



# Examining patient experiences of cataract service and treatment in Derbyshire



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October 2018

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## **1. Thank you**

Healthwatch Derbyshire would like to thank everybody that shared their experience of cataract services and treatment in Derbyshire. We would also like to thank our dedicated team of volunteers who assisted with this project, without whom this work would not have been possible.

## **2. Disclaimer**

The comments outlined in this summary should be taken in the context that they are not representative of all people that have or are receiving treatment for cataracts, but nevertheless these comments offer a useful perspective. The survey was carried out within a specific timeframe and therefore only provides a snapshot of patient experience collected at that point in time. The data should be used in conjunction with, and to complement, other sources of data that are available.

## **3. About us**

Healthwatch Derbyshire is an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

We listen to what people have to say about their experiences of using health and social care services and feed this information through to those responsible for providing and commissioning the services. We also ensure that organisations are held to account for how they use this feedback to influence the way services are designed and run.

Healthwatch Derbyshire was set up in April 2013 as a result of the Health and Social Care Act 2012, and is part of a network of local Healthwatch organisations covering every local authority across England. The Healthwatch network is supported in its work by Healthwatch England who build a national picture of the issues that matter most to health and social care users and will ensure that this evidence is used to influence those who plan and run services at a national level.

## **4. Understanding the issue**

To ensure a wide range of individuals are able to share their views on local health and social care services, Healthwatch Derbyshire undertake targeted pieces of work, paying specific attention to those who may otherwise struggle to be heard. The Intelligence, Insight and Action sub group of Healthwatch Derbyshire make recommendations for engagement priorities based on the intelligence they receive.

This particular piece of work was agreed as some mixed feedback had been received from patients in regard to cataract services and treatment. It was felt that a targeted piece of engagement would help to explore the issues and give organisations running, choosing and buying services a more detailed picture of patient experience.

The survey was available for completion between June and September 2018.

#### 4.1 What is a cataract?

According to [www.nhs.uk](http://www.nhs.uk), cataracts are when the lens of your eye, a small transparent disc, develops cloudy patches.

The website explains that, *“When we’re young, our lenses are usually like clear glass, allowing us to see through them. As we get older they start to become frosted, like bathroom glass, and begin to limit our vision.”*

#### 4.2 What causes cataracts?

Most cataracts develop as a normal part of the aging process. Most people start to develop cataracts after the age of 65, but some people in their forties and fifties can also develop cataracts.

Some inherited genetic disorders that cause other health issues may increase the risk of cataracts. Cataracts can also be caused by traumas or injury, other eye conditions, past eye surgery or medical conditions such as diabetes.

#### 4.3 Cataract symptoms

Most cataracts normally develop slowly. At first, the changes to sight may be slight or unnoticeable, but as the cataracts grow, people often notice symptoms such as:

- blurred, cloudy or misty vision
- being more sensitive to light
- difficulty with vision at night
- fading colours.

#### 4.4 Being diagnosed with cataracts

Cataracts are usually diagnosed by way of a professional eye examination by an optician or ophthalmologist (after referral by a GP). If a person’s vision can be corrected to an acceptable level with glasses or contact lenses, surgery may be avoided at this time. If the patient’s vision loss cannot be corrected in this way and if this interferes with their daily life (driving, watching television, hobbies) then the cataracts will need to be removed surgically.

#### 4.5 Cataract surgery

Cataracts get worse over time so eventually surgery will be needed to remove and replace the affected lens.

Surgery is the only treatment that is proven to be effective for cataracts.

The operation can be performed at any stage of cataract development. There is no need to wait until the cataract is “ripe” before removing it. Most people have their cataracts

removed when the change in their vision starts to cause them difficulties in everyday life, such as driving, cooking or reading. Cataract surgery usually takes about 10 - 15 minutes and is usually done under local anaesthetic.

Cataract surgery has a high success rate in improving visual function, with low morbidity and mortality. It is the most common operation performed in the NHS, with an ever growing need as the population ages.

#### 4.6 NICE guidance

The National Institute for Health and Social Care Excellence (NICE) <sup>1</sup>produced guidance on managing cataracts in persons aged 18 and over in October 2017. This aimed to improve care and the provision of information before, during and after cataract surgery.

The guideline provides advice for patients and ophthalmologists to help them decide when surgery is appropriate, taking into account how the condition is affecting a patient’s sight and their quality of life, the benefits and harms of the operation.

The guideline also says that a decision on whether to offer second-eye cataract surgery should use the same criteria.

The guidance suggests a patient centred approach to the treatment of cataracts with patients being given clear information about the options open to them and the risks and benefits of surgery. The decision to have cataract surgery should be based upon whether the patient thinks it is right for them.

### 5. What we did in brief

Between June and September 2018, we ran a survey aimed at people who had been diagnosed with cataracts within the past two years. The survey was designed to collect feedback about each step of the pathway, from developing cataracts, through to possible surgery and aftercare.

Sixty two people responded to our survey.

The district that participants live in was recorded, and, when known, was completed as follows:

Amber Valley	5
Bolsover	2
Chesterfield	8
Erewash	7
North East Derbyshire	2

<sup>1</sup> 1 National Institute for Health and Social Care Excellence (NICE) Cataracts in Adults: Management-  
<https://www.nice.org.uk/guidance/ng77>

Derbyshire Dales	3
High Peak	12
South Derbyshire	2
Glossop	1
Other areas	6
Unknown	14

## 6. Key findings

The key themes that emerged from the participants were as follows:

- The majority of people were very happy with the treatment they have had and feel that they have had an excellent experience
- Information and guidance appeared to be a key theme, and appeared to have a significant impact on patient experience
- Some people said that they were not offered enough information about the impact of cataracts upon their ability/fitness to drive
- Some people did not feel that they had been involved in the decision making process around the treatment of their cataracts
- Some issues around aftercare were also raised. For example, problems administering eye drops after surgery and others saying that no aftercare or follow up was offered to them
- Some people were concerned because they have been told that in Derbyshire the NHS only now perform cataract surgery upon one eye.

## 7. What people told us

Question One:

*Have you been diagnosed as having a cataract(s) within the last two years?*

Yes - in one eye	21
Yes - in both eyes	41

Question Two:

**Which statement best describes you?**

I have cataract(s), but have not yet had surgery	23
I have had surgery for cataract(s)	39

Question Three:

**How far would you agree or disagree with this statement?**

***When my cataracts were first diagnosed, it was clearly explained to me about what would happen next after the appointment.***

Strongly agree	24
Agree	16
Neither agree or disagree	7
Disagree	8
Strong disagree	6
Skipped	1

Positive experiences

65% of respondents agreed that it was clearly explained to them what would happen next.

*“The optician who first diagnosed cataracts fully explained what it meant to me in both the long and short term. He explained that before I could receive an operation on the NHS to remove a cataract a certain criteria had to be met which was explained fully to me.”*

*“Fully explained that I have an early stage cataract that doesn’t require any intervention at this stage and as I have an annual eye check-up they are happy to monitor me yearly. The optician did state that should I notice any significant changes that he would encourage me to be checked out sooner.”*

Suggestions for improvement

Comments received from respondents seems to indicate that the earlier that people are given this information, the happier they tend to be with the process and their expectations of treatment for cataracts is better managed. Those who have not received information upon diagnosis are left not knowing what the next steps are.

*“When I got as far as surgery and follow-ups, there was lots of information, reassurances and helpful suggestions. There was less of this at my initial eye examination appointments.”*

*“Earlier discussion about the course of monitoring/treatment would have been useful.”*

*“It would have been helpful to have been more involved at an earlier stage. It feels as if I was being monitored for the cataract but no one had thought that I might not be clear what was happening.”*

**NICE Guidelines** - NICE guidelines state that people with cataracts, and their family or carers (as appropriate) should be given both oral and written information about cataracts. It recommends that at referral for cataract surgery, people should be given information about what cataracts are, how they can affect vision and how they can affect quality of life.

Question Four:

***How far would you agree or disagree with this statement?***

***When my cataracts were diagnosed, I received information and advice about my ability to drive.***

Strongly agree	18
Agree	12
Neither agree or disagree	8
Disagree	10
Strong disagree	5
N/A or skipped	9

Positive experiences

The majority of people to whom it applied (57%) agreed they had received information and advice about their ability to drive.

*“Yes the criteria for the driving standards was explained and I was within the standard required to satisfy the DVLA.”*

The DVLA - Assessing fitness to drive - advice to medical professionals <sup>2</sup>states (in relation to cataracts) that it is, “Often safe to drive and may not need to notify the DVLA. The minimum standards set out for all drivers above must be met.”

Suggestions for improvement

Some people (28%) did not feel they were given adequate information and others were left to **assume** that they were fit to continue to drive.

*“This issue was never discussed so I have assumed that my cataract is not detrimental to my ability to drive.”*

<sup>2</sup> <https://www.gov.uk/government/publications/assessing-fitness-to-drive-a-guide-for-medical-professionals>

*“No mention at all from optician about driving.”*

*“I was told to contact DVLA but not told to stop driving. I knew my eye sight was not good enough so gave up my licence.”*

Question Five:

***How far would you agree or disagree with this statement?***

***I feel as if I am, or have been, involved in the decision about when I should have cataract surgery.***

Strongly agree	15
Agree	16
Neither agree or disagree	10
Disagree	11
Strong disagree	5
N/A or skipped	5

Positive experiences

Of those that answered, the majority of people (54%) agreed that they felt involved in the decision about when to have cataract surgery.

*“Fully explained re having both done, one done. I felt I had choices.”*

*“I saw the consultant and felt free in the decision we made together.”*

Suggestions for improvement

However, a significant portion of those that answered (28%) felt that they had not been involved in the decision about when to have surgery.

*“No options given - just what NHS rules say applies.”*

*“Haven't been given a date for decision - feel it's up to the professional.”*

NICE guidelines

NICE guidelines advocate for a patient centred approach to the treatment of cataracts. The guidelines say the decision to refer a person for surgery should be based upon a discussion with the patient (and their family members or carers, as appropriate).

There should be discussion about how the cataract affects the patient’s vision and quality of life, whether one or both eyes are affected, what surgery involves (including risks and benefits), how the patient’s quality of life may be affected by surgery and whether the patient wants surgery.

Question Six:

***How far would you agree or disagree with this statement?***

***I feel my surgery had been successful.***

Strongly agree	24
Agree	12
Neither agree or disagree	1
Disagree	2
Strong disagree	0
N/A or skipped	23

Positive experiences

The overwhelming majority of the 39 respondents who had cataract surgery (92%) had felt it had been successful.

*“Exceeded my expectations. Greatly so.”*

*“Cannot remember my eyesight being so good before. Amazing!”*

*“After surgery I could not believe the improvement in my vision and how colours were more vivid.”*

However, two respondents who had cataract surgery felt it had not been successful.

*“My surgery has not been successful and I cannot see as well as before. In fact I am struggling.”*

Question Seven:

***How far would you agree or disagree with this statement?***

***I received the information and support I needed to care for my eyes after surgery.***

Strongly agree	22
Agree	13
Neither agree or disagree	2
Disagree	2
Strong disagree	0

N/A or skipped	23

Positive experiences

90% of the 39 patients that had received cataract surgery agreed that they had received information and support needed to care for their eyes after surgery.

*“Received detailed aftercare information, eye drops, a handy, useful booklet and phone numbers to call should a problem arise. This was all supportive and good.”*

Suggestions for improvement

A number of patients expressed concerns about post-operative care and support, especially so from patients with other long term conditions such as arthritis.

*“Clearly explained to me. However, I have severe arthritis and it is extremely difficult for me to put in the eye drops but more importantly the eye protection at night which needs to be stuck on with tape is nearly impossible. It keeps coming off. My daughter has looked on the web to see if there is anything else that would protect my eye but could not find an alternative.”*

*“I live alone have very bad arthritis, Rynaurd’s, scloderma and have not been able to put the drops in myself.”*

*“Little help about when I could drive after surgery or about getting a prescription for glasses following surgery. Little communication with my optician/GP from hospital.”*

NICE guidelines

NICE guidance gives direction for post-operative assessment. This provides for processes that:

- Identify complications after surgery and ensure prompt access to specialist ophthalmology services
- Arrangements so that healthcare professionals discuss second- eye cataract surgery with people who have a cataract in their non-operated eye.

Other themes raised by respondents:

**Surgery on the second eye**

Three respondents mentioned that they have been told that it is policy within Derbyshire to only offer cataract surgery upon one eye which thus has an impact upon their quality of life. They commented as follows:

*“Not interested in looking at the other eye as it’s apparently no longer policy to operate on both cataracts.”*

*“I was told that the NHS would only pay for one eye operation.”*

*“It was explained that they would only operate on one cataract and that I would have to deal without being able to see out of the other eye, which still makes daily life difficult, and driving not easy. Shame I can’t have the other eye done, it means I need more care at home.”*

### NICE guidelines

NICE guidance contains economic modelling that shows that cataract surgery for first or second eye is cost effective compared with no or delayed surgery. The guidelines make it clear that restricting access to cataract surgery on the basis of visual acuity thresholds is inappropriate.

### Accuracy of information provided about surgery:

*“Also the hospital leaflet stated very clearly I was not allowed to have anyone accompany me on the day. I was the only person except one other who did not have anyone with me and I felt very scared. Fortunately that was the day it got cancelled so when it was rescheduled my son came with me. If it is a rule it should apply to everybody but it is not a reasonable rule as it is very scary having the operation and being left on your own.”*

*“I was given some useful information, but was misinformed about some matters. I was told to begin with that both eyes would be done on one day. Then I was told there would be a short gap between the two operations (up to a month). As it happened, the second operation did not take place until three months after the first.”*

Although not a theme, it is worthy of note that one survey was completed on behalf of a patient with a severe learning disability. They commented as follows:

*“The hospital consultant held two multidisciplinary meetings to explain the procedure and concerns to enable us to make a best interest decision which was very helpful. He was allowed time for the decision to be made ... I could not fault the information given by the consultants and specialist nurse ... the multi-disciplinary team were made aware of the operation and after care.”*

## 8. What should happen now?

Based on the topics raised by cataract patients, Healthwatch Derbyshire recommends that the following actions should be taken:

- Information

Patients, and their relatives and carers, should consistently be given early, clear, accessible and accurate information about cataracts both orally and in written form upon **initial diagnosis**.

- Driving requirements

Practitioners should discuss driving with people diagnosed with cataracts to avoid confusion. They should make sure patients are aware of DVLA guidelines, advice as to fitness to drive and make sure that this information is updated as a patients sight changes.

- Person centred approach

Practitioners should ensure that NICE guidance is followed in providing a person centred approach and ensuring patients are given an appropriate degree of choice over their treatment for cataracts.

- Post-operative care

Patients should be given information about the post-operative care they should expect to receive.

Practitioners should ensure that NICE guidelines for post-operative assessment are followed.

Patients with additional support needs should be identified and solutions found to ensure that post-operative care is not compromised.

- Surgery to the second eye

Practitioners need to ensure that the offer of second eye surgery should be made using the same criteria as for the first eye surgery.

In line with NICE guidance, there should not be higher thresholds for second eye surgery than the first eye thus delaying or denying patient's surgery.

## 9. Responses

➤ **Derbyshire Clinical Commissioning Group (CCG):**

During June/ July 2018, following publication of NICE guidance, key members of our Clinical Policies team undertook an engagement exercise with Ophthalmologists at both Chesterfield and Derby, to undertake a review on the clinical criteria set against first and second cataract criteria.

The Clinical Policies Advisory Group (CPAG) will:

- Continue to engage with both our providers, and our primary care colleagues regarding all restricted clinical policies, including that of cataract surgery.
- In order to address concerns that some patients are being misinformed that there is a blanket ban on second eye criteria, we will continue our engagement with providers to address any issues, coupled with our ongoing communication with both providers and primary care.
- The NHS needs to manage demand effectively to ensure the best possible outcomes for patients and the most efficient use of resources. The NHSE High Impact Interventions work is aimed at identifying good, evidence based practice and collating it into simple service specifications. The approaches and interventions NHSE are developing and testing with clinicians will ensure patients see the right person in the right place, first time and will help the Derbyshire clinical commissioning groups (CCGs) and Joined Up care Derbyshire to deliver their plans to manage the rise in referrals. They are also developing tools and guidance that

will support GPs and other health professionals in managing their patients, so they see the right person in the right place, first time. The Derbyshire Clinical Commissioning Groups are currently driving forward on a mandated NHSE Ophthalmology High Impact Interventions programme of work which will enable us to understand and manage capacity and demand for cataract surgery and intervention. This will ensure the identification of high and low risk patients and allow us to develop effective and efficient patient pathways respectively so that the patient is seen by the right person at the right time. This will improve the patient experience as well as clinical care.

➤ **Derbyshire Community Health Services NHS Foundation Trust:**

The provider received a draft copy of this report to check for factual inaccuracies and to provide a response to the recommendations. In order to get a quality response which addresses the recommendations outlined in this report, we will continue to work with the provider and update the report accordingly.

## 10. Your feedback

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

.....  
.....  
.....

3) Since reading this report:

a) We have already made the following changes: .....

.....  
.....  
.....

b) We will be making the following changes: .....

.....  
.....  
.....

Your name: .....

Organisation: .....

Email: .....

Tel No: .....

Please email to: [karen@healthwatchderbyshire.co.uk](mailto:karen@healthwatchderbyshire.co.uk) or post to FREEPOST RTEE-RGYU-EUCK, Healthwatch Derbyshire, Suite 14 Riverside Business Centre, Foundry Lane, Milford, Belper, Derbyshire DE56 0RN.