Supporting Research Involving the MSA Community

Guidance for researchers seeking MSA Trust support with PPIE

The MSA Trust is committed to supporting high-quality research that improves understanding, diagnosis, treatment and care for people affected by Multiple System Atrophy (MSA). We recognise the importance of Patient and Public Involvement and Engagement (PPIE) in ensuring research reflects the experiences, priorities and needs of people living with MSA and those who support them.

To ensure we can support as many worthwhile projects as possible while minimising burden on the MSA community, we ask that requests meet the expectations outlined below.

Support we may be able to provide

Depending on available capacity and strategic fit, the MSA Trust may be able to:

- Promote research opportunities through our website, social media channels and other communications.
- Share opportunities via email with our Involvement Network (people with MSA, carers and bereaved carers) and/or our MSA Community Research Group.
- Provide guidance on engaging appropriately with the MSA community.
- Provide a letter confirming that the MSA Trust intends to support promotion of a project, where appropriate.

Research we are unlikely to support

- Undergraduate student projects.
- Market research.
- Commercial marketing activities.
- Projects without a clearly identified sponsor or lead institution.
- Requests that may imply MSA Trust endorsement of a product, treatment or commercial service.
- Requests that place a disproportionate burden on the MSA community.

What we expect from Researchers

- Research must have the potential to improve outcomes, care, understanding or quality of life for people affected by MSA.
- Be well designed, ethically conducted and affiliated with a recognised research institution, NHS organisation or equivalent.
- Demonstrate a clear rationale for involving people affected by MSA.
- Consider equality, diversity and inclusion in recruitment and involvement activities.
- Commit to sharing findings and outcomes with the wider MSA community.
- Reimburse reasonable out-of-pocket expenses incurred by participants or contributors.
- Consider offering appropriate payment or recognition for PPIE contributors where appropriate.

Plain English requirements

All materials intended for people affected by MSA must be written for a non-specialist audience. Researchers should:

- Use clear, jargon-free language.
- Avoid technical terminology wherever possible.
- Explain any unavoidable scientific terms.
- Clearly explain what participants will be asked to do.
- Clearly explain the expected time commitment.
- Explain how involvement could influence the research.
- Explain how the research may benefit people affected by MSA.

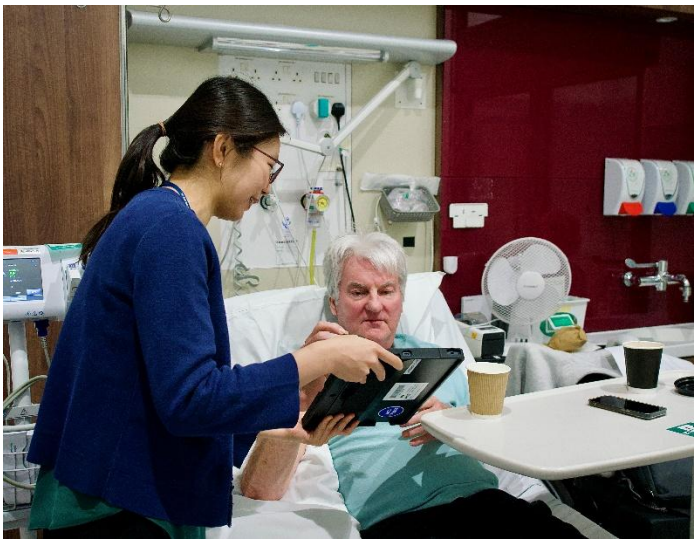
multiple system atrophy trust

Social media and email communication requests

Where researchers request promotion through MSA Trust communication channels, they must provide:

- Fully drafted social media posts or emails.
- Suitable images, graphics or videos.
- Website copy where required.
- Ensure any relevant links are working correctly.
- Suggested timelines or publication dates.

Due to limited resources, the MSA Trust cannot write social media content on behalf of researchers, create graphics, videos or other promotional materials, manage social media campaigns nor develop communication strategies for individual research projects.



Direct communication with participants

Researchers must provide a named contact and direct contact details for interested individuals to be able to contact the research team directly.

The MSA Trust will not:

- Collect expressions of interest.
- Screen or recruit participants on behalf of researchers.
- Collate responses.
- Coordinate participant communication.
- Store or transfer participant information.

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Important Information

- Support is provided at the discretion of the MSA Trust and cannot be guaranteed.
- Researchers should contact us before approaching MSA support groups or community networks directly.
- The MSA Trust reserves the right to prioritise opportunities that align with our strategic objectives, offer clear benefit to people affected by MSA, and make appropriate use of charity resources.

Requests should be emailed to support@msatrust.org.uk. Please allow a minimum of 6-8 weeks for requests to be reviewed and, where approved, promoted through our channels / networks

Thank you for helping us involve the MSA community safely and meaningfully.