

OBG AND THE PAST 12 MONTHS



It has been a long time since the last edition of the newsletter, but we certainly have not been resting on any laurels. The Oxford Blood Group has had a very busy year and a half, some

of which you will read about here.

One of the first things we have had to learn is how to do our work remotely, and we have all become adept at the use of Zoom or MS Teams. One of the lessons learned is that it is, in fact, sometimes a lot easier for people to take part when we meet online. We have had meetings with people joining from their beds, from the Day Treatment Unit, or from the Haematology Ward. We have also heard from people who would otherwise find it difficult to travel to a meeting because of mobility and other problems.

While it will be great to meet in person - and our feedback suggests we should organise a social very soon - we will also continue to embrace online patient engagement.

We hope you enjoy this summary of our amazing contribution to haematology research and OUH services.

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TELEMEDICINE AND VIDEO APPOINTMENTS (OR 'REMOTE CONSULTATIONS')



Readers will know all too well that we have experienced a sea change in the way we operate hospital appointments since the beginning of the pandemic. Oxford Blood Group members have played a major role in helping the haematology department learn more about patient experience of telephone and video consultations. We have contributed to telephone interview studies, helped to design questionnaires for patients, and contributed to discussions about remote consultations in a variety of contexts.

- Remote consultations save lots of time and the inconvenience of travel to Oxford and parking at the Churchill. This is a massive saving in terms of disruption to normal life and good for the environment.
- You can have the same conversation as you would in person - for many people, it is just as good as a face to face appointment.
- Most people who have tried a video consultation would be very happy to do it again. Only a small proportion experience major technical problems. You can also see your doctor's face, show the doctor something that worries you, and invite people to join the call from elsewhere.
- Lots of people report feeling more comfortable having these conversations in the privacy of their own home

- It is not for everyone, and it is not suitable for every situation. We need to be careful about patient safety and 'digital inclusion.'
- Most people would prefer to know that they will see their team in person again sometimes, and if they feel they need it. Most people did not feel that they could express a preference, so we need to check in with patients about how they feel, reassure them and offer choice.
- Remote monitoring means that all the other parts of your care become even more important: the letters, information about appointments, knowing you can contact the nurse specialist.
- It helps if you have met the health care professional before. And it is REALLY important that the person calling you has read the notes and is prepared.
- It is REALLY IMPORTANT for us to keep as close as possible to the scheduled appointment time.
- It helps if patients prepare for a remote consultation.

We have:

- Shared your feedback at departmental meetings and with colleagues across Oxford and nationally;
- Created resources for patients: look for 'video and telephone appointments' at www.ouh.nhs.uk/patient-guide/leaflets/
- Created resources for medical professionals.

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About video and telephone appointments

Video and telephone appointments allow you to speak to your health care professional (HCP) without having to travel to the hospital. They should be very similar to the appointments you have at the hospital. During the video or telephone appointment the HCP will ask you about your health and any symptoms or concerns you may have. You will discuss the results of any tests you have had recently.

You will have the opportunity to ask questions or discuss any concerns, just as if you were seeing the person in clinic.

We suggest you make a note or set an alarm on your telephone for the appointment.

How will I know about the appointment?

You will be informed about your appointment in the usual way with a letter from the hospital. Sometimes, we will call or send a text message to tell you that your appointment will be over the phone or as a video appointment.

You will be given a time for your appointment.



Oxford Blood Group Member feedback July 2021

96%

...of members would recommend joining the Oxford Blood Group to others:

"It's a great opportunity to be able to use my experience to give something back and hopefully improve future treatment and patient experience"

"It's a no brainer really. Having been a patient in need, if I can give back a relatively small amount of my time to help future patients, clinical staff, research staff and the NHS generally then I feel it is the least I can do. I recommend the OBG to all!"

"It has many benefits for the patient. It keeps us up to date with new technologies, procedures, treatments and even thinking. It is also empowering. A cancer diagnosis is very "disempowering" - so much of your life is regulated and controlled, so it is motivating and stimulating to be part of a such a group."

94%

of members

Enjoy being part of the Oxford Blood Group

94%

of members

Enjoy being able to give back to the Haematology Department

You said:

- need better promotion of the group
- need more feedback on individual projects about what happened next
- need more regular feedback about the group's work, either as catch-ups or newsletters
- it would be good to meet face to face some time
- would be good to see other people's comments on documents
- would be good to know more about the membership of the group

We will:

- redesign leaflet and revisit promotional work
- revisit newsletter production to make it easier to produce these regularly
- plan a social activity for late 2021
- create a monthly email update for all members to summarise recent activity

I try and participate when I can to help other people grapple with what I had to deal with. And yes, I'd recommend that other people participated too.

The bone marrow biopsy working group which showed very tangible, positive results and has made a difference to patient experience. It is very motivating and fulfilling to be part of such a project.

It helped me enormously during lockdown, while I was shielding, to be able to give a little back. It is hugely important that patients are encouraged to participate and be listened to when planning future projects/changes

involvement for me has meant learning from the professionals and contributing as a patient. Both experts in our own ways and complementing each other.

Member Feedback

We recently asked our members for feedback about their experience of being part of the Oxford Blood Group. People reported very positive experiences and enjoyment of the work, including:

- opportunity to use their experience to improve the service for others
- opportunity to learn more about cancer research and medicine
- opportunity to contribute to the work of the department
- feeling that they are empowered, listened to, and that their experience is valued.

In response to the feedback:

- We will look at better ways to produce regular newsletters. This will include inviting members to get involved and share stories about the work you have done with the group.
- We will improve feedback on the outcomes of our activities
- We will look at the possibility of a social event for anyone who would like to be involved when it is safe to do so.
- We will re-design the promotional leaflet and consider better ways to share this with patients.
- We will share the feedback with colleagues so that they can see what being part of the group means to their patients.

Our work has meant that, over the last couple of years, hearing from patients and involving them in our service is becoming more and more a standard part of the day to day work in haematology and haematology research. Our work has also attracted attention from other parts of OUH, from the Oxford BRC and other parts of the University, and we are often cited as exemplar of good practice in patient engagement.

Thank you to all who are part of it!

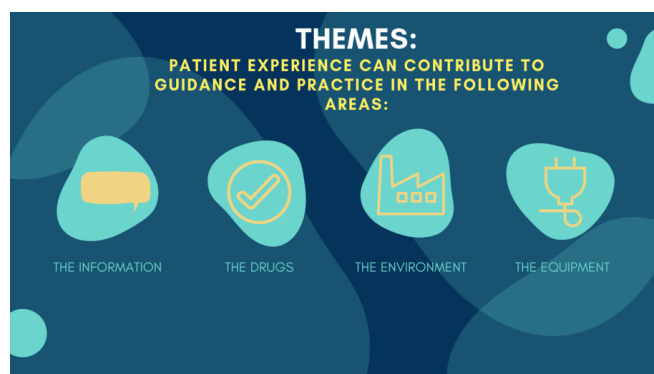
A patient perspective of being involved in a bone marrow biopsy working group

No-one looks forward to a bone marrow biopsy. I have found them very unpleasant but it appears that experiences vary widely. Some people dread the procedure so much that they would consider compromising their treatment rather than have a biopsy. Have I just been lucky? Was it luck that I had clear information before hand, an experienced clinician, a kind nurse, adequate pain relief, a calm environment, and a relaxing cup of tea and a chocolate biscuit afterwards?

When the element of luck was mentioned in a meeting of the Oxford Blood Group, the clinicians in the meeting were quite shocked. Your experiences of a bone marrow biopsy should not be down to luck! From this throw away comment, a sub-group of the Oxford Blood Group was formed to look into patient experience of bone marrow biopsies to see what could be done to improve it for everybody. This involved putting together a small working group of patients and doctors who have to perform the biopsies. The idea, and the evidence, is that working together produces much more meaningful and sustained change.

So far we have had 4 meetings – some online and some face to face – over about 18 months. (The pandemic has obviously had an impact on timings.) Discussions have centred around a wide variety of aspects of having a bone marrow and three main areas were identified

- information to patients, including getting the results
- the environment
- resources and equipment, including pain relief



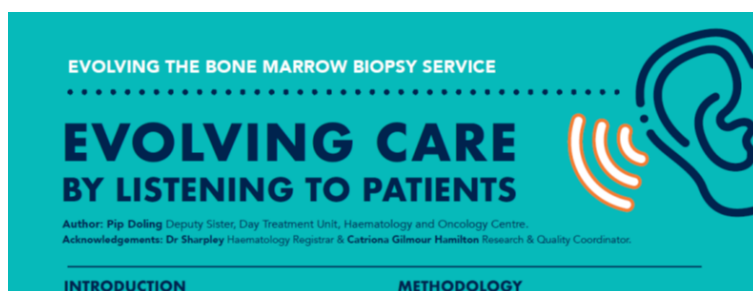
The meetings were very well-organised with agendas, presentations and action points to follow up on. But there was also a lot of time for discussion. The atmosphere was very relaxed and everybody felt very comfortable to make suggestions. Ideas from patients were taken very seriously. As a patient it was also very interesting to hear the doctors' and nurses' points of view - we don't always appreciate the various constraints that they are working under. However, many of the ideas which were thrown into the ring were taken on board and the patient voice was instrumental in the changes that came about.

The fact that we, as patients, can help to make improvements to everybody's experience and you can see tangible results from your input is very fulfilling.

The new initiatives were:

- a questionnaire to get patient feedback of their experience
- revised and updated patient information sheet
- new signage was made so people could find the room easily
- introduction of a new device for taking the bone marrow sample
- a diagram about the pathway for a bone marrow biopsy test results
- a video to inform patients and help doctors understand what bone marrow biopsies feel like from a patient's point of view.

The fact that we, as patients, can help to make improvements to everybody's experience and you can see tangible results from your input is very fulfilling. Sitting together, hearing the doctors point of view and other patients' experiences was very valuable. I feel very lucky that I was able to be part of this group - or should it be down to luck? Patient representation is becoming much more common and I think that research has shown that it has a very positive impact. Certainly my experience as a member of the Oxford Blood Group and the Bone Marrow Biopsy Sub-group would bear this out.



The work of the group was presented at the UK Oncology Nursing Society in Summer, 2020

Sally Jeans, August 2021

HAEMATOLOGY PATIENT PANEL



The Haematology Patient Panel was established in 2020 to create the opportunity for regular consultation and feedback between senior clinical and managerial staff and a group of patients.

- Provide a forum of patients with a range of experiences that serve as consultees for senior managers on current issues, challenges or new developments within haematology.
- Provide a forum for patient representatives to raise or discuss issues with senior managers as highlighted in departmental reports of patient experience data and complaints.
- Create a transparent and inclusive means through which patients have an opportunity to contribute to, and learn about, the management of the Haematology Department.
- Contribute to an organisational culture that fosters collaborative working relationships between staff and patients.

The forum includes 5 members of the Oxford Blood Group, and members serve a fixed term before leaving to allow someone else to join. .

Isabelle Gent

I have been a part of the Haematology Patient Panel throughout 2020. My history with the department is that during 2016 I received treatment for Hodgkin lymphoma, culminating in a stem cell transplant in 2016.

The Patient Panel has been a brilliant way to involve patients in decisions being made in Haematology. As a patient, it has allowed me to provide constructive feedback which it would not feel right to discuss in my own hospital appointments. One of the things that has struck me during the panel video calls is that the participants have widely different opinions on most of the topics we have covered. That has highlighted for me the need to use panels such as this to provide patients' perspectives. A lot of the issues being discussed are very personal and can be deeply emotive, and it is really important that doctors and clinicians consider the vastly different ways in which patients might interpret the same situation, or might want something to be handled.

I feel that through the Patient Panel I have given something back to the hospital, after they did so much for me. Selfishly, I have enjoyed the panel because it allowed me to find out things that were going on in the hospital, and to ask the hospital staff my own questions. Being asked to participate also showed me that the hospital cares about patients' perspectives and values our input.

If I were to suggest any improvement it would be to widen the panel to include more people, so that more conditions and a wider demographic of people could be included.

If you would like to know more, please email Catriona at OxfordBloodGroup@ouh.nhs.uk

Your information online: "Health for Me"

"I think Health for Me is great: it allows me to see results, view correspondence and check upcoming appointments without having to wait for the next consultation or letter in the post. It is easy to use, the information is clearly presented and it enables me to have questions ready before I meet with the Doctor. Although there is a lot of terminology I don't always understand, being able to view reports and correspondence between different clinicians helps me to follow planned interventions."

We have recently introduced an online service to allow you to look at your records on your home computer or smartphone. The aims of Health for Me are to:

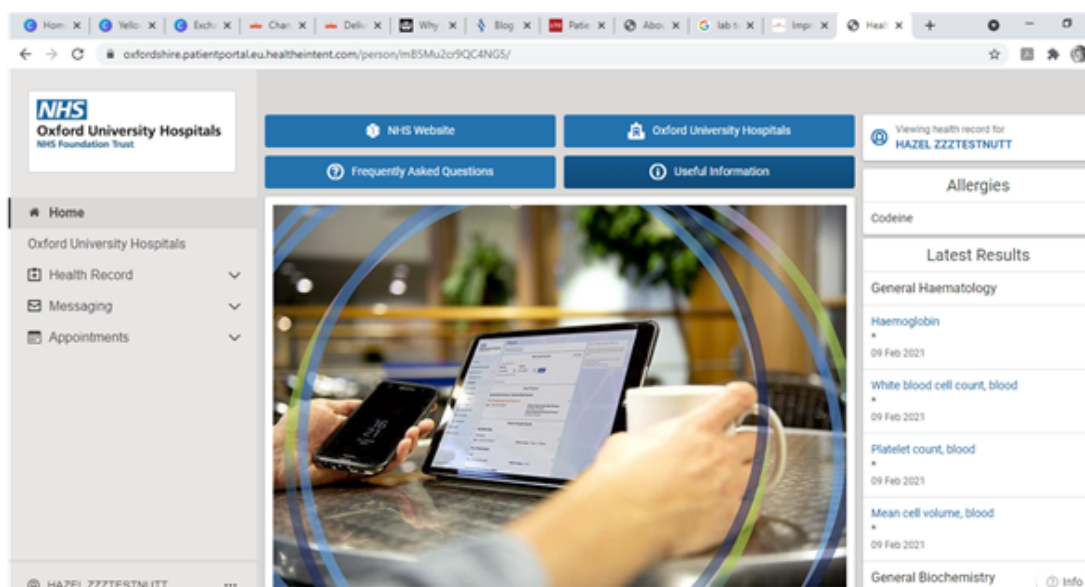
- make it easier to find information about your care
- provide one location for most of your hospital records
- enable you to check your appointments
- offer access to your hospital letters in digital format
- allow your medical team to share information with you.

International and local research on patients' experience of similar portals has shown that:

- they help patients feel more in control and better informed
- patients prefer to find out test results from home rather than at hospital
- they help patients educate themselves about their condition
- they can improve the quality of appointments with a doctor, for example if information has been shared between you beforehand
- they can drive improvements to hospital services.

It uses the same security measures as internet banking, and you will be asked for answers to security questions when you sign up. It is not compulsory, but lots of users find it really helpful.

TO SIGN UP, ASK AT OUTPATIENTS OR EMAIL:
ONCHAEMH4M@OUH.NHS.UK



WHAT MATTERS MOST? WORKSHOPS FOR PEOPLE WITH MDS





The What Matters Most method was designed as a way of bringing people together to talk about shared experience of illness and agree a list of priorities for research and service / resource development.








As a result of the COVID pandemic, face to face meetings were impossible. The Oxford Blood Group worked in partnership with Milly Sinclair Associates, a professional facilitating and training provider, to adapt the face to face approach to the online environment.

The first of the online workshops was held in March 2021 with a group of people with myelodysplastic syndromes (MDS).

People with MDS from local and national support groups were invited to attend. We had hoped to attract 20 participants, as this is a number that remains manageable in a Zoom environment. By the time of the first workshop, we had 14 confirmed participants. The people who took part were of varying age and experience. Most were patients being treated at OUH, but some were from other parts of the UK. The online environment had the major benefit of allowing people with severe fatigue or mobility problems to take part in a way that they would not have pre-COVID.

We generated a huge amount of material; at the end of the first workshop, there were 56 'questions' and comments under the themes of: Prognosis; End of life; Treatment; Supportive Care; Medical Staff Training; Diagnosis; Communication; Organisations and resource sharing. The number of delegates allowed everyone to have a say within a tight schedule.


what matters most to people with MDS?
patient workshop outcomes


- 
1. how can we more accurately predict an individual's prognosis?
- 
2. Can we predict what treatment pathways will mean for quality of life: e.g. time in hospital, supportive care needs?
- 
3. Can we better adapt survival predictions as the disease progresses? Can we better understand people's assumptions and thoughts as their condition changes?

- 
4. Is there a better alternative to stem cell transplant as a curative treatment for people with MDS?
- 
5. How can we better address the management of fatigue?


Between sessions, the questions were reviewed and refined, before being shared with the group for comment in advance of the second meeting. The second meeting was dedicated to discussion, further grouping of the questions under umbrella headings, and then voting on the issues that matter most.

Professor Paresh Vyas, Dr Alex Sternberg and Dr Oni Chowdury and Kirsty Crozier joined the workshop for the final half hour to hear the results of the workshops and discuss with the group. It was agreed that the outputs would be shared at the next meeting of the National Cancer Research Network specialist MDS subgroup, with some of the group invited to attend the meeting and present the patients' priorities.

what matters most to people with MDS?
patient workshop outcomes

OXFORD BLOOD GROUP

6. How do we improve communications between medical teams to ensure integrated care?

7. How do people tend to die from MDS? How can we predict and communicate what end of life might look like for someone with MDS?

8. How can we ensure better communication about MDS biology and its complexity for all patients and those that know them?

9. How can we ensure that all people with MDS have good quality evidence-based information to support shared decision making about all MDS treatments?

10. How can we ensure that the diagnosis and management of MDS is not compromised by assumptions about the age of the patient? ?

what matters most to people with MDS?
patient workshop outcomes

OXFORD BLOOD GROUP

11. Is it possible to explore the potential for DNA direct-to-consumer analysis (eg 23andMe) to inform potential bone marrow donor matches??

12. Can we create personalised information packages to account for individual disease characteristics or prognostic factors including personal case studies? ?

13. Can we explain or predict the variability in types of complications that people will have with MDS despite having common FBC results (eg WBC count)? ?

14. Can we better predict how long a specific treatment will remain effective?

take home messages

- Living well with MDS is what matters most to patients: good supportive care; equality of access to expert advice and treatment; treating the person not the blood test results; improved management of fatigue.
- Improving communications about MDS would improve patient experience: explaining the diagnosis and its complexities to patients and significant others; improved communications between and within health care institutions; helping people to feel better prepared for what they might face in the future. This includes: prediction of individual outcomes; better understanding of how MDS will cause individual symptoms; and information about what to expect at the end of life.
- People with MDS would welcome alternatives to stem cell transplants as curative therapy. They feel that decision making about stem cell transplant should be better supported with evidence and improved shared-decision making.
- In addition to research questions, the workshop generated outputs that we can create relatively quickly, in partnership with colleagues and the national support group, MDS UK. These include resources: to facilitate sharing of stories from patients in similar situations; resources to explain MDS and other issues around diagnosis and prognosis; resources about end of life; materials to share and better explain MDS research.

what happened next:

- Three of us presented the workshop outcomes to the national panel of experts on MDS
- We are drafting documents in partnership with colleagues in Oxford in response to the feedback
- Local nurse specialists will do more to explain how prognosis is calculated, and will revisit this regularly at more points on the patient pathway
- We will work with MDS UK to promote these resources and develop patient stories for other people to read or listen to
- We will repeat the same workshops with other blood cancer groups in Oxford

For more information about the group, or to unsubscribe, email OxfordBloodGroup@ouh.nhs.uk

WHAT HAPPENED NEXT

"15 STEPS CHALLENGE" IN HAEMATOLOGY OUTPATIENTS



In late 2019, we organised a '15 Steps Challenge' to identify improvements to the outpatients area. One of the recommendations of this project was to make better use of the screens in the outpatients department, which are hard to read and don't include information relevant to our patient groups. This is now being taken forward with our senior nurse specialists - so keep an eye out over coming months.

We would like to hear from you about what the outpatient department should include on these screens. Please email Catriona at OxfordBloodGroup@ouh.nhs.uk with your thoughts.



CONTRIBUTING TO RESEARCH:



GENOMICS & PPI

The value of involving patients and the public in research is at the heart of most research practice. At the very least, it is something that funding bodies and ethics committees expect of people who conduct medical research. But it is not always clear how best to do it. For researchers who conduct clinical trials, there are clear ways to involve patients in research design – they can help researchers

see things from the patient perspective to ensure that their research is relevant and that it will attract patients to participate.

For other sorts of research, it is not so simple. One example is genomic research. Genomics and the sequencing of the human genome have had - and will continue to have - a huge impact on haematology research. But how do you involve patients in something that is so complicated for most people to understand? How do you ensure that their contribution is enriching, that it means something to the research and improves it in tangible ways?

We have decided to try and find out. Members of OBG have formed a working group and, during a series of meetings, we will attempt to answer the following:

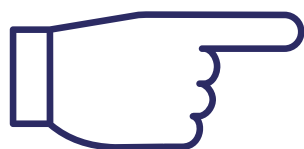
- What do people understand about genomics?
- What is the best way to teach people about genomics?
- How do we use patient experience to inform genomics research?

We will tackle these questions using the work of local colleagues, and see what we can apply to work that is taking place in Oxford. First up will be Professor Tom Milne, who works on the genomic environment and the development of childhood leukaemia.

We hope that the work will be fruitful for genomics research globally – Genomics England has already expressed enthusiasm for the project and its objectives. Watch this space!



Are you a researcher in haematology? Want some help with PPI?



**Get in touch with Noémi & Catriona at
OxfordBloodGroup@ouh.nhs.uk**

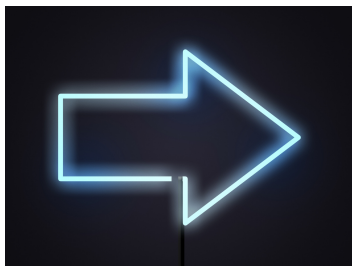
The Hill Oxford: how can we improve the blood test pathway?



Oxford Blood Group members participated in a workshop to contribute to discussions about blood tests. The Hill Oxford is a group that advises on technological innovation in the NHS. It held a series of workshops between February and May 2021 to identify the challenges clinicians are facing with blood tests, understand opportunities within the ecosystem, and explore innovative solutions to improve pathways.

The topic was highlighted due to the heightened difficulty of getting appropriate blood tests done for patients during the COVID-19 pandemic, which has exposed systemic frustrations. The workshops brought together clinicians, GPs, innovators, commissioners, and patient representatives to talk about the barriers and enablers to start building a more seamless management of bloods between primary, secondary and community care. A full report of the workshops is in progress and we will share the details with you when available.

Group member Evelyn, who was one of the patients involved, learned about a very useful resource about blood tests, that others might be interested in. See the details below.



LAB TESTS ONLINE^{UK}

Your Trusted Guide

Peer Reviewed • Non-Commercial • Patient Centred

Lab Tests Online-UK is written by practising laboratory doctors and scientists to help you understand the many clinical laboratory tests that are used in diagnosis, monitoring and treatment of disease. It is produced by the Association for Clinical Biochemistry and Laboratory Medicine in collaboration with the Royal College of Pathologists and the Institute of Biomedical Science.

Improving statistical literacy



Do you struggle to understand it when doctors talk about statistics? Or maybe you misunderstand when you are told something about, for example, cure rates or survival. You might be interested in an online resource organised by the National Institutes for Health Research (NIHR), in partnership with a group of statisticians from academia, health trusts and industry. For more information visit

<https://statistics-group.nihr.ac.uk/research/improving-statistical-literacy/>

UPDATES AND FEEDBACK ON OUR ACTIVITIES



Readers of this newsletter may recall a discussion in the last issue about a workshop with people with Sickle Cell Disorder (SCD), which identified priorities for research. One of the priorities was the issue of racism and its impact on the care of people with SCD.

Subsequent to this workshop, Dr Noémi Roy successfully bid for funding for a series of workshops to begin a conversation about racism. The three workshops took place in May, June and July of this year, bringing together people living with SCD, doctors, nurses and members of the local community. In the capable hands of our skilled facilitators, Milly and Amaragita, we came together to talk frankly about this issue, share experiences of racism, and identify projects that might influence the situation.

The first workshop involved getting to know each other and sharing stories. For all of us, this was an emotional and powerful experience. It was an opportunity to speak to people about issues that some of us might never have shared before, with people from a range of perspectives and experiences. We heard about what it is like to experience racist assumptions that compromise access to care for people who are in acute pain and potentially life threatening situations. We heard about racism in day to day life and the impact this has on families, communities – and ultimately its impact on trust in our institutions. We heard about stigma about SCD and how that silences conversations within communities. We heard about what it is like to witness racist behaviour in the workplace. We also heard about how white people acknowledge privilege but experience a range of emotions that make them feel less entitled to contribute to conversations like these. These conversations allowed us to produce a number of statements and questions to inform and structure the next steps of the process.

For the second workshop, we began to think about what is important and what is feasible. This allowed us to acknowledge the bigger picture, but also focus down on tasks that were within our gift to influence in some way. And at the final workshop, we organised into groups to identify two or three projects to take forward.

It would be no exaggeration to say that this process felt transformative for all of us. We felt enormous privilege having the opportunity to take part. And given the enormity of the challenge, the fact that we came away with small steps – things that we can do to make a difference – made us all feel hopeful, optimistic and determined.

WORKSHOP OUTCOMES

AS A RESULT OF THE WORKSHOPS:

People reported feeling more comfortable having conversations about racism - with strangers, and with people of a different race. Some of the projects we will pursue include:

- **Sickle cell "disorder" not disease: working with patient groups and professionals to change language that perpetuates stigma**
- **Pod cast / 'listening project': Recording conversations between people with SCD**
- **Community health awareness event: in partnership with church communities in Oxford**
- **Recording our experiences – sharing what we did with others within our organisation and elsewhere**
- **Better support for SCD patients - a subgroup to address resources and opportunities for supporting new and existing patients**
- **Medical training and induction – drafting content on SCD to include patient stories, workshops, patient-led events to staff education**
- **Pain and SCD - a series of interventions to improve understanding, training, management and communication about pain.**



"I now have greater awareness of racism and the experiences of people of colour in the health service. I am maintaining my commitment to the power of stories"

"as a result of the workshops, I will be bold, be confident, be courageous – have the difficult conversations & tell my story as someone living with sickle cell and working in healthcare. Dream big!!!!"

"Such an excellent model to talk about a difficult topic like this"

UPDATES AND FEEDBACK ON OUR ACTIVITIES

Data Driven Blood Transfusion Practice



Group members recently contributed to two workshops to help local experts Professor Simon Stanworth and Professor Mike Murphy with the design of a research programme to use data to streamline and improve the supply and administration of blood products. How can data reduce inappropriate variation in clinical practice? How can we ensure the best results for people having transfusions? How can we minimise waste and maximise efficiency in this very complex but critical part of our care?

We had a fascinating couple of meetings with a great deal of lively debate. We discussed what issues matter most from a patient point of view, and the panel were given plenty of opportunity to ask questions of the experts. This discussion ensured that the research application was written with adequate explanation of some of the difficult issues, and that Simon and Mike could proceed with a strong sense of the important questions from a patient perspective. We look forward to hearing further about the success of their application, and to ongoing involvement with the project.

COMING UP



Please email
OxfordBloodGroup@ouh.nhs.uk
for more information about:

- **Haematology Patient Panel**
- **New information videos for patients**
- **Contributing to medical training**
- **"Involvement Cafés"**
- **Learning more about lab research**

and lastly...

We are an involvement and engagement group for anyone with experience of a haematological illness. Your experience gives you a perspective that can be valuable in research and service improvement.

But, we need our professional colleagues and researchers to get involved with us too - so get in touch with any project that would benefit from involving patients.

Thank
you!