**Supplementary Material: Appendix A1**

**Motivations for Participation in DemReg Questionnaire**

**Patient Questionnaire :**

**Part 1 – completed by interviewer**

**Instructions for Interviewer:**

Please read out the questions exactly as they appear and document responses in the box below each question as accurately as possible.

Awareness of register

**1. Are you aware of the research register; DemReg?**

Please Circle:  Yes  No

**2. Do you remember consenting to be included on the research register DemReg?**

Please Circle:  Yes  No

**3. How did you find out about the register? (please record nil responses)**

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**4. How satisfied were you with the explanation of DemReg and what was expected of you?**

Please rate on a scale of 1 (very satisfied) to 4 (very dissatisfied) by ticking one box below:

|  |  |  |  |
| --- | --- | --- | --- |
| 1  (Very Satisfied) | 2  (Mildly Satisfied) | 3  (Mildly Dissatisfied) | 4  (Very Dissatisfied) |
|  |  |  |  |

**5. Not including this study, how many times have you been contacted about possible participation in clinical research since you registered?**

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**6. Are you aware you can opt-out from the register?**

Please Circle:  Yes  No

Motivations for consenting to be on DemReg

**8. Why did you agree to enrol on a register of dementia patients?**

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**9. How much input did your carer have in your decision to join the register? Please score on a scale of 1 (A Lot) to 4 (None).**

Please tick one box below:

|  |  |  |  |
| --- | --- | --- | --- |
| 1  (A lot of input) | 2  (Some input) | 3  (A little input) | 4  (No input) |
|  |  |  |  |

**Please write any additional comments below:**

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**Part 2 – completed by participant**

**Instructions for Interviewer:**

Please now give the next page of the Questionnaire (Part 2) to the study subject. Read out the following:

“We would like you to identify the reasons you joined DemReg. On the sheet I am about to give you there are 10 possible reasons.

Firstly in the left hand column we would like you to indicate which reasons were important to you by placing ticks in the relevant boxes. You can tick as many boxes as necessary.

If you don’t understand what any of the reasons mean then please just ask.

Then, in the column on the far right please tick one box only to indicate the most important reason to you.

If there were other reasons for joining DemReg that we have not listed, then please write them in the space provided at the bottom of the sheet.

Once you have completed the sheet please put it in this envelope (give them envelope) and seal it. It is important that I don’t know how you have answered.

Do you have any questions?”

Once satisfied the participant understands the instructions, hand them Part 2 of the MoPiD Questionnaire and an envelope. Return this envelope and Part 1 of the Questionnaire to Lisa Curry at WLCDTRU. Please read all the reasons before filling out the table.

**NEXT**, in this column, please tick **one** box to indicate the most important reason.

**FIRSTLY,** in this column, please tick all the reasons important in your decision to join DemReg.

|  |  |  |
| --- | --- | --- |
| Important  (tick all relevant boxes) | Reasons | Most important (tick one box) |
|  | The person who asked me to register said it would be a good idea. |  |
|  | I thought being on DemReg could get me involved in research that might help me. |  |
|  | I thought that DemReg would be a good way to get involved with research trials. |  |
|  | I thought that being on DemReg could get me involved in research I would be paid for. |  |
|  | I thought that the person who asked me would think poorly of me if I didn’t join. |  |
|  | I thought that being on DemReg would enable me to be involved in research that could help others with the same condition. |  |
|  | I thought that being on DemReg would get me access to trials of treatments that are currently unavailable on the NHS. |  |
|  | I thought that being on DemReg would give me information on what research was going on locally. |  |
|  | I thought that being on DemReg could get me involved in research that may help my condition be monitored better. |  |
|  | I did not foresee any downside to being on DemReg |  |
| Please note any other reasons that were important to you: | | |