

Patient priorities in Myeloproliferative Neoplasms (MPN): The ‘What Matters Most’ workshop and its impact

Background

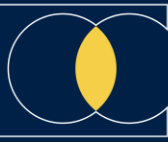
The What Matters Most method was designed by the Oxford Blood Group as a way of bringing people together to talk about their shared experience of malignant blood disorders and agree a list of priorities for research and NHS service delivery.¹ The workshops were conceived as a way for haematology researchers in Oxford to make themselves aware of the most pressing issues facing their patients. It was an effort to demonstrate a commitment to learning from the experience of patients. It also created a space and a structure that allowed people to express their views with those in a position to influence research and service delivery.

Following a successful workshop with people with myelodysplastic syndromes (MDS), the model was repeated in October 2021 with MPN patients.

Method

- Participants attend two online sessions of two and a half hours duration each. Workshops were conducted using Zoom. Two staff members and two facilitators managed the sessions.

¹ For a description of the WMM method, see <https://oxfordbrc.nihr.ac.uk/category/news-blood/oxford-blood-group-news/>.



- We used the online platform Miro, with the assistance of a skilled technical facilitator, to replicate a white board, post it notes and sticky dots for voting.
- People with MPN from local and national support groups were invited to attend. The people who took part were all white and middle aged. They were people with essential thrombocythaemia (ET) or polycythaemia vera (PV). They were all reasonably well controlled and monitored via a telephone clinic with regular blood tests. Patients with myelofibrosis and chronic myeloid leukaemia were also invited but none participated. Most were patients being treated at OUH.
- Session one involved sharing concerns and discussion. Individual concerns were grouped into themes and agreed with the group. Participants identified 52 individual issues that fell under the themes of: Medication; Communication; Care Management; Relationships; Future research; Terminology; and Symptoms.
- Staff members worked to refine these questions in between the two workshops to streamline and address areas of duplication. The final list of 24 questions was shared with participants in advance of the 2nd workshop
- The second meeting was dedicated to agreement of the revised questions and then voting. Clinical and research colleagues joined the group at the close, and the participants presented their priorities to the expert panel.

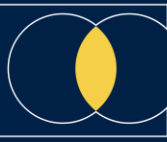


Figure 1: The Top 10



what matters most to people with MPNs?



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The TOP 10



1. What are the long term side effects of hydroxycarbamide? Are some people more at risk of serious long term effects?



2. What are the reasons for molecular abnormalities that arise (JAK2/CALR/MPL) and can anything be done to avoid them occurring or progressing?

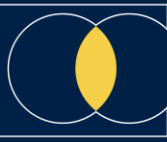
3. Can we develop drugs that are specific to target MPNs rather than use drugs which happen to reduce counts?



4. Can we develop national best practice guidelines to ensure that all people with MPN have access to a specialist nurse? This model would include continuity of care and regular contact with nurse specialist.



5. What factors will influence the stability of my condition? Can any intervention help to improve stability?



**what matters most to people with MPN?
the TOP 10**



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6. What additional risks are there of getting COVID19 for people with MPNs?



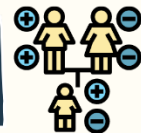
7. How can we ensure that people have access to precise, tailored information about individual risks and vulnerabilities?

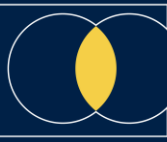
8. How can we better share information with GPs to ensure they understand MPN?



9. How can haematology teams ensure adequate training to develop nurse specialists and others with deep knowledge of MPNs for the future?

10. Is there any inherited aspect to MPNs?





Impact and suggestions

- The workshop brought together a group of people who feel very isolated and overlooked. They enjoyed the opportunity to share experiences with others like themselves.
- The findings were shared with the NCRN MPN expert sub-committee. Participants attended this meeting.
- Together with the outcomes from the MDS and Myeloma workshops, this workshop resulted in a statement of shared concerns about NHS support for people with rare chronic blood disorders. This statement was shared with the Haematology Department clinical and operational lead staff, with suggestions for best practice in communications and shared decision making.
- Information resources were commissioned in response to the areas where patients feel poorly informed.
- Team to discuss with Professors Adam Mead and Bethan Psaila the potential for Oxford-led research projects in response to the Top 10, in partnership with Oxford Cancer, perhaps as part of their DPhil student programme.