

Patient and carer engagement in research agenda setting



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Introduction

Patient engagement in setting research priorities is about identifying issues that are important for patients as the end-users of research.

Why do it?

- Patients have the right to be involved because the outcomes might affect them
- It improves the acceptance of research by patients
- It results in higher-quality research

Methods

We conducted an online and paper survey among current and former patients and their carers. We asked the respondents to:

- Pick and rate ten aspects of TB care that need to be improved
- Identify any aspects missing from our list in their own words
- Report willingness to get involved

The questionnaire was co-developed with an activist with lived experience of TB and the MSF patient-support team.

Results

We collected 155 responses via MSF projects in Russia and Belarus and online patient communities. Both online and paper questionnaire groups demonstrated similar priorities. Pooled top-10 priorities for both groups are shown below.

Top-10 priorities

1. New diagnostics for latent TB
2. Short oral treatment regimens
3. Wider use of molecular diagnostic technologies
4. New diagnostics for active TB
5. Better TB diagnostics for children
6. Active case finding of latent TB
7. Person-centred TB care
8. Active case finding of TB disease
9. Better TB treatment for children
10. Monitoring resistance to new and repurposed drugs

Conclusion

Stakeholder feedback was elicited to develop a responsive research agenda through a method adapted to the COVID pandemic context. While online participants provided more free-text answers, priorities were very similar for both groups. One limitation of this study is that it is likely that where questionnaires were administered by healthcare workers, respondents felt less free to share opinions. Patient involvement in research setting is feasible and yields useful insights.

Additional aspects

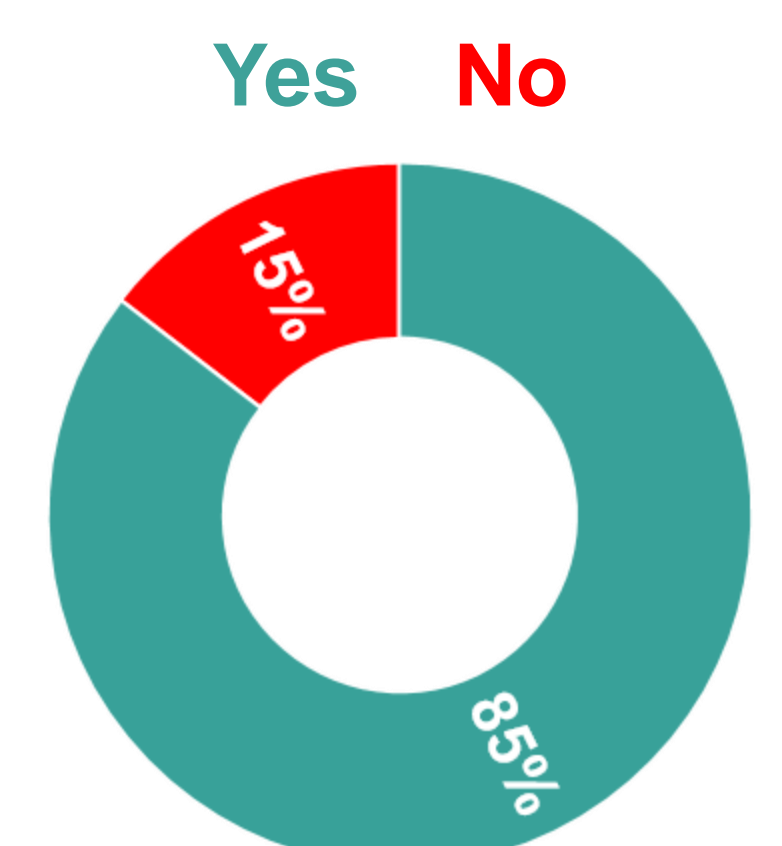
Respondents who said our list was incomplete suggested the following aspects:



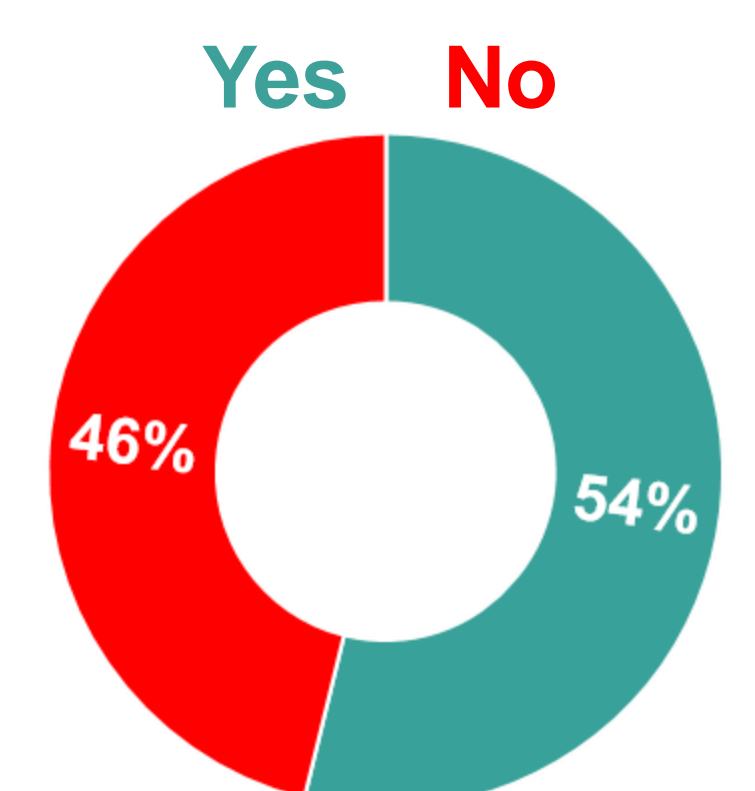
Willingness to get involved

While not many patients were willing to get actively involved, the overwhelming majority of our respondents said that patients should be consulted about care delivery and the directions of research.

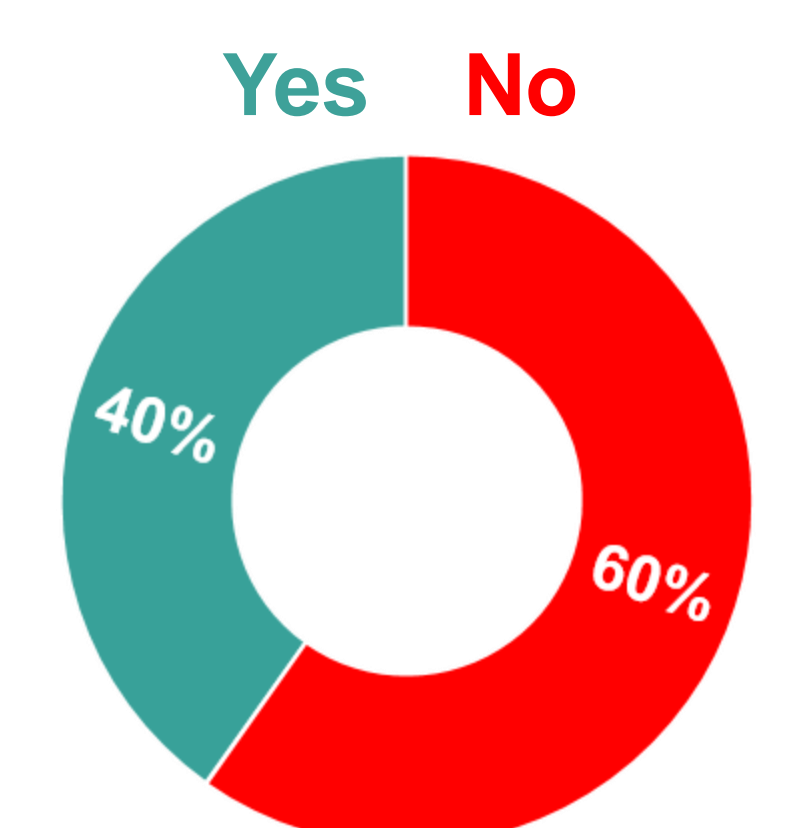
“Do you think TB patients and those that got better should be consulted about directions of research and administration of TB care?”



“Would you personally like to be contacted to be consulted?”



“Would you like to be more actively involved, for example, as a member of an advisory committee in a clinical trial or a TB hospital?”



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