# Summary analysis of the patient survey

1. Introduction

1.1 This paper is a summary of analysis of the patient survey that was run for five-weeks between the 11th September and 20th October 2017, for the Inquiry into capacity problems in NHS eye care services and avoidable sight loss in England, by the All-Party Parliamentary Group (APPG) on Eye Health and Visual Impairment. The survey gathered data from patients who had received treatment within the last three years, (not including the routine provision of glasses or contact lenses) about their experiences of eye care services in England. The text of the survey is shown in the Annex.

1.2 This is a version of the paper that the secretariat produced for the Expert Advisory Group to consider which has been supplemented by the addition of patients’ quotes in unedited form.

1.3 In addition to providing brief demographic information about respondents, the paper analyses the following:

* respondents’ experiences of delay(s) and/or cancellation(s)
* what action(s), if any, people took if they had experienced a delay(s) and/or cancellation(s)
* the impact of delay(s) and/or
* what people thought worked well and not so well about their care, and
* suggestions for improvement.

2. Demographic information about the people who responded to the survey

2.1 557 people completed the patient survey - 518 patients (93 per cent) and 39 friends, family and/or carers (7 per cent).

2.2. Respondents self-reported their eye condition and most had more than one condition. See Table 1 below.

**Table 1: Respondent eye condition(s)**

|  |  |  |
| --- | --- | --- |
| **Eye condition** | **Number of people** | **Proportion** |
| Cataracts | 161 | 29% |
| Glaucoma | 122 | 22% |
| Wet AMD | 114 | 20% |
| Dry AMD | 79 | 14% |
| Wet and Dry AMD | 53 | 10% |
| Eye diseases caused by diabetes | 27 | 5% |
| Retinitis Pigmentosa (RP) | 15 | 3% |
| Not sure | 4 | 1% |
| Other eye condition\* | 157 | 28% |

**Base: 557**

**\*** ‘Other’ eye conditions reported included Birdshot, Keratoconus, and Punctate Inner Choriodopathy (PIC) among others

2.3 In terms of gender, 29 per cent were men and 66 per cent were women (the remaining respondents did not answer this question), and in terms of respondents’ ethnicity, 89 per cent were White British.

2.4 People who responded were spread across England, with most being in the South East (23 per cent), North West (16 per cent) and South West (10 per cent).

2.5 People of different ages were represented:

* 4 per cent were aged 18-34
* 6 per cent were aged 35-44
* 14 per cent were aged 45-54
* 19 per cent were aged were aged 55-64
* 25 per cent were aged 65-74
* 19 per cent were aged were aged 75-84
* 9 per cent were aged 85-94
* 1 per cent were aged over 95
* The remaining respondents did not answer this question

3. What were respondents’ experiences of delay(s) and/or cancellation(s)?

3.1 Just over half of respondents (53 per cent) had experienced a delay(s) and 20 per cent had experienced a cancellation(s). A total of 15 per cent reported having experienced both.

3.2 Looking at the main individual eye conditions, 65 per cent of the people with glaucoma had experienced a delay(s), along with 50 per cent of the people with cataracts and 48 per cent of the people with dry age-related macular degeneration (AMD).

3.3 Similarly, about a quarter of people with glaucoma (27 per cent) had experienced a cancellation(s), along with a quarter of people with cataracts (24 per cent). However, a higher proportion of people with wet-AMD (14 per cent) than dry-AMD (8 per cent) had experienced a cancellation(s).

3.4 Of those who had experienced a delay, most people had experienced either one (26 per cent), two (21 per cent) or three (26 per cent) instances of a delay(s) and/or cancellation(s). However, 16 per cent reported more than five instances. There doesn’t appear to be a correlation between the number of delays and eye condition.

3.5 The length of the longest delay ever experienced varied, but more people reported their longest delay as being one month (17 per cent), two months (13 per cent) or three months (11 per cent). 5 per cent of respondents (16 people) reported a longest delay of over 12 months.

4. What action(s), if any, did people take if they had experienced a delay(s) and/or cancellation(s)?

4.1 Most people (85 per cent) had taken at least 1 action following a delay/cancellation. We found that 1 in 5 respondents (20 per cent) had taken four or more actions.

4.2 Most commonly, respondents had phoned the clinic (reported by 36 per cent of people) or contacted the consultant’s secretary directly (reported by 25 per cent of people). A small number of people had emailed the clinic (9 per cent) - these were all people aged 74 or under.

4.3 Very few people (5 per cent) contacted their local MP or sought help and/or advice from Citizen’s Advice Bureau (2 per cent).

4.4 We asked respondents who had made enquiries at the hospital to tell us whether they were able to find someone to resolve the issue for them. Of those who responded (231 people), the majority (66 per cent) were able to find someone who resolved the issue for them. However, 22 per cent had not and for 12 per cent the issue was on-going.

5. What is the impact of delay(s) and/or cancellations?

5.1 Overall, the majority of respondents agreed that experiencing a delay(s) and/or cancellation(s) had caused them anxiety and/or stress (77 per cent).

5.2 Similarly, a higher proportion agreed (54 per cent) than disagreed (21 per cent) that experiencing a delay(s) and/or cancellation(s) has had a bad effect on their day-to-day life. 25 per cent neither agreed or disagreed; 17 per cent disagreed and 4 per cent strongly disagreed.

5.3 We asked those respondents who had agreed that experiencing a delay(s) and/or cancellation(s) had a bad effect on day to day life to tell us what the biggest impact had been on their life. Five key themes emerged from the responses:

* feelings of worry/anxiety/stress (one response typical of many was “Increased stress and worry not knowing if my condition was stabilising”)
* worsening condition/health impact (“I have lost a considerable amount of sight in my right eye”)
* negative impact on day-to-day functioning (“I cannot plan my life because I'm constantly waiting to hear when my next appointment will be”)
* unmet expectations, and
* a lack of information.

5.4 Although a slightly higher proportion of people agreed (37 per cent) than disagreed (28 per cent) that the delay(s) and/or cancellation(s) experienced had made their eye condition worse, 35 per cent of people actually reported a neutral response. It is possible this may indicate that respondents did not feel able or willing to make a more medical judgement about the impact of delays/cancellations on their sight condition.

5.5 A small number of respondents reported NOT being upset or worried about the delay(s) and/or cancellation(s) they had experienced (17 per cent).

5.6 We asked these people to tell us why they felt this way. Reasons included understanding that the NHS is under pressure and that delays/cancellations can happen (“[I] accept cancellations are part of the service and await the next appointment”) and being a non-urgent case, so not feeling the need to be seen straightaway (one person said “[I] didn't mind being delayed as [I] felt more people could have more urgent cases”).

5.7 Some people replied that, apart from the delay(s) and/or cancellation(s) they had always received a good standard of care from the eye clinic and others felt that if there was a real emergency then they would be prioritised or be able to be seen by Accident and Emergency (“I knew if there was a serious problem I could be seen in A&E or get a quicker appointment”).

6. What did people think worked well and not so well about their care?

6.1 Although overall more people reported being satisfied with their care (64 per cent) than being dissatisfied with it (22 per cent), of those people who had experienced both a delay AND a cancellation, a higher proportion reported being dissatisfied (43 per cent) than being satisfied (34 per cent).

6.2 People were grateful for the aspects of their medical care that had gone well (from one-off surgery to diagnosis to ongoing treatment such as injections) and there were many comments about experienced and supportive staff, particularly clinical staff, even from those who had experienced delays. The following are typical of the many comments:

* “The care in the…hospital has been excellent and the surgery and aftercare I had there has also been excellent”.
* “I cannot fault the consultants for the care and reassurance they give me”.
* “First class treatment”
* “The consultant staff are wonderful, understanding and caring”
* “Fantastic treatment from my consultant and team and nurses, they bend over backwards to help!”
* “The clinical expertise has contributed to the quality of my life. I am registered as 'severely visually impaired' and I recognise that without the treatment I have received I would be a position of virtual sightlessness”
* “My consultant was extremely competent and had a fantastic bed side manner”
* “Treatment and consultants are very good; the problem is trying to get an appointment within the relevant timescales to see them”.
* “Apart from the delays mentioned, all other aspects of my care have been brilliant, from the nurses to consultants, support and treatment, I can't fault them.”

6.3 Positive comments included those valuing good communication about treatment and eye conditions such as the following:

* “Communication from clinical staff is very good - they take time to explain my condition and treatment to me and involve me in decisions.”

6.4 There were also some positive comments valuing provision of, and signposting to, emotional and practical support such as low vision clinics, charities, and Eye Clinic Liaison Officers. People often valued continuity of care or made positive comments about particular clinicians. A few people mentioned valuing expertise from someone with particular qualifications or a specialist in their condition:

* “Since I was transferred to glaucoma specialist, I have nothing to complain for as he is the best specialist I could not have dreamed of.”
* “Seeing the same consultant who is a specialist in the rare eye disease I have has made a world of difference. The continuation is key to my condition being treated and monitored properly.”

6.5 Although the experience of delays and cancellations were consistent themes for the majority, there were quite a lot of comments valuing the impact of prompt/ regular and efficient treatment where this occurred, with some patients having mixed experiences:

* 10/10 for everything including having injections in my eye within two weeks of diagnosis.”
* “Treatment initially improved my eyesight, and was delivered promptly, but the recent delays seem to have failed to control the condition and my sight is deteriorating.”

6.6 Some people had no response when asked what aspects of their care worked well, and others listed more things that hadn’t worked well, such as:

* “Not really - I feel like I've had to fight for the care I knew I needed”.

6.7 The experience and impact of delays and capacity issues were prominent in things that didn’t work well, including long waiting times in clinics, problems securing appointments and poor communication from the clinic.

6.8 The following responses about appointment delays were typical of many. People raised concerns about administrative staff and processes which don’t take account of clinical need or understand the impact of delays on certain sight conditions. People also complained about lack of communication about appointments or having to proactively chase these. Some mentioned lack of co-ordination between different appointments – e.g. over-running and clashing with each other on the same day or requiring lots of different appointments, impacting on their life.

* “it's length of time between appointments that is the issue. I feel like I've struck gold if I get an appointment at the clinically appropriate time”,
* “Appointments! Always up the creek, if the consultant says he must see me in 6 weeks it comes through for months, situation has got worse!”
* “When MD was diagnosed, a delay of six weeks for an appointment at eye clinic (my phone calls, a letter and calls from GP complaining at delay) caused bleed in the wet eye to increase rapidly”.
* “NEVER get an appointment when the specialist has said I will be offered one. This is now "normal" in this area and friends tell one another always to ring and make an appointment yourself"
* "I was surprised to find that in order to be given appointments for ongoing treatment I had to ring up each time to get appointments which were often delayed or cancelled."
* "The bureaucracy is out of synch with the clinical staff. They make arbitrary decisions regarding timing of injections that they are unqualified to do."
* "The annoying thing is that you cannot book your next appointment whilst you are at the hospital and when notified by a letter 3 months later it is for a date within the next fortnight. This can on many occasions impact negatively on your other commitments".
* "Despite everyone doing their jobs to the best of their ability, the wheels seem to be coming off somewhere. When I was first diagnosed with glaucoma, I would have the tests, see the Consultant and he would tell me when to come again. I went to reception, they gave me an appointment, I felt reassured. Now, my appointments are all over the place, often having to attend as many as four times when one would have done the job 3 or four years ago! It is evident that the staff are frustrated, I'm frustrated and also very stressed and sometimes frightened. Eyesight is not something that can be told to wait while this gets sorted out. Now, in addition to glaucoma my cataracts are becoming more and more of an issue and I am worried that there is going to be a long wait before they will be sorted. I can't risk a fall as I have osteoporosis".

6.9 The following comments about busy clinics were also typical of many comments received with some emphasising the effect of capacity issues on communication with doctors or physical space for appropriate care:

* “Eye clinics are hugely and depressingly overcrowded”,
* “Each time I go for a normal appointment it is a day taken out of my life because of the ridiculous waiting time at the hospital”
* “Attending chaotic "clinics" for 3-4 hours a time (approx every 6 weeks) is a huge waste of my time and is tough on my employer.”
* “The hospital building…is unfortunately old and insufficient for modern day patient and treatment needs. Eye tests in the corridor with glare and constant flow of people trying to use the lift make it impossible to focus on an eye test”
* “The clinics are very busy and over booked and therefore long waits occur, also this means the doctors are pressured and sometimes I leave feeling very negative as nobody has had a chance to talk to me and explain what is happening in relation to my sight.”
* “Constant slipping of appointments. Not knowing who you will see. Long waits in crowded and uncomfortable waiting rooms. You lose the ability to talk sensibly to the doctor.”

6.10 There were some comments about aspects of medical treatment or care which didn’t work well, ranging from diagnosis to one off or ongoing treatment to the whole end to end process. In some cases, these were attributed to poor care, and/or impact of delays.

6.11 Other issues raised were lack of continuity of care and poor communication with patients including lack of information about people’s conditions, treatment, and treatment options, lack of emotional and practical support, lack of empathy, disability awareness or other issues with the attitude of staff. Poor information sharing, and referral processes which result in delays were also mentioned, and some made reference to lost notes or clinicians not reading notes. The following example comments reflect some of these concerns:

* “Communication has been poor. Very little information given regarding what I can expect from my sight in the future.”
* “At the end of the treatment the results of the final scan and effectiveness of the treatment were not explained to me. The doctor is only available on demand and seemed annoyed that I wanted to know about my health!”
* “although all staff are very professional they forget how scary it is to have this condition knowing that blindness is the most likely outcome. They can be harsh and abrasive”
* “There is never any opportunity to ask questions”.
* “I honestly felt so shocked by my diagnosis I really wish counselling would have been offered or even an option”.
* “No information given about the condition or treatment of AMD on diagnosis, not even that advice and support could be sought from the RNIB and Macular Society. Phone numbers would have been nice.”
* “When there was no continuity of staff then getting told conflicting information by different people.”
* “You always have to be on top of your appointments, make sure that information is communicated to the people who need to know and that appointments are arranged when they are meant to happen. This is difficult for a lot of people.”
* “When I attend clinic, if I do not see my consultant, and see another doctor, they do not always give me the correct information and correct results from my tests”.
* “The health care staff didn't know what a white cane was. Two years on they don't know how to guide staff and continually speak to the person who I attend with and not the patient.”

6.12 A few people mentioned difficulties getting accessible transport to the locations of their appointments, lack of accessible information, or inaccessible buildings. Also, a few people mentioned lack of access to consultants or other clinicians with appropriate qualifications or experience dealing with their condition:

* “The main problem for me is travel, I have a number of other health issues as well as sight issues, the 6 hours, sometimes 8 hours on public transport to get to and from the hospital is extremely tiring for me.”
* “I'm totally blind. The hospital is totally inaccessible. If I could, I would get the bus to hospital, but they won't meet me at the bus stop, so I have to use hospital transport, which is very slow”.
* “I have notified the hospital four times asking for appointment letters to be in large print - they do not do this.”
* “The communications are not accessible and do not meet the NHS accessible information standard”
* “Signage and information at the eye hospital were not accessible without sighted assistance”.
* "Everything has been fantastic apart from 2 occasions when I saw trainee doctors as my condition is so rare they didn't have a clue. I only see one consultant now after I complained".

6.13 Quite a lot of people did not report any aspect of care that didn’t work well, saying they were satisfied with all aspects, e.g.

* “Not one negative thing can be said. Everything has been top-notch.”

7. What suggestions for improvement did people make?

7.1 We asked respondents to make suggestions for improving their experience of services. The majority of those suggestions received were about avoiding delays and cancellations to appointments, shorter waiting times, less overcrowding and more co-ordination in clinics, improvements to booking processes, and more funding.

7.2 The following are typical of the many suggestions about delays, cancellations, and appointment booking processes:

* “if follow up treatment is needed, send an appointment, don’t expect the patient to chase you”,
* “I would like to come out of the eye clinic, go to the desk and make my next appointment. Other NHS departments and clinics can manage this perfectly well. It works. I don't want to have to wait 9 months for a 6-month appt when my eyesight is still deteriorating. Think of the money you would save with unnecessary phone calls and letters”.
* “not having appointments cancelled, especially at short notice”,
* “I would like my appointments to always be on time if I've been told to be seen in 3 months that is what I want.”
* “Appointment organisation could be bettered to accord to consultant's treatment. The admin does not recognise the importance of timely intervention”.
* “An appointments system that does not require my putting pressure on people to achieve an appointment would be most welcome.”
* “Increase the coverage for injections clinics so that it is possible to have an appointment in the time period determined by your clinician”
* “Perhaps the database/patient record system could notify secretaries when follow up appointments have not been made to ensure these are not missed.”

7.3 The following comments are typical of the many suggestions about improving clinics:

* “clinics shouldn’t be overbooked as this can be stressful for people, patients should be informed of how long it may take to be seen and if there are any delays etc”,
* “Environment needs improving - facilities are overcrowded and eye tests are difficult in noisy areas”.
* “there are too many people to turn up at the same time slot”.
* “More careful running of the clinics - managing the number in attendance at each so I don't end up waiting till 5.25pm to be seen and then getting about a minute and a half with the consultant”.

7.4 There were a large number of comments like these about more funding for more staff and resources, with a few people mentioning funding for equipment such as scanners:

* “Employ enough doctors,[ nurses etc to cut the waiting time for appointments!”
* “Better resources i.e. staff and funding for the service to balance what I understand is the constant increase in cases of various eye problems and diseases. this would help all patients”.
* “Sight needs to be given more importance in the NHS and have more funding.”
* “More consultants, more staff.”
* “The ones we have are excellent but they just can't cope with the volume of patients”.
* “Just more clinics for the injections so more staff.”

7.5 There were a smaller number of suggestions about better communication and better support. These included communication about conditions and treatment, time to ask questions, more emotional and practical support, and better engagement with patients including empathy, disability awareness, and listening to patients. They also included better communication between departments, continuity of care, and information about patient care being available to the right professional as treatment could suffer or be delayed where information had not reached the right person:

* “Being given a timetable of treatment indicating what should be happening and when would be very reassuring.”
* “Tell the person everything and discuss it with them”
* “I wasn't listened to as I knew my problem had the potential to be serious. I was treated like an idiot, which I am not. Listening skills need to be improved. We are not all fantasists!”
* “Train NHS staff, speak to the patient not the person who accompanies them, alter signage and most importantly listen to the patient”.
* “In actual care, not really, it's already so good. But information about coping should be better”.
* “My only comment would be that, clerical staff/receptionists should be made aware of what it's like to have a sight problem and have more empathy with patients”.
* “Make sure patients are referred to the right people”
* “Personally, and think this applies to everybody, is that the doctors have time to talk to me about my eye condition. Although sometimes there is a long wait it would be acceptable if you could come away with positive information of the eye condition and perhaps refer to a clinic where practical advice could be offered.”
* “I feel there is far too much paperwork involved in communications between hospitals, doctors and pharmacies. It would make everyone's job easier and more efficient if one doctor could easily forward details by email / drop box or if my 'team' had access to the same systems/information regardless of location.”
* “Patients should see the same doctor every time they attend a clinic so they’re able to build a relationship and feel comfortable and so they feel like they’re truly cared for”.
* “better more cohesive working and communication”
* “Yes, stop sending people from clinic to clinic, why cannot one doctor/clinic take responsibility, instead of fobbing people off to clinic after clinic, just another tick box exercise.”
* “Shorten the time between GP referral and initial hospital appointment”
* “Opticians should be able to refer direct to the hospital. When letter from optician is sent to GP the GP doesn't see you just sends a request to eye department, this causes delay”.

7.6 There were suggestions from a few people on the following issues - more accessible information, accessible transport to hospitals, or treatment in locations closer to home, access to treatment, research to improve treatment/ find cures, developing the role of local optometrists/ community eye care within the eye care pathway, to help relieve current pressures, and more access to specialists/ consultants e.g. for rare and complex conditions:

* "as I don't drive, I would prefer my 'maintenance' care to be more localised with the option of specialist care if needed. I also worry what will happen if my sight deteriorates and the journey becomes more difficult.”
* “Patient transport needs to be available and reliable”
* keep clinics at a local hospital and not centralise them to hospitals miles and hours away.
* would like to have leaflets and appointment letters in a format you are able to read
* “Only by national research to find a cure. I hope this will happen in the near future”.
* “Adequate staff at hospital clinics. High quality community care to monitor eye health, with rapid referral to consultant clinic if problems develop.”
* “Extra clinic capacity could be achieved by getting local optometrists to do routine eye pressure checks for people with glaucoma who do not require hospital follow up”
* “if you could see the top consultant at least once a year, or before a big change in your care.”
* “I would like to see the same doctor each time and for that doctor to be an expert in my condition.”

7.7 Some respondents made no suggestions for improvement.

Annex: Text of the patient survey

The All-Party Parliamentary Group (APPG) on Eye Health and Visual Impairment is running an Inquiry during 2017 into the issue of capacity problems in NHS eye care services in England.  
  
The APPG on Eye Health and Visual Impairment is made up of both members of the House of Commons and the House of Lords from all political parties.  
  
The APPG Inquiry needs to hear from patients who have received treatment within the last three years (not including the routine provision of glasses or contact lenses) about their experiences of eye care services in England (both positive and negative experiences).  
  
The survey is voluntary and will take about 15 minutes, is completely anonymous, and will help Parliamentarians make recommendations to improve the commissioning and planning of eye care services in England.

We will also use the findings to support the future work of RNIB in improving the care for people with eye conditions.  
  
If you would prefer to take part in this survey over the phone, have any questions or are having difficulty completing this survey, please contact the campaigns hotline on 020 7391 2123.  
  
The survey will close on 20th October 2017.

1. Please tell us which eye condition(s) you have (select all that apply)?

* Wet AMD
* Dry AMD
* Wet and Dry AMD
* Cataract(s)
* Glaucoma
* Eye diseases caused by diabetes
* Retinitis pigmentosa (RP)
* Not sure
* Other (please specify)

1. ‘Delay’ refers to an appointment/treatment time longer than recommend by the clinician. For example, the clinician said that your next appointment/treatment would be in the next three months but it actually took four months. ‘Cancellation’ refers to an appointment/treatment which was cancelled rather than rescheduled. Within the last 3 years, have you experienced any of the following (tick those that apply):

* You have experienced a delay(s) to your care
* You have experienced a cancellation to your care
* Or none of the above (if you select this open please skip to question 13.)

1. Within the last three years, approximately how many times have you experienced a delay or cancellation to your appointments:

* 1
* 2
* 3
* 4
* 5
* More than 5 instances of delay(s) and/or cancellation(s)

1. Within the last 3 years, approximately what has been the **longest** **delay** that you've ever experienced:

Not experienced any delays

* 1 week delay
* 2 week delay
* 3 week delay
* 1 month delay
* 5 week delay
* 6 week delay
* 7 week delay
* 2 month delay
* 3 month delay
* 4 month delay
* 5 month delay
* 6 month delay
* 7 month delay
* 8 month delay
* 9 month delay
* 10 month delay
* 11 month delay
* 12 month delay
* A delay of over 12 months

1. Following on from the question above - which eye condition was that delay in relation to?

* Wet AMD
* Dry AMD
* Wet and Dry AMD
* Cataract(s)
* Glaucoma
* Diabetic eye disease
* Retinitis Pigmentosa
* Other, please specify

1. Please tell us how much you agree or disagree with this statement:

The delay(s) and/or cancellation(s) I have experienced have had a bad effect on my day-to-day life.

* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree

1. This is only for respondents who ‘agree’ or ‘strongly agree’ to the question above.

In your own words, can you tell us what the biggest impact of the delay(s) and/or cancellation(s) has been on your life?

1. Please tell us how much you agree or disagree with the following statements:

‘The delay(s) and/or cancellation(s) have made my eye condition worse’ and

‘The delay(s) and/or cancellation(s) I have experienced have caused me anxiety and/or stress’

* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree

1. Please tell us how much you agree or disagree with this statement:

‘Other than being irritated/ inconvenienced, I was not upset or worried about the delays and/or cancellations I experienced’

* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree

1. For respondents who ‘agree’ or ‘strongly agree’ to the question above:

In your own words, can you tell us why, apart from being irritated/inconvenienced, why you didn’t mind being delayed or cancelled?

1. Have you ever taken any of the following actions following a delay and/or cancellation (tick all that apply)?

* Emailed the clinic
* Contacted the consultant's secretary
* Phoned the clinic
* Went to the clinic in person
* Sought help/advice from friends/family
* Sought help/advice from another health professional (e.g. your GP)
* Contacted my local MP
* Went for an appointment/treatment at a private provider
* Sought help/advice from the Citizens Advice Bureau
* Sought help/advice from RNIB
* Sought help/advice from another voluntary or charitable organisation
* Made a formal complaint to the hospital
* None of the above

1. Respondents who contacted the hospital in the question above will also be asked:

When you made inquiries at the hospital, were you able to find someone who is able to resolve the problem for you?

* Yes
* No
* The issue is on-going

Comment box: Can you give us a brief overview of what happened/is happening?

1. Can you tell us about any aspects of your care that have worked well (this can be any aspect of your diagnosis, treatment and on-going care, from the staff, to communications from the service, to accessibility, to how things were managed, to the effect on your life, etc.)?
2. Can you tell us about any aspects of your care that didn’t work well (this can be any aspect of your diagnosis, treatment and on-going care, from the staff, to communications from the service, to accessibility, to how things were managed, to the effect on your life, etc.)?
3. Do you have any suggestions for how your treatment and care could be improved?
4. Thinking about your care within the last three years, how would you rate your overall level of satisfaction?

* Very satisfied
* Satisfied
* Neither satisfied nor dissatisfied
* Somewhat dissatisfied
* Very dissatisfied

1. Do you know when your next appointment or treatment is?

* Yes
* No

1. Respondents who answer yes to the above question will also be asked:

Approximately how far away is your next appointment?

* Less than 3 months
* Between 4-6 months
* Between 7-12 months
* Over a year away

1. Would you mind telling us which age band you are in?

* 18-34
* 35-44
* 45-54
* 55-64
* 65-74
* 75-84
* 85-94
* 95 or over
* Prefer not to say

1. Would you mind telling us what your ethnic group is? Choose one option that best describes your ethnic group or background:

* White: 1. English / Welsh / Scottish / Northern Irish / British 2. Irish 3. Gypsy or Irish Traveller 4. Any other White background, please describe
* Mixed / Multiple ethnic groups: 5. White and Black Caribbean 6. White and Black African 7. White and Asian 8. Any other Mixed / Multiple ethnic background, please describe
* Asian / Asian British: 9. Indian 10. Pakistani 11. Bangladeshi 12. Chinese 13. Any other Asian background, please describe
* Black / African / Caribbean / Black British: 14. African 15. Caribbean 16. Any other Black / African / Caribbean background, please describe
* Other ethnic group: 17. Arab 18. Any other ethnic group, please describe

1. In which region do you live?

* South East
* London
* North West
* East of England
* West Midlands
* South West
* Yorkshire and the Humber
* East Midlands
* North East
* Prefer not to say

1. Do you have any other conditions which affect your general health?

* Yes
* No

1. Respondents who answer yes to question above will also be asked:

‘Does (Do) this (these) condition(s) affect your ability to attend appointments at hospitals?'

* Yes
* No

If yes, please tell us how you have been affected?

1. Are you:

* Male
* Female
* Prefer not to say

1. And finally, how did you find out about this survey (tick all that apply)?

* Through social media
* Through RNIB newsletters or other communications
* Through another charity's newsletters or other communications
* Through friends/family
* RNIB called me as I have previously taken part in other research
* Other (please specify)