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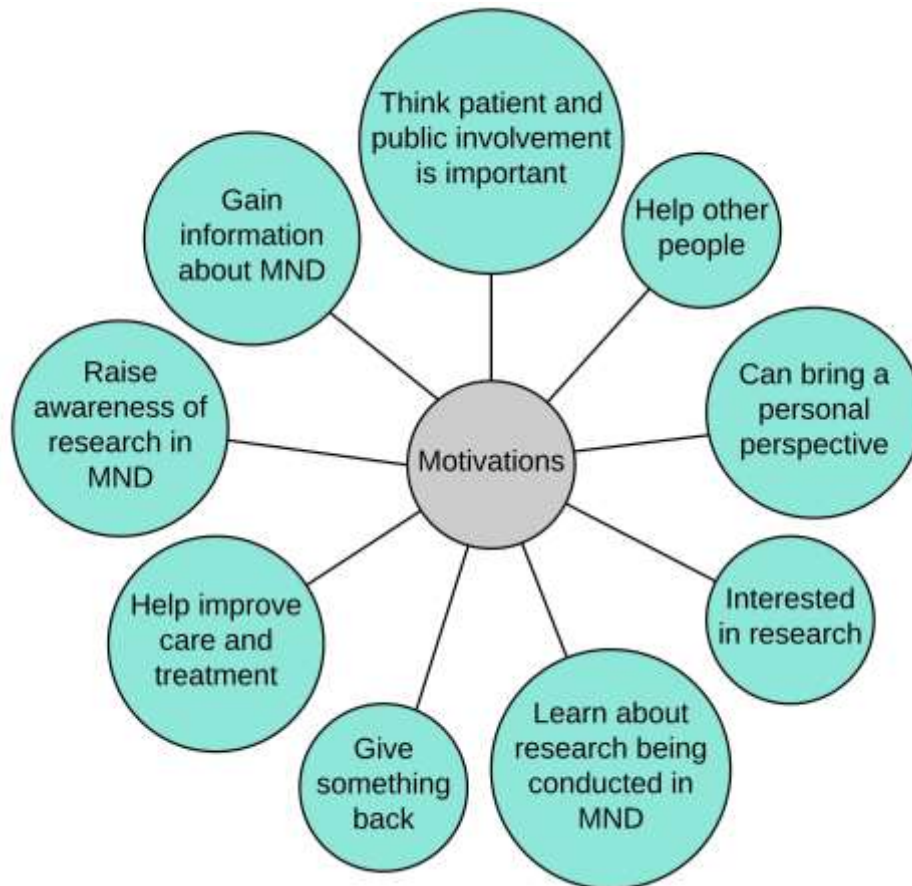


Figure 1. Reported motivations for joining and participating in the SMNDRAG.
MND, motor neuron disease

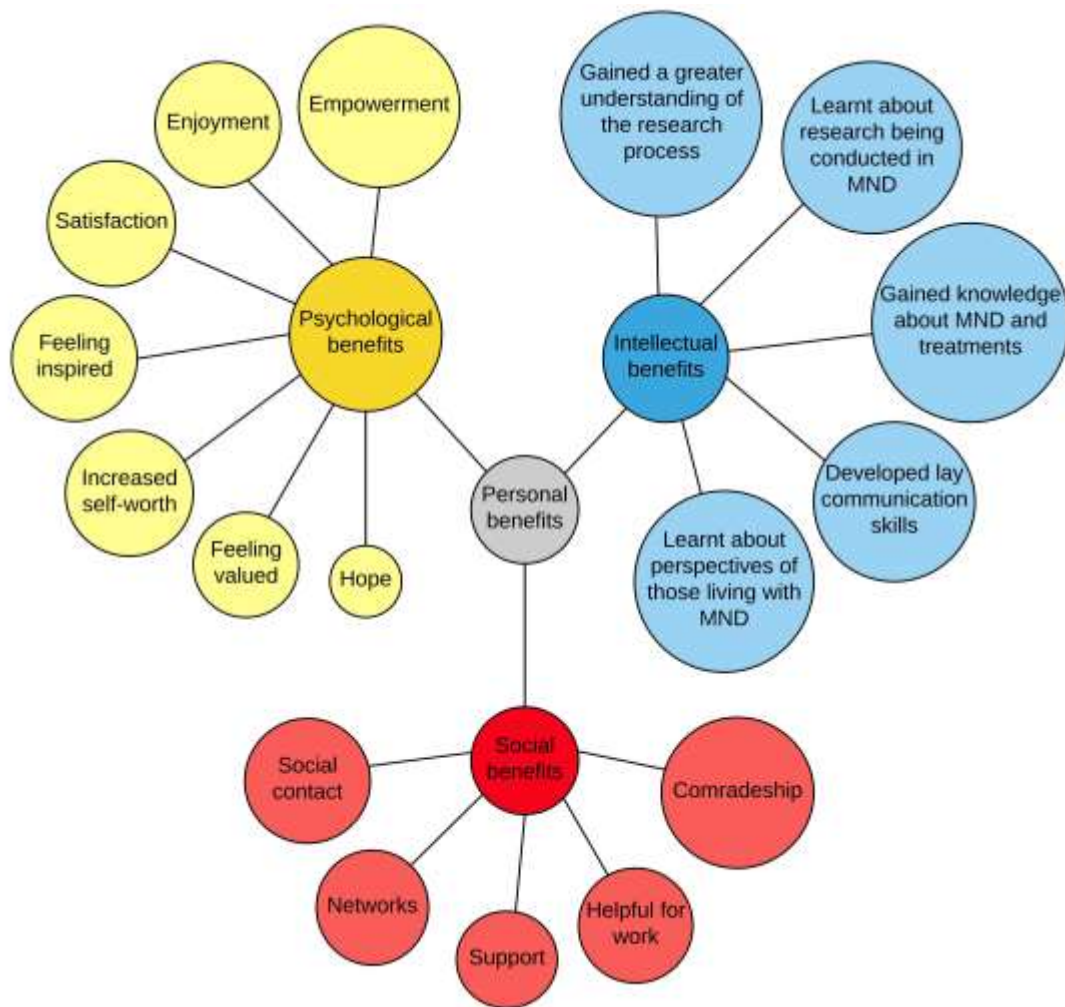


Figure 2. Personal benefits of PPI.
MND, motor neuron disease

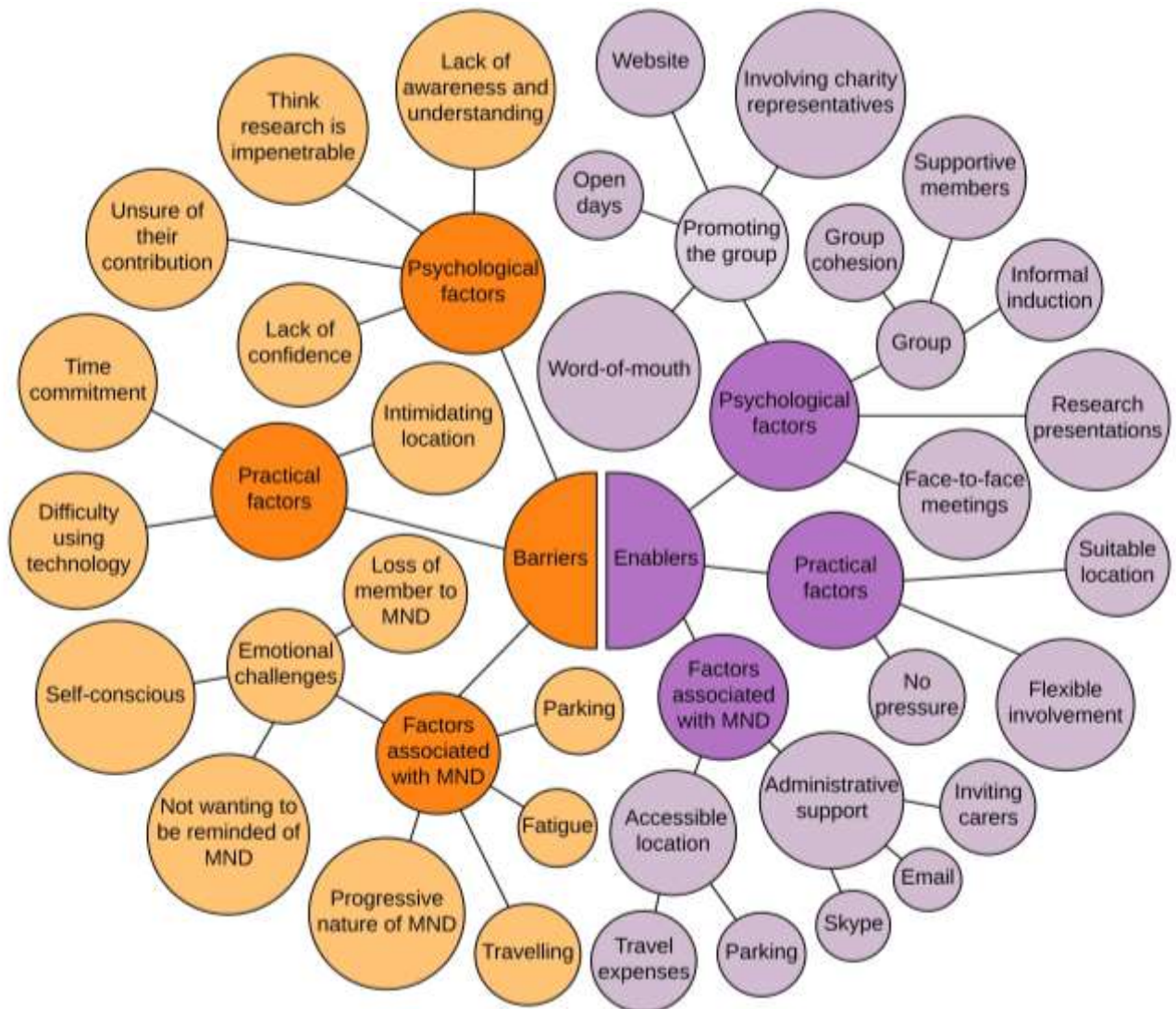


Figure 3. Reported barriers and enablers to participating in PPI.
MND, motor neuron disease

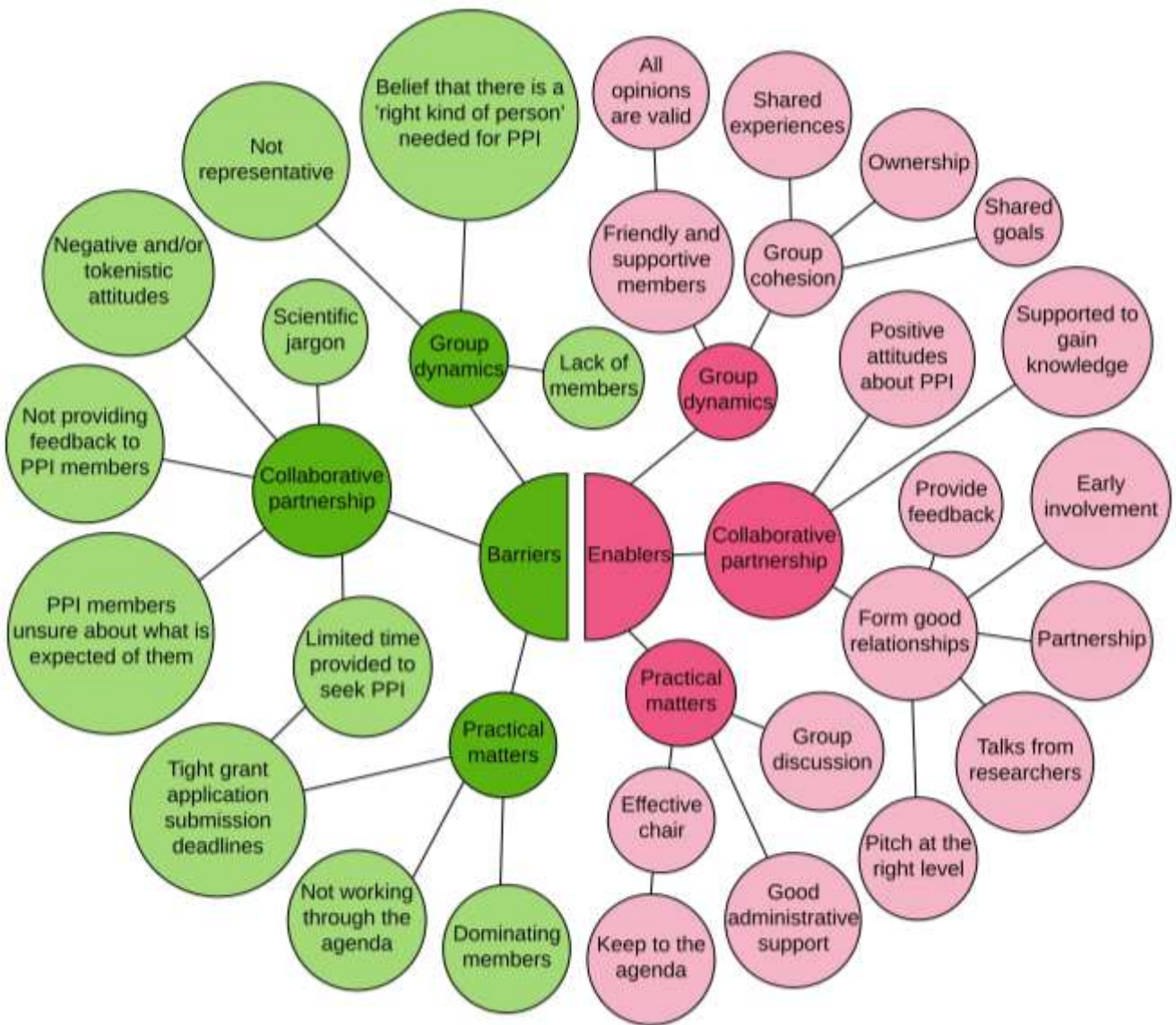


Figure 4. Reported barriers and enablers to effective and meaningful PPI.
 PPI, patient and public involvement

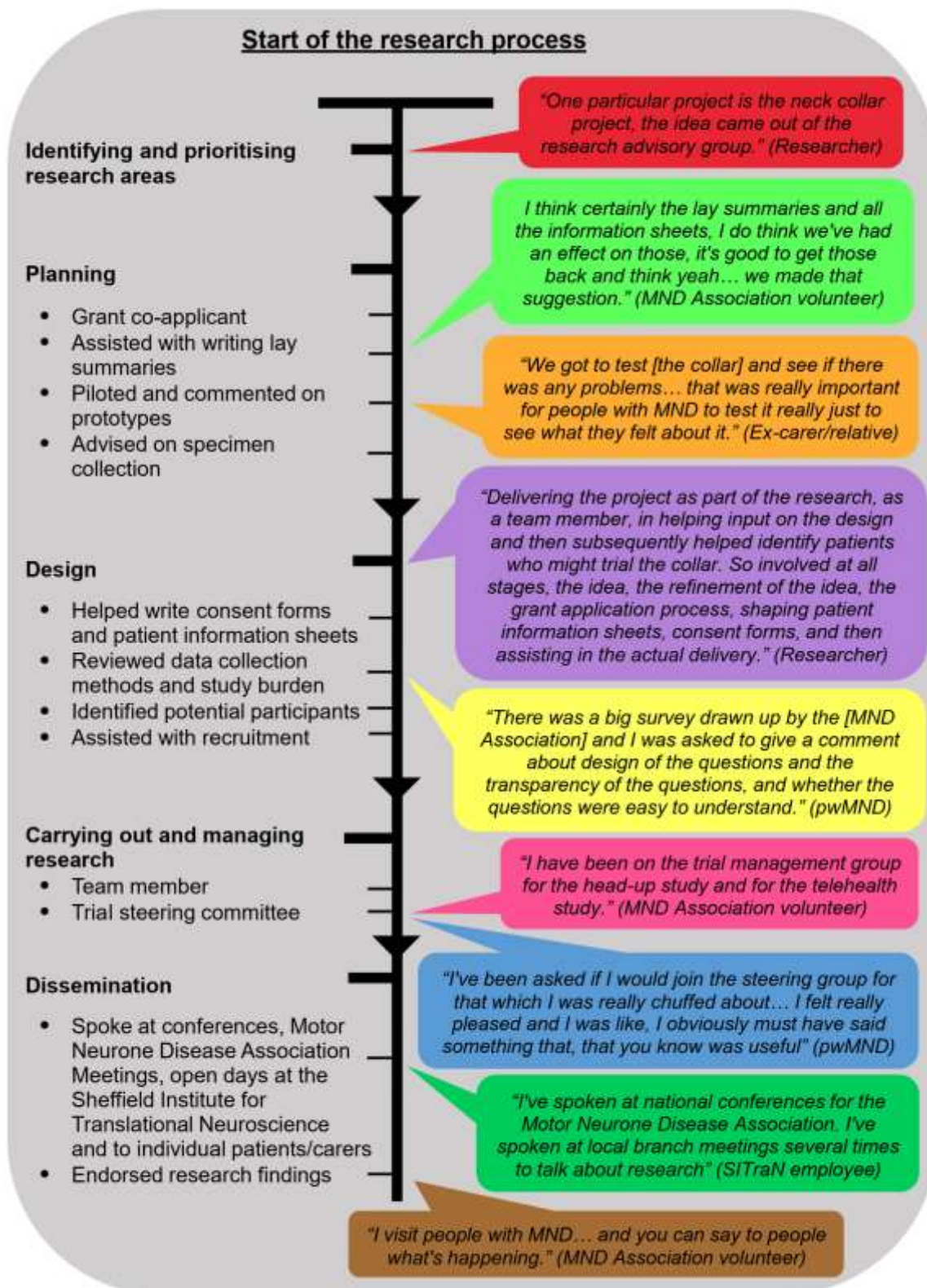


Figure 5. Stages of the research process that participants reported the SMNDRAG had been involved in and supporting quotes.

MND, motor neuron disease

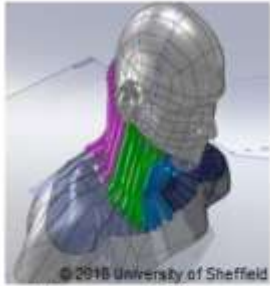
PwMND, person with motor neuron disease

Box 1. The involvement of the SMNDRAG in the Head-Up project.


SMNDRAG, Sheffield Motor Neurone Disorders Research Advisory Group

PwMND, person with motor neuron disease

MND, motor neuron disease



The SMNDRAG identified neck weakness and the lack of an appropriate neck collar as a major problem impacting on the quality of life of pwMND. The Head-Up project was a collaborative partnership involving members of the SMNDRAG, others with lived experience of MND, healthcare workers, engineers and fashion designers (14, 15). A new collar was developed and tested in 100 pwMND (16). 80% chose to use the collar in preference to other collars and it scored significantly better than other collars in satisfaction, level of support, residual head movement possible, appearance and lack of interference with eating ($p < 0.005$). The SMNDRAG were involved in workshops to develop the collar and testing prototypes, research planning and governance including the trial management group and in recruitment and in dissemination through social media and using videos describing the benefits of the collar. This new collar is now available at an affordable price (17).



Box 2. A list of our recommendations for those organising and running PPI groups, researchers and funding bodies.

PPI, patient and public involvement

Those organising and running PPI groups such as healthcare providers

- Promote the group using a variety of methods to increase awareness of PPI.
- Provide good administrative support and an effective chairperson.
- Provide an introductory guide detailing what to expect.
- Highlight to potential PPI members that no formal training is needed.
- Offer personal invites and an informal induction.
- Ensure participants feel no obligations to attend every meeting and review all of the documentation.
- Involve carers and charity workers.
- Provide additional support and enable different methods of participation, i.e. email, face-to-face, Skype.
- Hold meetings at convenient locations and times.
- Provide out-of-pocket expenses and refreshments.
- An annual review to assess the group's progress, to monitor the demographics of PPI members and to assess for change.

Researchers

- Form a collaborative relationship with PPI members.
- Involve patients and the wider public early in the research process.
- Attend meetings and give presentations using appropriate language.
- Be explicit in their expectations when asking members to comment on research.
- Provide feedback.

Funding bodies

- Allow sufficient time for PPI at each stage of the grant application.
- Provide funding for PPI groups