**Embedding Research Consultation Delivery Plan**

**Delivery plan Version 2**

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| Objective | Actions | Lead | Timescales | Risks | Measure of success |
| 1. Establish baseline measures and produce high-level delivery plan. | Engage LRN team and key PPI stakeholders in developing the delivery planTo conduct a data analysis and consultation to establish geographical scope of project (see note 1)Review any other PPI projects by the NHS /NIHR with a view to working in partnership and optimizing resources including making links to appropriate PPI websites (see note 3)Identify stakeholders/ focus group in selected regions (see note 2)To agree baseline measures (see note 1)Review best practice at Merseyside and Newcastle | Alison / Mary  | By early May 12 | Size of region with different demographics and number of topic disease areas means project needs to be selective in what it is trying to achieve.Availability and access to consent data | Delivery plan signed off by LRN leadBaseline measures agreed, obtainable and sourced. |

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| 2. Agree all ‘activities’ to support engagement e.g. Survey, workshops, focus groups, talks, 1-2-1 meetings | Establish a calendar of current PPI activities and events during May – Sep. Ask DeNDRoN staff and charities. Agree a process that is compliant with info governance to send patient info from consultation project to established local consent lists Take the opportunity to link with DeNDRoN’s RAFT project (Recruitment And Feasibility Tools)Develop DeNDRoN material for agreed activitiesTest material in selected regions (see note 4)a. Posters, publicationsb. Focus groups c. Targeted surveysd. Passive website info and feedbackIf possible use local media too, e.g. radio, newspaperConduct an evaluation on effectiveness of the agreed activities applied in different regions to patients with different diseases | Alison, Debbie, ChristineEngage with Teresa Gudge, IT security specialist | By mid May 12 | Difficulty in evaluating success of activities when applied to different topic areas in different regions |  |

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| 3. Agree questions for consultation | Literature review of existing PPI questionsTest questions with service users (see note 4) | AlisonEngage with:Local comms leadsDeNDRoN commsMedical charities | End of May 2012 |  | Signed off by local comms teams and DeNDRoN commsTested with service users |
| 4. Undertake engagement | Test engagement and refine Ask service users preferred level of involvement:- Newsletter- Advisory panel- Consent listEnsure robust information governance around patient information storage | Alison | June 12 – August 12 | Holiday season may impact on numbers of people engaged. Will continue to engage through September if required.Consent, confidentiality and info governance processes to be adhered to. | Gain input from over 200 people, distributed across the region and the disease areasIncreased patient engagement in - Newsletters- Advisory panel- Consent list |
| 5. Complete final project report, measurement of success, case studies and report on feedback from sessions | Develop TORs and governance for Patient Advisory Panel | Alison / Mary | September 12 – October 12 |  | Report completed on time |

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| 6. Establish PPI / 3rd sector advisory board for long-term support / agree on individuals support for work (what can they do to help) |  |  | Aug 2012 – Sep 2012 | Region’s geography means face to face meetings are difficult, no practical video-conferencing facility | Sustainable and effective PPI advisory group established |
| 7. Identify future actions/ possible projects resulting from consultation | Engage with MHRN and PCRN | Alison | Sep 2012 |  | Submission of recommendation for future actions / projects to SW LRN and DeNDRoN CC |

**Note 1** – choosing sites and sourcing baseline data

The geographical scope of the project was predominantly based upon access to existing patient forums within our timeframe, local PPI networks and structures, and the opportunity to work in partnership with other research organisations undertaking current PPI research activity.

In addition data from the Atlas of Variation and SW Observatory was used and a literature review of recent PPI reports generated in the south west was undertaken.

Very importantly, discussions were held with stakeholders from DeNDRoN researchers, charity organisations, and leads from regional PPI forums from each disease area, for views on the suitable geographical scope of the project

**Note 2**

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| Reference group for Exeter region | Reference group for Bristol region |
|  - Christine Cosby (senior CSO))* Alan Payne – LRN PPI lead (Devon)
* Emma Lomax - SW PPI forum, RD&E
* Chris Gardener, R&D manager, RD&E
* ? RD&E PPI lead
* Rob James, research practitioner, RD&E
* Nathan Vernon, DeNDRoN research nurse (Barnstaple)
* Exeter community memory clinic
* Trevor Twinley, Alzheimer’s Society (Exeter)
* Chris Maden, MND Assoc (Exeter)
* ? HD assoc (Exeter)
* Bill Nevin, MND Association SWANO
* Cynthia Hopkins MND Association (Exeter)
* Social services
* Local council (care homes, carers support)
* Dr Harrower : HD research dir (Exeter)
* Megan Liddiard: PCRN (Torbay)
* Emma Hughes: Research Interest Group for Parkinson’s
 | * **Debbie Howcroft** (senior CSO)
* **Dr Jean Waters,** LRN PPI lead (S Gloucester)
* **Kate Schneider**, SW Dementia Partnership and Involve project
* Beverley Hayward, Neurosciences Clinical Research Nurse
* Sharon Nolan, North Bristol PPI Research Panel
* Melanie Thorne, Dementia advisor based in GP practices
* **Rosemary Davies**, Uni of West England
* Kate Brooks, PCRN (Bristol)
* **Paula Shears**, Alzheimer’s Society (Bristol)
* **Geoff King**, Neil Smart, Parkinson’s UK, SWANO
* **Hilary Fairfield**, MND Association SWANO (Bristol)
* Bristol community memory clinic
* Social services
* Local council (care homes, carers support)
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NB. Highlighted names indicate those that have been contacted to date (24 April)

Best practice:

* Margaret Piggott – Newcastle
* Claire Jones at Merseyside

**Note 3**

For example the Parkinson’s Disease Academy Project is conducting focused interview with Parkinson’s patients in order to look at how research opportunities for Parkinson's patients might best be built into an integrated care pathway, In particular, looking at when would be the best time to approach patients and whether a standard referral process from consultants could be set up post diagnosis.

**Note 4**

* Jean Waters is chairing the MNDA Spring conference on May 26th at Taunton - contact is Chris Maden chris.maden@mndassociation.org. This could be an opportunity to test consultation material
* Also Debbie is speaking at a PPI event on 16 June in Bath, another opportunity to test.
* International Clinical Trials day on 20 May, may be an opportunity to consult with patients
* SW Parkinson Forum at Tiverton on 9 May