



# **Reconnect, Reset, Rebuild.**

## **Bracknell Macular Group**

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## Background

Healthwatch Bracknell Forest partnered with Frimley Health and Care Integrated Care System (ICS) to support their engagement project- Reconnect, Reset, Rebuild. The aim of this project is to bring together people in communities across the Frimley area to spark conversations about health and wellbeing priorities. The information in this report will help Frimley ICS to identify what matters most to the residents of local care homes empowering them to better join up health and care services, to improve population health and reduce health inequalities.

### Why is Frimley Health and Care carrying out this engagement now?

Recent reports, such as the Darzi review and the recommendations from Grenfell, remind us of the urgency to listen and understand the needs of our communities. As the government's 10-year plan for the NHS takes shape, it is essential that it is rooted in and reflects the true needs of our communities. This is our chance to make it happen.

## What we did

Healthwatch Bracknell Forest visited Bracknell Macular group 17<sup>th</sup> February 2025. The Bracknell Macular, supported by the UK Macular society provides information and support to local residents with Macular disease. The group meets monthly and provides the opportunity and a space for people to talk, reduce isolation, and have informative talks from local groups and organisations.

We spoke to 19 attendees, conducting informal interviews and providing signposting and information.

## What we heard

### We asked people, what are your top priorities when receiving health and care services in your community?

#### GP Appointments Access and Choice

Many people talked about the importance of being able to access timely appointments at their surgery in order for them to remain healthy. People also wanted to see a GP when necessary. They wanted more choice about which surgery they went to within the PCN.

**"As an older person with macular disease and other illness, it is important that I can get easy access by phone on the day for appointments as I can't use online options."**

“Getting access to surgery appointments should be an easy task to ensure your health problem is dealt with quickly, it shouldn’t be an endurance test.”

“Being able to get an appointment and see a health professional at your surgery in person is really important. Any delays can have knock on effects, particularly for older people. Also, it would be beneficial for older people to have a choice of which GP they see so there is continuity in care.”

“As an older individual with my macular degeneration and long term conditions, getting quick access to a GP is a priority. Having a choice of which surgery I go to is also important as ability to travel is restricted.”

#### Timely Secondary Care at Hospital and Being Kept Informed While Waiting

As older people with long term conditions including their macular disease, people said that it was important that any requirement for secondary care was timely. There was concern that unnecessary delays further impact their health and wellbeing. While waiting for treatment people wanted to be kept informed about the timeline for their treatment.

“Shorter waiting lists for hospital treatment and operations is very important, particularly if you are older and have multiple health problems, long waits are very detrimental”.

“It is important that waiting times for treatment come down to a reasonable level, so that people aren’t left suffering with things like hip replacements, knee replacements and other operations. When waiting for an operation I would want to be kept informed about progress”.

“Long waits for treatment isn’t any good for anyone. If you do have to wait, then you need to be updated regularly. You also need health advice about how to manage your issue while waiting”.

### Transport Options To Health Settings and Care Closer To Home

Reliable transport options were highlighted as a priority. The usual methods of transport aren’t always possible, or are more difficult, for people with macular disease and people said there needs to be reliable alternatives. Care closer to home was also highlighted as a way of reducing transport difficulties,

“Transport options are a necessity if your partner can’t drive or you live alone with macular disease and need to visit health services, particularly as some of those services are as far away as Slough, Aldershot, Farnham, Frimley, Windsor. If your partner can’t drive, then they could accompany you on public transport but some of the health services require multiple public transport changes. If you live alone then those transport options are really inaccessible”

“Good transport options, other than a car or public transport, are needed. Public transport would be more possible for those with sight impairment if the public transport had direct routes to health settings rather than needing to change several times. If more health provision was done locally then it would be easier using local transport links.”

### Accessible Information and Communication

People with Macular disease said getting health information in a way that is accessible to them is vital. It ensures they understand any health information they are given. Good communication was also highlighted as a priority, whether that be communication from primary care, secondary care, communication between GP and secondary care, or between hospitals from different areas that serve the same patient.

“GPs and Hospitals and other health services need to provide me with information in a format I can see and understand due to my macular condition.”

"I receive different treatments from two different hospitals, Frimley Park and Royal Berks. For my wellbeing it is really important that they can both see my electronic medical history."

"It is important to get hospital discharge papers and to have them in the correct format I can read"

"GPs should be able to identify those patients with sight problems and send them information in the appropriate way and not assume texts, digital links etc are suitable for all patients."

### Loneliness and Isolation

Some single people with macular disease talked about the importance of being able to get out and about and remaining connected with the community in order to maintain health and wellbeing.

"I live alone, and it is difficult to get out of the house and go shopping or to the café and I am unable to get a bus myself to go anywhere because of my sight. So, I stay at home a lot of the time, it can get lonely and I'm sure it isn't good for my health."

## **We asked people, have you experienced barriers to getting great care?**

### GP Access and Appointment Barriers

We heard about the difficulty in accessing GP services, including difficulty getting through on the phone and lack of availability of GP appointments. Patients in Bracknell have three options to access appointments, telephone, fill out an online form, or they can walk in and fill out an eConsult form. However, those with macular disease and sight problems, told us the only real option for them is to phone for an appointment. We also heard that choice is a barrier, for example some people told us they want a choice about which surgery they attend for appointments.

I can't use online to fill out a form for an appointment due to my sight. My only option is to ring and I constantly get stuck in a long queue and after a while I just give up. Older people with macular also have other long term conditions but it is so difficult to get an appointment and see a doctor."

"The whole 8am ring to GP does not work. You are either stuck in a long queue or you don't even get into the queue as a message says there are no more appointments left"

"I am in my 80s, I haven't seen a GP for a long time, I am given appointments with other staff like a nurse or paramedic, you'd think at my age a GP would want to see you if only once a year"

"I want to be given a choice about which surgery I go to for an appointment. Transport is a problem for me and it is very difficult to get to Bracknell from Sandhurst for appointments. If I could choose to have appointments at my Sandhurst surgery that would help"

"Patients need real choice about where they have their appointment, rather than just accepting what they are given. Choice is important particularly if you have disabilities and need adjustments."

### Waiting Lists For Hospital Treatment Barriers

Several people talked about long waiting lists, the delay in treatment and how this was impacting their wellbeing. Some also mentioned the lack of communication and updates while waiting for an operation.

"I have been waiting a long time for treatment with a problem in my back. Apart from dealing with my macular condition I am now having more and more problems with my mobility. They can't tell me how long I'm going to

have to wait for treatment and when I ask what I can do to help myself while waiting, I was told to carry on taking paracetamol.”

“I am waiting for a hip operation and the constant pain is affecting my mental wellbeing. There needs to be better communication while you are waiting to give you some idea about when you will get treatment otherwise you have no idea whatsoever, could be 2 months, could be 9 months, could be longer. If I was buying a product from a retailer and it was out of stock, they would at least let me know when it would be in stock, that’s what good service is.”

### Transport Barriers

Some of the macular group highlighted transport difficulties. Those with macular disease are unable to drive so they rely on the partner/carer. However, if the partner/carer can’t drive, or, if there was no partner/carer then this caused difficulties regarding transport to health appointments. Having care closer to home was mentioned as a solution to transport issues

“Neither of us can drive and this causes difficulties and stress when needing to get to appointments. We can’t afford to go by taxi, It is too expensive, the last time we did use a taxi it was £25 return. If we can’t get a friend to take us, then we rely on patient transport but unfortunately this service is not very reliable or doesn’t have enough capacity. That can mean we arrive late or have to rearrange which is a waste of an NHS appointment.”

“I live alone and am unable to drive so getting to appointments is difficult. I have been sent to various places for a blood test as my surgery doesn’t do them. I’ve been sent to Heatherwood, Frimley and Wexham. It has caused great difficulty in getting to those appointments. It would be a great help if you could have blood tests locally in a single place, getting help with transport would then be easier.”



“Transport to health appointments can be a barrier because of the distance you have to travel sometimes and poor public transport. If the NHS could provide more tests and diagnostics in local communities, it would help”.

### Accessible Information Barriers

People with macular disease told us that they need information in a format they can understand. Too often the information they receive from health providers is not accessible for them and they are concerned about how it might affect their health if they can't access the information easily. People mentioned that they are feeling left behind with digital progression.

Information from GPs and hospitals and other services are now sent to phones with a link or to a health app. I am not able to use these. Those services should be able to send you important information another way, by a phone call or by letter with large font”

“When I get a letter about an appointment it is in standard text, exactly the same as they are sent to be people who don't have sight problems. I need large font text and different colour backgrounds to be able to read the information.”

“GPs should not assume texts and digital links are suitable for all patients. They know which patients have certain disabilities so they should adjust their method of communication to meet individual's needs”

“A barrier to getting great care and ensuring ongoing wellbeing, is the consistent lack of providing me information in the format I need it”

## **We asked people what improvements they thought would have the greatest impact?**

### **The Macular degeneration group identified these top themes**

- Improved access to GP appointments for those who can only use a phone as method of contact
- Choice of which surgery they attend for appointments
- Shorter waiting list/times for secondary treatment
- Providing communication to patients while they are waiting for secondary treatment
- Improved transport options for health appointments
- More care closer to home
- Accessible Information – All NHS services providing information consistently in a format that can be understood by those with sight loss

These findings will be shared with Frimley Health Integrated Care System to be considered alongside other feedback received as part of the Reconnect, Reset, Rebuild project and will be presented to their board for consideration. We will update the public with any actions agreed at a later date.

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