

EXCHANGE



THE NEWSLETTER OF THE OXFORD BLOOD GROUP

OCTOBER 2022

5 YEARS OF THE OXFORD BLOOD GROUP



It is now five years since the Oxford Blood Group was established in 2017. This newsletter will summarise the work we have done and celebrate our contribution to haematology in Oxford.

The Oxford Blood Group has provided an unusual model for working with patients. It sits at the intersection of NHS service delivery and the design of clinical research, bridging the gap between the two. It has also been managed by paid members of staff who work side by side with colleagues in the haematology department at the Churchill hospital. This model has meant that involving patients has become more visible and easier for colleagues to pursue. It has also meant that we can offer members the opportunity to take part in a wider variety of activities.

The future promises further opportunities to innovate and expand patient involvement in cancer research in Oxford, and the group will be at the heart of ongoing research into the identification, monitoring, treatment and support for people with haematological conditions. In the meantime, we hope you enjoy reading about the achievements you have all contributed to. Thank you again for sharing your time, energy and expertise with our clinical experts in Haematology.

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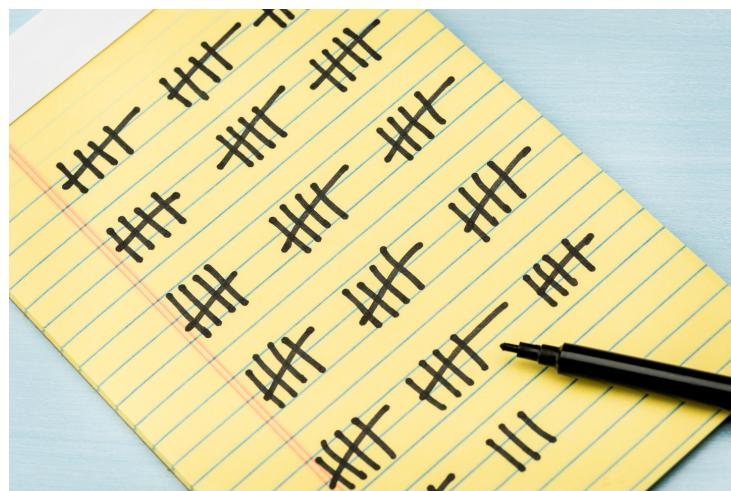
I was in a meeting recently where Oxford Blood Group was referred to as the 'gold standard' in patient engagement. Well done to all involved.

Cath, Oxford Blood Group member

OUR WORK ON HAEMATOLOGY CLINICAL TRIALS

**We have
contributed to the
design of a total of
20 clinical trials**

AS OF OCTOBER 2022



This means that we have worked with the researchers to help them refine their ideas for a research project. Panels of our members have:

- commented on the importance of the research question
- discussed potential obstacles to patient participation in the trial
- discussed what outcomes mean the most to patients
- highlighted the issues that patients will struggle to understand

We have provided written summaries of the group's input and their comments, and this information has been used by the researchers to support applications for funding and submissions to research ethics committees.



The meeting last week really helped us to consolidate our thoughts and explore issues and concerns of members of the public/hospital users. And equally, the subsequent comments on the information sheets/consent forms that we sent out have been very gratefully received and we have adjusted these forms accordingly.

Professor Nicola Curry

**In addition to these
20 trials, we have
contributed to a
further 21 lay
summaries and
patient information
sheets**



Your feedback on the PIS was absolutely fantastic and the sponsors described our input as 'transformative.'

Professor Paresh Vyas

ENABLING AND PROMOTING PPI

We have promoted our work and supported colleagues who need advice about PPI



We have:

- helped researchers devise PPI strategies
- assisted with the description of PPI plans in grant applications
- presented our work at annual meetings of the Oxford Centre for Haematology
- presented our work at quality improvement conferences organised by NHS Improvement
- talked to pharmaceutical companies about the importance of understanding patient experience
- shared our work with NCRI committees specialising in haematology conditions
- participated in networks nationally and in Oxford to talk about PPI and share our experiences.

PPI IN COMPLEX SCIENCE: HOW TO EXPLAIN GENOMICS AND EPIGENETICS



This work included a project to help scientists explain epigenetics and genomics to a group of OBG members, to see if non-scientists could understand enough of the science to contribute meaningfully to research projects. Over a series of 4 workshops, 4 scientists presented their work and talked about it to a panel of patients. **at** the end of this project, the scientists learned more about what works and what doesn't. The patient panel also learned about this incredible - and incredibly exciting - area of medical research.

"The panel were so helpful. I learned that I need to simplify some of my concepts better and tell a story. I also need to know more about the patients diseases beforehand becuae they were very keen to know how this work related to them directly." Professor Tom Milne

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

WHAT MATTERS MOST WORKSHOPS



Over the past two years, we have conducted a series of professionally facilitated workshops with groups of haematology patients who all share a diagnosis.

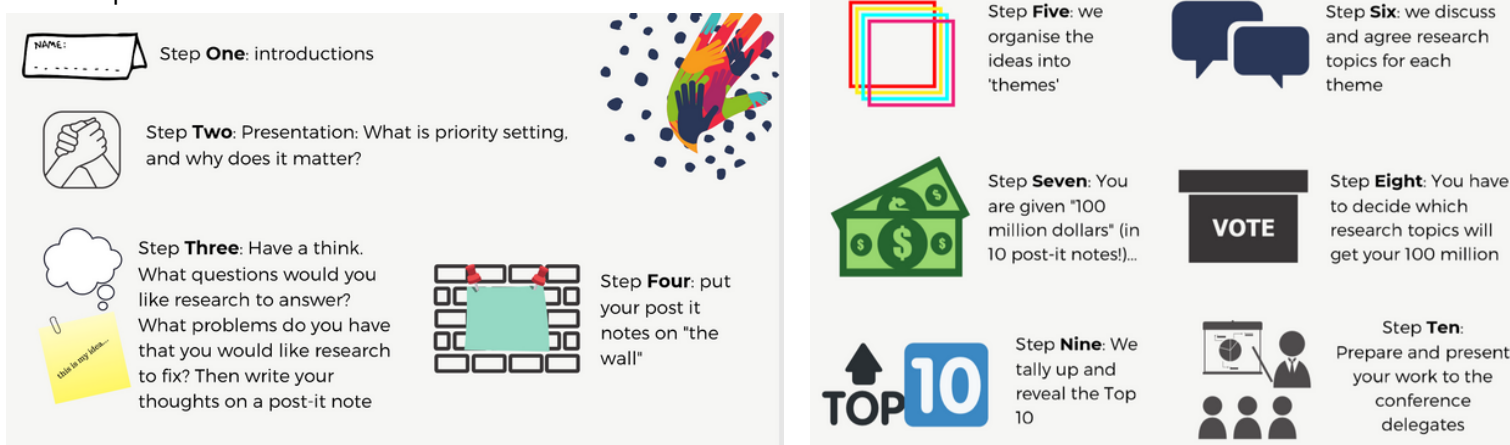
The first of these workshops was held in person at an international conference on sickle cell disorder and thalassemia. A group of people with sickle cell disorder from all over the world worked together to talk about their priorities, agree a top ten, and present these priorities from the podium to the assembled audience of experts.

The COVID pandemic meant that subsequent workshops had to be held online, but this has meant that it is easier for people to take part from home.

The purposes of the workshops were as follows:

- to open up conversation with haematology patients about what matters most to them
- to give people the opportunity to talk about their difficulties living with their illness
- to discuss possible subjects for further research
- to identify issues relating to service delivery
- to vote on a top ten of things that are most important.

The workshops follow a ten step process. Beginning with introductions, the group are invited to talk about their experiences and the issues that they feel need more attention from health care professionals. These issues are then arranged into themes, and summarised into a series of questions that the group is invited to refine and vote on before presenting the top ten to a group of experts.



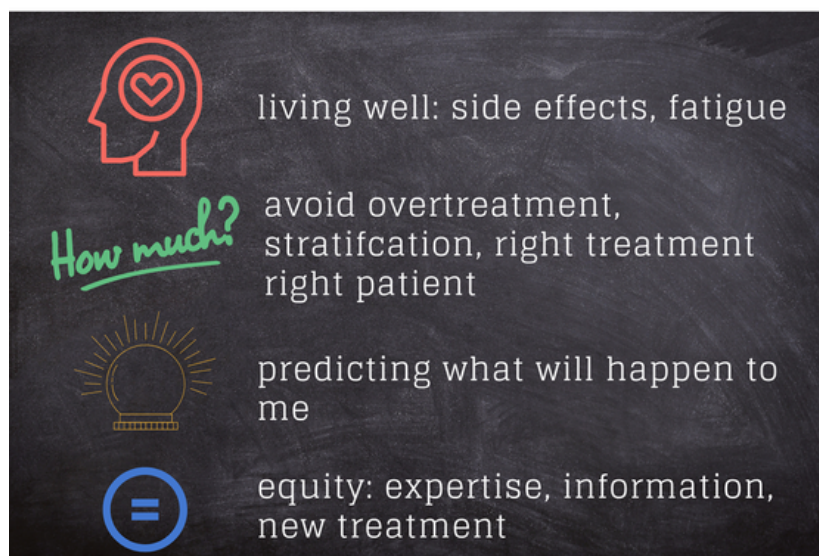
The process has not ended in Oxford. Haematology consultants and researchers have **shared the patient priorities with national research committees**, such as the National Cancer Research Institute subcommittees for myelodysplastic syndrome and myeloproliferative neoplasms. National **patient support organisations have shared them with their members** to promote further discussion. **Local research projects have responded to the top ten** and invited patients to contribute to study design. Above all, the workshops have given patients the opportunity to come together and share their experiences. They have demonstrated that **haematology researchers really want to hear** from the people who live with these conditions, and we hope that the model can be replicated across other patient groups in Oxford.

WHAT MATTERS MOST WORKSHOPS

SHARED CONCERNS AND COMMON THEMES

Having taken part in workshops with several different groups of patients, it was immediately apparent that there were themes and concerns that cut across all disease groups.

Firstly, it is surprising that cure of the condition is not always the first thing that patients want to talk about. The emphasis of the workshops was on how to live well with a condition: how to deal with fatigue, how to manage side effects, how to make sure you are getting the treatment that is right for you, avoiding too much treatment, how to know what will happen in the future.



There are also many shared concerns about communication and information:

- awareness of rare disorders
- importance of access to specialists who understand the condition
- delays in diagnosis
- poor communication between different parts of the NHS.



Sadly, people report poor experiences of getting a diagnosis and struggle to know who to turn to for advice when they only have relatively infrequent appointments with their specialists. And everyone agrees on the importance of the right information for the right person. People with haematology conditions often struggle to fully understand their illness, and information often needs to be adapted - and repeated - to help people understand what to expect.

A group of patients are working with Catriona, the OBG co-ordinator, to write a statement for the haematology department. The statement of collective values and concerns will bring together these shared issues and their implications for the delivery of our service. By doing this, we hope that the workshops will have an ongoing influence not just on research priorities but on patient-centred delivery of care.



SERVICE IMPROVEMENT PROJECTS

The group has contributed to several improvement initiatives to support the delivery of services in the haematology department.

Three of these projects from the last 5 years are discussed below.

BONE MARROW BIOPSY WORKING GROUP

It may not come as a surprise to readers to learn that the experience of having a bone marrow biopsy is sometimes not great. Back in 2018, we convened a working group of people with good and not-so-good experiences of bone marrow biopsy. The group also included a consultant, a junior doctor and the lead nurse for the bone marrow biopsy clinic. The work of the group has resulted in:



- improved patient information
- improved signage
- new technology to extract bone marrow samples
- patient experience questionnaires
- video resources for doctors and patients
- new artwork for the clinic wall.

The work has also been shared at national meetings of the NHS England improvement group.

RACISM AND THE CARE OF PEOPLE WITH SICKLE CELL DISORDER

We knew from our workshops with people with sickle cell disorder that racism frequently has an impact on the care they receive. Dr Noemi Roy successfully bid for funding to pay for professional facilitators to help us design the workshops and **manage** them. Over the course of the three workshops we:

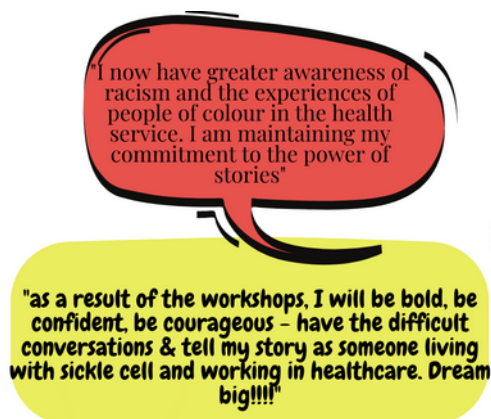
- shared experiences of racism in the health care setting
- identified the issues and challenges, and talked about what might help to improve the situation
- decided on what was in our power to implement



- came up with a series of 'small steps' towards improvement.

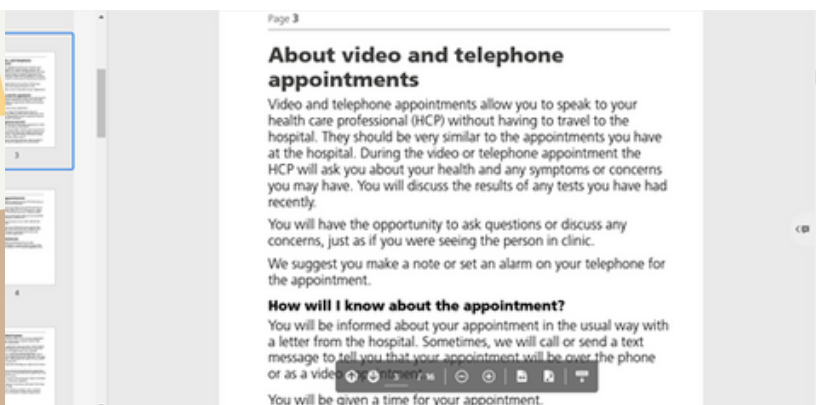
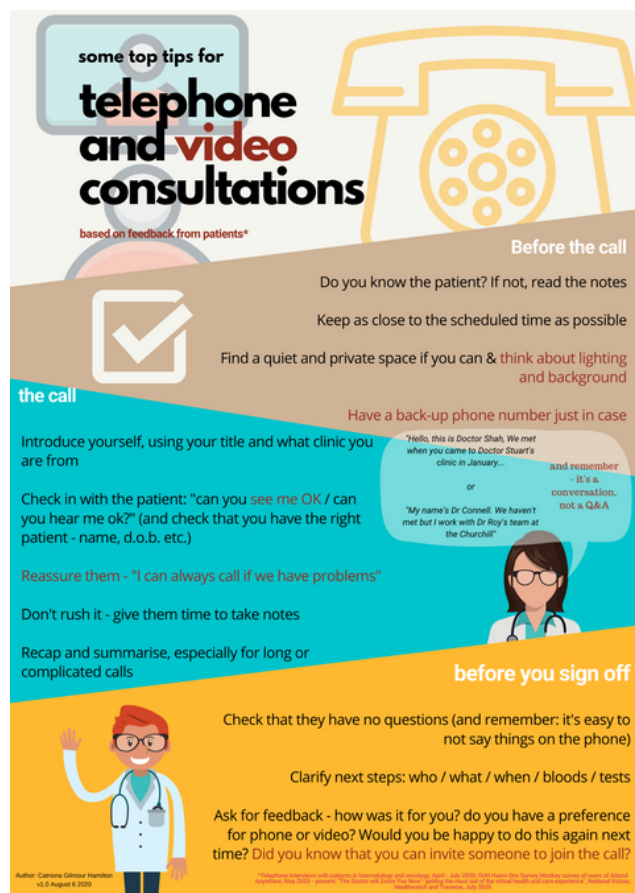
These steps include:

- participation in the BBC's Listening Project
- sharing our work and the workshop model nationally and internationally
- contributions to the medical school curriculum
- improving the understanding of pain and its management in SCD crisis.



SERVICE IMPROVEMENT PROJECTS

COVID 19 - TELEPHONE AND VIDEO CONSULTATIONS



The Oxford Blood Group was ahead of the pack when it came to understanding patient experience of telephone and video consultations. Early on in the COVID pandemic, group members participated in an interview study, which led to the creation of resources for staff and patients. We then contributed to another study run by a group of nursing and allied health professional research fellows, which looked at the experiences of professionals and patients. One of our members, Evelyn, had the following reflections about taking part in this research and what she learned about the experience of doctors and nurses:

ENGAGEMENT: A TWO WAY PROCESS

The pandemic forced all of us to adapt. As patients we had to get used to remote consultations. In some ways there were benefits to this: no travelling to the hospital; no circuits of the car park looking for a space; no waiting when a clinic was running late. There were downsides of course: no physical examination of a new or changed condition/symptom; not being able to read the clinicians body language; no direct contact when faced with bad news or a difficult decision; plus the difficulties many people faced generally with having other family members around and lack of privacy to talk.

I took part in a study*, conducted during the pandemic, which evaluated the experiences of both patients and clinicians as they adapted to remote consultations, highlighted these obvious pros and cons but interestingly for me as a patient, identified the difficulties and concerns expressed by clinicians; these had not really crossed my mind. Just as there are many patients who are not tech-savvy, there are clinicians who rely on support staff to make sure their computers are working, upload documents, update results, safeguard data etc; suddenly they were doing all this themselves from home. Much of their time was taken up with administrative tasks. Clinicians often run things past colleagues, make decisions as a team, share new information in ad-hoc conversations,

offer support. All this was lost as they worked in isolation at home. The nature of the job is working with people face-to-face. Just as we patients like to build up a relationship with our clinicians, the clinicians do too. "Meeting" a new patient remotely is not ideal for either party and the communication process is different. Clinicians use body language as much as we patients do and are skilled at picking up on what a patient isn't saying during a consultation and teasing out information.

Reflecting on the report that followed this study it seems to me that this is an opportunity to develop the use of remote consultations; not to replace face-to-face ones, but to supplement them. But this needs more planning than time allowed when the restrictions of the pandemic were suddenly thrust upon us. We live in a technological world and it makes sense to make this technology work for us. However, it will only work if the 'powers that be' consult with both clinicians and patients to find out what worked and what didn't and then provide the ongoing support and resources needed to develop and maintain a successful hybrid model of patient care.

*<https://journals.sagepub.com/doi/full/10.1177/20552076221115022>

NEW INFORMATION FOR PATIENTS

Having the group at the heart of the haematology department, with members who are current and recent users of the service, gives us fresh insight into how people interact with our clinics and health care professionals.

This insight has been invaluable in our contributions to:

38 NEW AND REVISED RESOURCES FOR PATIENTS

Members of staff have used to the group to test existing resources for readability, and to make sure that the right issues are covered. And the group has been a first port of call when drafting new information, to ensure that the content of the resource is based on a good understanding of patient experience and the questions they want to ask.



These new and revised resources have included:

- information about shielding during COVID 19
- leaflets about telephone and video consultations
- animations about haematology research
- information about many haematology treatments
- information videos about the Ambulatory Care Unit
- information video about the Day Treatment Unit

The email link for the video taken in the unit was brilliant. It helped me see what to expect during my treatment. It also helped my family realise that having the treatment the patients are in a very comfortable and caring environment. That video was fantastic.

CLOSING REMARKS AND THE FUTURE



The Oxford Blood Group has helped to ensure that the patient voice is at the heart of the culture of haematology in Oxford. The projects outlined here are just part of a wider programme of work that will be ongoing, fostering working partnerships between staff and patients, and setting the example for other parts of the Trust. Exciting developments will continue to come our way, including opportunities to participate in innovations in PPIE that promise to put patients and their families in the driving seat of the Oxford cancer research agenda. Watch this space!