Patient priorities in Myelodysplastic Syndrome (MDS): 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.

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

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.

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[1] For a description of the WMM method, see https://oxfordbrc.nihr.ac.uk/category/news-blood/oxford-blood-group-news/.
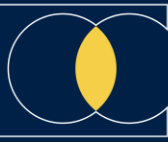
- We used the online platform Miro, with the assistance of a skilled technical facilitator, to replicate a white board, post it notes and sticky dots for voting.
- People with MDS from local and national support groups were invited to attend. Attendance was fixed at a maximum of 20 participants to ensure manageable numbers in an online environment. 14 people took part. All participants had MDS of varying degrees of severity. They were aged 38 – 88, all white British. Most were patients being treated at OUH, but some were from other parts of the UK.
- Session one involved sharing concerns and discussion. Individual concerns were grouped into themes and agreed with the group. 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.
- Staff members worked to refine these questions in between the two workshops to streamline and address areas of duplication. The final list of 26 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.
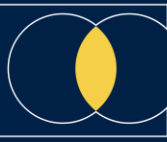
Figure 1: The Top 10

what matters most to people with MDS?
patient workshop outcomes

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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?
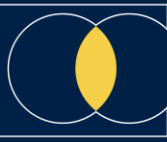
4. Is there a better alternative to stem cell transplant as a curative treatment for people with MDS?

5. How can we better address the management of fatigue?

what matters most to people with MDS?
patient workshop outcomes

what matters most?
CAPTURING PATIENTS' PRIORITIES

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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? ?
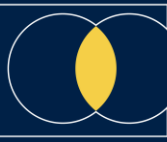
Impact

- Workshop attendees found the process empowering and enjoyable.

- The findings were shared with the NCRN MDS expert sub-committee and circulated in partnership with MDS UK. Participants attended this meeting.

- Participants became PPI contributors to the design of a project about better use of blood transfusion for MDS patients.

- Information resources were commissioned in response to patients feeling ill informed about, for example, end of life with MDS.

- The findings were used to support Dr Daniel Royston's successful application to CRUK for a project that will use machine learning in the laboratory to allow visualisation of the changes in a person's bone marrow. This will help patients to understand their individual illness and how their bone marrow might change over time.

- The original participants in the workshops, and partnership with MDS UK, will collaborate with Dr Royston as PPI contributors, providing the opportunity to contribute to a project that responds to the priorities of patients.