

# ABOUT PUBLIC INVOLVEMENT IN THE STUDY

## 1. How many lay people/service users are or have been involved in the study?

- |   |                          |                            |           |                          |
|---|--------------------------|----------------------------|-----------|--------------------------|
| 0 | <input type="checkbox"/> | (please go to question 10) | 3         | <input type="checkbox"/> |
| 1 | <input type="checkbox"/> |                            | 4         | <input type="checkbox"/> |
| 2 | <input type="checkbox"/> |                            | 5 or more | <input type="checkbox"/> |

## 2. How did they get involved in the study?

(Please tick **all** that apply)

- |  |                          |   |                          |
|--|--------------------------|---|--------------------------|
| They responded to an open invitation (e.g. Newspaper, website) | <input type="checkbox"/> | You approached patients/service users known to the clinicians involved in the study                     | <input type="checkbox"/> |
| You approached a voluntary organisation                        | <input type="checkbox"/> | You approached an established Patient/service user/public involvement Group in your research centre/HEI | <input type="checkbox"/> |
| You approached the RDS   | <input type="checkbox"/> | Other (please specify)  |                          |
| You approached the CLRN  | <input type="checkbox"/> |   |                          |
| You approached a topic specific CRN                            | <input type="checkbox"/> |   |                          |

## 3. From which groups are the lay people/service users involved in the study from?

(Please tick **all** that apply)

- |                                    |                          |                               |                          |
|------------------------------------|--------------------------|-------------------------------|--------------------------|
| Children & younger people under 18 | <input type="checkbox"/> | Service users/patients        | <input type="checkbox"/> |
| Adults under 65                    | <input type="checkbox"/> | Members of the general public | <input type="checkbox"/> |
|                                    |                          | Older people over 65          | <input type="checkbox"/> |

## 4. In what capacity were these people involved?

(Please tick **all** that apply)

- |   |                          |                        |  |
|---|--------------------------|------------------------|--|
| As people with prior experience of a condition/disease/service    | <input type="checkbox"/> | Other (please specify) |  |
| As a member of the general public with a non clinical perspective | <input type="checkbox"/> |                        |  |

**5. At what stage have or will the lay people/service users been involved in the project?**

(Please tick **all** that apply)

Identification of the research topic

Design of the research methodology

Development of participant information materials

Co-researchers in data collection

Co-researchers in data analysis

Report writing

Advisory/steering groups

Review of reports, lay summaries etc

Dissemination activities (please specify)  
*Free text*

Other (please specify)  
*Free text*

**6. Have the lay people/service users received any training for their involvement in the study?**

No

Yes

Please specify

*Free text*

**7. Has service user/public involvement in the study been directly costed for in the grant application?**

No

Yes

If so how much?

**8. Are service users/lay people involved in the study reimbursed for the following?**

(Please tick **all** that apply)

Time

Travel and out of pocket expenses

No reimbursement  (please go to question 10)

**9. How is/was the reimbursement managed?**

(Please tick **all** that apply)

Service user/lay person submits regular travel & out of pocket expense claim form

Lump sum for specified activity

Honorarium

Other (please specify)  
*Free text*

**10. Do you know of any local or regional PPI groups that support research?**

Yes

No  (please go to question 13)

**11. How often do you use this group as your first resource for PPI?**

Never  (please go to question

Frequently

13)

Occasionally

Sometimes

Almost always

**12. Has working with these groups altered your practice when writing proposals?**

No

Yes

If so how?

*Free text*

**ABOUT THE STUDY**

**13. What is the study design?**

Clinical trial of an investigational medicinal Product

Study involving qualitative methods only

Clinical investigation or other study of a medical device

Study limited to working with data and/or human tissue samples or other biological samples

Combined trial of an investigational medicinal product & an investigational medical device

Research tissue bank

Other clinical trial or clinical investigation

Research database

Other (please specify)

Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

*Free text*

**14. What group are you recruiting as research participants? (i.e. research SUBJECTS)**

(Please tick **all** that apply)

Children & younger people under 18

Service users/patients

Adults under 65

Members of the general public

Older people over 65

Not applicable

**15. Who is funding the research?**

NIHR Research for Patient Benefit

NIHR Service Delivery & Organisation

NIHR Programme Grant

NIHR Health Services Research

NIHR Health Technology Assessment	<input type="checkbox"/>	NIHR Public Health Research	<input type="checkbox"/>
NIHR <b>Invention for Innovation (i4i)</b>	<input type="checkbox"/>	Charity (please specify)	<input type="checkbox"/>
		Other (please specify)	<input type="checkbox"/>
		<i>Free text</i>	

**16. What was the amount of grant awarded?**

Under 50K	<input type="checkbox"/>	401-500k	<input type="checkbox"/>
50-100k	<input type="checkbox"/>	501-600k	<input type="checkbox"/>
101-150k	<input type="checkbox"/>	601-700k	<input type="checkbox"/>
151-200k	<input type="checkbox"/>	701-800k	<input type="checkbox"/>
201-300k	<input type="checkbox"/>	801-900k	<input type="checkbox"/>
301-400k	<input type="checkbox"/>	901-1000k	<input type="checkbox"/>
		Over 1000k	<input type="checkbox"/>

**YOUR OPINION**

**17. In your opinion at what stage of the research does service user/public involvement have the most impact?**

*Free text*

**18. In your opinion, what are some of the challenges of service user/public involvement in research?**

*Free text*

**Thank you very much for taking the time to complete this survey. We will feedback the results as soon as possible.**