**Request to involve people affected by MND in research**

If your research proposal, or enquiry, is seeking to access the perspective of people affected by MND, please complete this form so we can assess whether MND Scotland is able to assist with accessing or acquiring the information you require.

**Part I: About you**

|  |  |  |  |
| --- | --- | --- | --- |
| **Lead applicant** |  | | |
| **Job Title** |  | | |
| **Institution & department** |  | | |
| **Co-applicants** |  | | |
| **Email** |  | | |
| **Phone number** |  | | |
| **Study title** |  | | |
| **Location of research** |  | | |
| **Funding body** |  | | |
| **Ethical approval**  (Has ethical approval already been received? If yes, please attach a copy of approval letter) | Yes/No | **Does this request accompany a grant application to MND Scotland for research funding?** | Yes/No |

**Part II: Details about your study**

|  |
| --- |
| **Title of the study in plain English** (please ensure this is suitable to be shared with people affected by MND) |
|  |
| **Summary of your study, suitable for a lay audience** (max 250 words, in plain English). Please also include any relevant links to online information about the study. |
|  |
| **What stage of the research are you at?** |
|  |
| **At what stage(s) of the project are you wanting to involve people?** Please circle the option(s) most relevant |
| Developing priorities  Developing research questions  Co-producing and co-designing the research  Evaluating documents  Undertaking research  Sharing findings  Something else (please provide details here) |

**Part III: Taking part**

|  |
| --- |
| **Why do you want to involve people in your research?** |
|  |
| **What will taking part involve?** (what will you be expecting participants to do?) |
|  |
| **At approximately which dates are you wanting to involve people?** |
|  |
| **What format will being involved take?** (e.g. – online, face-to-face; group or individual conversations) **and what time commitments are required?** |
|  |
| **How will your research help people who are affected by MND now, and/or in the future?** |
|  |

**Who will be involved?**

|  |
| --- |
| **Please specify whether you are looking for people with particular experiences or particular characteristics** (i.e. – are you wanting to involve anyone with experience of MND; more specific groups such as people diagnosed with MND, family members, carers, bereaved family members/carers; or with particular experiences such as length of time from diagnosis, or geographical location?). Please also outline if any symptoms will exclude, or make it unsuitable for people to take part. |
|  |
| **How many people are you wanting to involve?** |
|  |

**Supporting those involved:**

|  |
| --- |
| **What considerations have you made in designing the research to ensure that it is accessible for people living with MND?** How are you ensuring that people can take part in a way that is suitable for them, and for their needs? (please describe considerations and mitigations which you have made/will make around the duration of participation, mobility, speech loss, fatigue, and any other aspects). |
|  |
| **Will costs be incurred (including travelling) for those taking part?** If yes, will you be reimbursing these costs? |
|  |
| **Do you plan on sharing the outcomes of the research with those involved?** If yes, what does this look like? |
|  |

**What can we do:**

|  |
| --- |
| **Please briefly describe how you would like MND Scotland to support you** (for example, help with recruiting participants, support around working with people with MND, opportunities to visit a support group). Please add your own suggestions for what would help you too. |
|  |

**For MND Scotland Use:**

|  |  |  |  |
| --- | --- | --- | --- |
| **Date Request received** |  | **Who Received request** |  |
| **Outcome of request** | | | |
|  | | | |
| **Who reviewed request** |  | **Date review completed** |  |