drops only have a limited lifetime, once they've been opened 28 days, I write on my box 'started on Sunday evening at such a time' and I know 28 days on from that. I know a lot of people who don't do that and they haven't ordered the prescription in advance so they throw the old bottle away or they carry on using that, or they run out of drops and they don't bother. It could be something that you might consider when doing your studies.

A5. If you ever do run out of your drops that you use regularly you can always go to your pharmacist and they will give you an emergency supply. There's always a date on the bottle, it's not going to harm if you go a day over and we normally say 'look at the date on the bottle and if it's the 1st September throw them out on the 1st October. I don't personally have a problem but I know people who do and they throw the bottle out and then they don't bother getting a fresh supply. This is where compliance comes in.

Q6. I was diagnosed in 2007 and I was asked to take part in a programme which involved one interview with the nurse face to face and then a lot of telephone interviews in which she checked that I was taking the drops and I also had to keep a drop diary for about a month. I think the programme went on for at least a year and at the end of that I had a final interview on the telephone. I never heard whether it was decided that this nurse involvement at that stage was useful or not. Was it the precursor of the programme that you're talking about?

A6. The study you are referring to has only just come to an end. I can confirm is that it worked. It is going to be published in the journal called 'Eye'. It's just been accepted.

Q7. I wanted to ask whether we can enrol for the next study?

A7. We're going to be doing the next studies at different hospitals, it depends where you are.

Q8. I do always try and write on the bottles but sometimes it's very difficult to write on the bottles so if you can get the manufacturers to put a bit (the date) on the actual bottle itself rather than the container.

A8. Actually getting manufacturers to do something like this is incredibly difficult. I know it seems obvious but the writing on most of these bottles is so small I for one would not be able to see them. Your pharmacist can give you large print labels. If you ask for them they will put large print labels on for you.

I thought I'd heard that it was good to keep your bottles in the cardboard containers that they arrived in and there's plenty of room to write on. I've always kept my bottles in the containers that they arrive in, it's probably a good idea and that will solve your problems.

Q9. There is one added nightmare. If you've got to take antibiotic drops as well for any period of time and they have to be kept refrigerated it's really difficult on holiday. I've done things like leaving them in a kitchen in the hotel, I even had to go to the local Co-op store and ask if they'd put them in the fridge overnight, but there must be some better way of dealing with this.

A9. Certainly as far as the glaucoma drops are concerned the IGA sells a pouch, the Cool Wallet, in which you can put the drops. You soak it in cold water and it will keep them at a safe temperature right through a 48 hour period just because of the evaporation of water. Then you can just re-soak the pouch again.

Regarding individual antibiotic, you can take a little cool pack with the little gel insert that freeze and hotels or somewhere else may be able to freeze that for you rather than just storing your drops in their fridge. They may be happy to put the little chill pack in their fridge. I recommended that to people in the past. If you've got two or three of them you can have one freezing whilst one is in the pack and that's what a couple of my patients have done while they were going abroad somewhere warm. I don't know if that's helpful. Camping stores sell very little ones as well.

Q10. I've met the glaucoma group at Henshaws Society for the Blind and ran a survey of the group which raised and matched the same issues than the ones highlighted by Professor Waterman's study. I heard about Heather's work and met with her. She agreed to run the course as part of a day we run called 'Living well with glaucoma'. I have to say it completely mirrored this study: there were three people who it transformed their understanding and their use of the medication in particular and one person had an incorrect prescription. Fortunately they

had an appointment the next day and had their prescription changed the following day. It was very, very empowering I would say for those people and we now have a glaucoma support group that runs every two months. There is some education in all those groups but we are hoping to run the same day if we can and we might be begging Professor Waterman to run the same one. If anyone is interested in attending something like this we can actually set that up quite quickly in the New Year or sooner if possible. I would be very happy to take any details and it's very easy to park where we are as well.

A10. Yes, I've got absolutely no problem at all with going back with Jane and doing one of these as part of Henshaws and if anybody here would like to attend you'll be most welcome to attend.

Q11. I've had open chronic glaucoma for the last 26 years. I've had the most information and help that I could've had. I cannot fault the professionals who have taken care of me over the years. I've had every little bit of information and I've always been asked 'any questions?'

A11. Yes, I agree some patients do have a very good experience but some people feel very shy and when asked if they've got any questions will say 'no' like that gentleman.

I don't think all Consultants give you the time for questions.

It can be difficult to educate everybody singularly and that's why we've done this group education in order to try and get across the essentials to groups of people because it seems to be a more efficient use of time.

Yes, The IGA is here to answer the questions that either you didn't get an answer to or you forgot to ask when you were in the clinic because you only get that little bit of time with the healthcare professional, be it a nurse or a doctor or someone else. They have only a limited time to be able to answer you, although they are so much better than they were thirty odd years ago. The IGA is here to answer all your questions, whether you didn't get an answer, didn't get the time to ask or simply forgot the answer. It is well known that we often remember about a third of what we are being told when having conversations, with this simple fact in mind, as long as you get that third that's fine, and we are here to complete the answer and make up the other two thirds therefore please do make use of

us and our information services including our helpline, Sightline.

Q12. Why do opticians not always pick up on glaucoma? This has been my experience.

A12. There are a number of reasons why an optician may not pick up on glaucoma. One of them may be that they don't perform all of the relevant tests to make the diagnosis. Of course all of our lives would be a lot easier if we had one test that gave us the answer 'do you have glaucoma or not' and it's about how those pieces of information interact together.

The second thing is that our understanding of glaucoma has changed over the years and so optometrists nowadays are getting plenty of education on how glaucoma can present, what the appearance of the nerve in the eye can be like, what the pressure can be like and a number of other things. I know how much things have changed. I started in ophthalmology in 1988 and at the time somebody with normal tension glaucoma would have been so rare that everybody would have been called in to see them in the Consultant's room. Now our understanding is that probably 40% of our glaucoma patients are within that bracket nowadays which means that we were probably missing 39% of them at least in those days so again that message has gone out to optometrists and they're beginning to understand that. If it was very easy to diagnose, or there was one simple test, then obviously we wouldn't be still missing people. Some of that is about general education and understanding and how that's moved on over time. I think one of the results of the NICE guidelines in management and treatment has been that optometrists have looked differently at patients, although it's not about diagnosis and referral. They've referred more people into the hospitals than they had before, and it has also made a difference to the number of people being picked up, so I think there's a multi-factorial reason for that and some of it is just about change in our perception and our education which is improving.

Q13. I have narrow angle glaucoma and I heard recently that opticians cannot pick that up. This was a shock to me?

A13. I think that depends, narrow angles may be obvious at the microscope but may be less obvious when doing other tests. In some people who have sub-acute pressure rises, there can be symptoms that can alert you to thinking that's the case but most optometrists don't do gonioscopy so they cannot make the definitive diagnosis.

Anybody who is suspected of having narrow angles or whose pressure is high nowadays should be referred in for gonioscopy. Now that could be happening in the community, it doesn't have to happen in the hospital eye service. It could be in a clinic of referral refinement in the community but gonioscopy should be done, it is mandatory really as part of the diagnosis of glaucoma, but optometrists can't necessarily do gonioscopy. Things are changing though, there are a number of optometrists who are trained to do it now and any optometrist whose going to be working in a screening service generally does something towards the Diploma of Glaucoma Certificate in Diagnosis which at the moment involves gonioscopy. I've been involved in that and in the examination of it and I know that those optometrists have to be able to do gonioscopy and be able to diagnose narrow angles, so if you're being referred in that should be picked up now by them.

Q14. Can you actually say how long glaucoma can be there for undetected? Can it go on for years and years and one goes to the opticians and each time is told everything's fine?

A14. It depends on how much damage there is when it's picked up as to what the prognosis may be in individuals. Certainly a number of people will have had glaucoma for quite a period of time before they're referred in and it depends on whether they have a normal pressure range or a very high pressure range and what they're referred for.

I know of one piece of work which looked at patients who had initially been referred and were then maybe lost to follow up. Their referral letter was sent in from the optometrist, but they never actually made it to the hospital eye service and then represented later on. There was a paper in the late 80s or early 90s (Murdoch J.R. & Jay M.L. (1993) The rate of visual field loss in untreated primary open angle glaucoma. Br J Ophthalmol. 1993 March; 77(3): 176–178) that looked at how much vision people appeared to have lost and how much change there was in the nerve in the eye when they represented and looked at the rate of change.

It was very clear that people with much higher pressure do deteriorate faster than people with normal or lower pressures generally, and that's the only piece of evidence that we have. Therefore if somebody has very, very high pressure, we have to assume (if they still have got good functioning nerve and feel) they haven't had it for a very long time when we see them. But you can't tell on the day you meet somebody

in the clinic how long they've had glaucoma for.

Of course it is difficult to diagnose glaucoma because by definition it is a progressive condition. If you take a snapshot, so you look at somebody on one occasion you don't know if it's progressing because that's what it is now, so we need to see some more snapshots later on and see if there's change. It is quite possible to have a visual field defect that is not glaucoma and that's why in some cases it can take months, maybe even one or two years to fully confirm a diagnosis of glaucoma.

Of course we don't wait that long to start treating you because if it looks as if it's glaucoma, and there's all the signs and symptoms of glaucoma, there's a very good chance it will be glaucoma so the consultant is going to give you the drops anyway.

Q15. If you're actually told to have laser treatment, could there be a mistake in the fact that you might not have glaucoma but they think you've got glaucoma, and therefore if you have the treatment of laser surgery you're putting yourself at risk.

A15. Yours is narrow angle glaucoma?

Is that different?

With narrow angle glaucoma you can see with gonioscopy you've got a narrow angle and it's likely to close, so rather than let you have an acute attack, which is extremely painful and does do some damage, they will do the iridotomy, they will provide the little safety valve, the bypass and it won't do any harm at all it'll just stop you having a problem in the future.