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## **An Analysis of Priority Areas for PPI in DeNDRoN**

DeNDRoN has a Patient and Public Involvement (PPI) Working Group – this includes patient representatives and people from some of the medical charities, alongside DeNDRoN staff. This Working Group has recommended where DeNDRoN should focus most of its PPI efforts to have a real impact in DeNDRoN.

This Working Group looked at the potential added value which PPI could bring to each of DeNDRoN's processes, and the PPI methods thought to be most suitable for each process. This version was agreed by DeNDRoN Patient and Public Involvement Working Group in Feb 2008.

THE FOLLOWING WERE RECOMMENDED AS THE HIGH  
PRIORITY PROCESSES FOR PPI:

**Strategic Management** (locally and nationally)  
**Study Adoption – Feasibility assessment**  
**Study Development – Strategy and gaps**  
**Study Development – Working up specific proposals**  
**Patient recruitment to studies**  
**Communications**

Over time, priorities will become clearer and these may well change.

Your comments and views would be gratefully received by  
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## Here's a KEY to all the involvement methods or 'models' which are referred to in each section:

The main recommended PPI mechanisms are:

- formal representatives on committees, and
- working with medical charities and patient representative bodies.

Other significant methods recommended are focus groups and in-depth interviews.

- (1) = **Representatives on committees**
- (2) = **Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)**
- (3) = **Working with medical charities and other patient representative bodies**
- (4) = **Surveys and consultations**
- (5) = **Focus groups and in-depth interviews**
- (6) = **Patient/Carer Advisory Panel (a permanent reference group set up to monitor and advise on a specific activity – either local or national)**
- (7) = **Joint PPI projects with other research networks**
- (8) = **Public meetings**

### SOME INITIALS USED

<b>PPI</b>	=	Patient and Public Involvement
<b>LRN</b>	=	Local Research Network
<b>CSG</b>	=	Clinical Studies Group
<b>SIG</b>	=	Special Interest Group
<b>OSG</b>	=	Operational Steering Group (generally more strategic discussion than in the smaller DeNDRoN Executive)
<b>IAP</b>	=	Industry Adoption Panel

## An Analysis of Priority Areas for PPI in DeNDRoN

<h3 style="margin: 0;">STRATEGIC MANAGEMENT</h3> <p style="margin: 0; font-size: 0.9em;">Setting strategy and monitoring performance</p>		
Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ Nationally via <b>'Operational Steering Group'</b> (fortnightly)</li> <li>▪ Local STRATEGIC management is via each LRN's <b>'Steering Group'</b> (<i>every three to six months - name varies from LRN to LRN</i>)</li> </ul> <p>(Other arrangements exist for supplementary resource areas)</p>	<p>Individual lay members can contribute to grasping the overall picture</p>	<p>MAINLY: (1) <b>Representatives on committees</b></p> <p>ALSO: (3) <b>Working with medical charities/patient representative bodies</b> (8) <b>Public meetings</b> (4) <b>Surveys and consultations</b></p>
Potential impact of PPI is ... <b><u>HIGH</u></b>		

**Comments:**

*In addition to representatives on committees, the other models of PPI can be used as particular topics arise.*

(For Performance Management, see also 'Study set-up and delivery')

# OPERATIONAL MANAGEMENT

Proactive and reactive planning of DeNDRoN activity, and day-to-day performance management

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ LRN, Supplementary Resource, and Coordinating Centre staff</li> <li>▪ Nationally via <b>DeNDRoN Executive</b> (ad hoc/frequently by telephone)</li> <li>▪ Local operational management is via each LRN's '<b>Core Executive</b>' or '<b>Management Group</b>' (<i>roughly monthly - name varies from LRN to LRN</i>)</li> </ul>	Limited added value	<p><b>MAINLY:</b>            (1) <b>Representatives on committees</b></p> <p><b>ALSO:</b>            (6) <b>Patient/Carer Advisory Panel (a permanent reference group set up to monitor and advise on a specific activity – either local or national)</b>            (3) <b>Working with medical charities/patient representative bodies</b></p>
Potential impact of PPI likely to be ... <b><u>low or variable</u></b>		

Comments:

*May be useful to have patient/carer perspectives in operational decisions, but not a priority at national level. May be a priority in some LRNs. This depends on local arrangements, although representation on strategic LRN steering groups likely to be more valuable.*

## Assessment Of Research Proposals And Study Adoption: **FEASIBILITY**

Determining the overall feasibility of DeNDRoN supporting a study

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>Clinical Studies Groups</b></li> </ul>	Pt validation of proposed pt benefits. Pt consideration of likelihood of reaching accrual targets and how study objectives may be presented in such a way as to reach accrual targets.	(1) <b>Representatives on committees</b>
Potential impact of PPI is ... <b><u>HIGH</u></b>		

## Assessment Of Research Proposals And Study Adoption: **CAPABILITY**

Determining whether an LRN is practically capable of running a study

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>LRNs and supplementary resources</b></li> </ul>	Limited added value	None
Potential impact of PPI likely to be ... <b><u>low / variable</u></b>		

Comments:

*Generally a clear-cut functional decision.*

## Study Development: **STRATEGY AND GAPS**

Identifying and prioritising themes for research, including under-investigated themes

Calling for research proposals and identifying clinical studies

- Detailed processes will vary from group to group, such as facilitating wider awareness of specific research needs, or establishing properly defined funding areas. Especially relevant for PPI is the **Methodology Special Interest Group**, looking towards developing improved research outcome measures across neurodegenerative disorders and conditions, with patient-focused outcome scales, particularly around quality of life. Additionally, the Brain-Banking And Neuropathology CSG will work towards improved neuropathological endpoint measures, and towards enabling a practical infrastructure for brain-banking.

Main groups or staff responsible	Potential added value	Main models
<b>DeNDRoN's national Clinical Studies Groups &amp; Special Interest Group(s)</b>	<ul style="list-style-type: none"> <li>▪ A variety of individual and organisational perspectives to enhance the authority of proposals</li> <li>▪ Access to detail of prioritisation work already undertaken by medical charities</li> <li>▪ Increasing the legitimacy of research protocol designs</li> <li>▪ Input of 'service user' knowledge and perspectives of diagnosis, treatment, and research processes could lead to research designs with a higher recruitment potential</li> </ul>	<p>(1) <b>Representatives on CSG and SIG committees</b></p> <p>ALSO:</p> <p>(5) <b>Focus groups and in-depth interviews</b></p> <p>(6) <b>Patient/Carer Advisory Panel (a permanent reference group set up to monitor and advise on a specific activity – either local or national)</b></p> <p>(4) <b>Surveys and consultations</b></p> <p>(7) <b>Joint PPI projects with other research networks</b></p>
Potential impact of PPI is ... <b><u>HIGH</u></b>		

Comments: As some groups only formally meets maybe twice a year, representation on committees needs to be combined with the option to consult broadly about certain specific topics or questions using other PPI methods.

## Assessment Of Research Proposals And Study Adoption:

# COMMERCIAL STUDY PROPOSALS

Reviewing confidential industry-proposed studies for adoption onto portfolio (protocols, forms, findings from CSG/LRNs)

Very rapid process, involving very detailed, high-level scientific papers

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>Industry Adoption Panel</b> (teleconference monthly)</li> </ul>	<p>Potentially very valuable in some very occasionally contentious ethical decisions, where lay member perspectives could make outcomes more authoritative. However, the general process seems to require too high a degree of scientific knowledge (or mentoring) for PPI to add value. Only limited scope for referring issues to other people due to confidentiality, and speed.</p>	<p>(1) <b>Representatives on committees</b> (6) <b>Patient/Carer Advisory Panel (a permanent reference group set up to monitor and advise on a specific activity – either local or national)</b> In view of the time pressures and challenges involved, the PPI Working Group recommended a pilot to look at principles and practicalities</p>
Potential impact of PPI is ... <b><u>HIGH</u></b>		

**Comments:**

*Typically not contentious proposals which are nearly always quickly adopted. Lay members on the IAP would not be called upon every month – would generally rotate. For rare contentious issues, could have a rapid mechanism in place for discussing with the relevant CSG lay members who are aware of those proposed studies, or alternatively perhaps set up a specific panel.*

**Assessment Of Research Proposals And Study  
Adoption:  
NON-COMMERCIAL STUDY PROPOSALS**

Current non-commercial adoption for the relatively small number of non-commercial proposals which are not NIHR-funded

<b>Main groups or staff responsible</b>	<b>Potential added value</b>	<b>Main models</b>
<ul style="list-style-type: none"> <li>▪ <b>CSGs</b></li> <li>▪ <b>LRN Management Groups</b></li> </ul>	<p>Not a lot of value as most non-commercial studies have NIHR-partner approval and thus are automatically adopted</p>	<p><b>(6) Patient/Carer Advisory Panel (a permanent reference group set up to monitor and advise on a specific activity – either local or national)</b>            Could be useful for occasional non-industry, non-NIHR partner studies.</p>
Potential impact of PPI likely to be ... <b><u>low / variable</u></b>		

Comments:

*PPI here would be mainly useful in considering feasibility in the cases of non-NIHR-partner studies, when these are not already satisfactorily peer-reviewed.*

**Study Development:**  
**WORKING UP SPECIFIC PROPOSALS**  
 Development of research proposals into workable questions

<b>Main groups or staff responsible</b>	<b>Potential added value</b>	<b>Main models</b>
<p>Not only within <b>CSGs</b> and <b>SIGs</b>.            Working up will be done more broadly, including by:</p> <ul style="list-style-type: none"> <li>▪ <b>other groups of collaborators,</b></li> <li>▪ <b>work within LRNs</b></li> <li>▪ <b>single investigators</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ Medical charities being in support and seen as participating would strengthen all messages and processes</li> <li>▪ Increased relevance of question, as in <u>specific</u> outcome measure</li> <li>▪ Helps ensure protocol is workable</li> <li>▪ Pt info more accessible</li> <li>▪ Potential for better accrual</li> </ul>	<p>(1) <b>Representatives on committees as above</b>            (3) <b>Working with medical charities/patient representative bodies</b>            The PPI Working Group also recommended considering JOINT work with other charities or Topic-specific CRNs – the example of joint work around Stroke was given</p>
Potential impact of PPI is ... <b><u>HIGH</u></b>		

**Comments:**

*Close consultation needed with medical charities is important, so may invite relevant officers from the medical charities – particularly including the PDS brain-bank work.*

## STUDY SET-UP PROCESSES

Practical setting up and delivery of study following the set protocol

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ LRN Management Groups</li> <li>▪ LRN staff</li> </ul>	<p>Maybe a study-specific, local patient/carer panel could contribute valuable ideas to ensure set up and general delivery is successful. However, much of the methodology will already be fixed in the protocol</p>	<p>(1) <b>Representatives on committees</b>            (6) <b>Patient/Carer Advisory Panel (a permanent reference group set up to monitor and advise on a specific activity – either local or national)</b></p>
<p>Potential impact of PPI is MEDIUM but in future should be seen as ...</p> <p style="text-align: right;"><b><u>MEDIUM TO HIGH</u></b></p>		

## PATIENT RECRUITMENT

Recruiting patients to studies

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ LRN Management Groups</li> <li>▪ LRN staff</li> </ul>	<p>Active patient and carer involvement around study recruitment, and work with medical charities nationally and locally may improve public perception of the study.            PPI in design of study publicity may aid recruitment.</p>	<p>MAINLY:            (3) <b>Working with medical charities/patient representative bodies</b></p> <p>ALSO:            (5) <b>Focus groups and in-depth interviews</b>            (8) <b>Public meetings</b></p>
<p>Potential impact of PPI is ... <b><u>HIGH</u></b></p>		

Comments:

*Although most activity will clearly be in LRNs and Supplementary Resources, there is a role for some national level PPI*

(See also 'Communications')

## INTERPRETATION OF RESULTS AND DISSEMINATION

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>CSGs</b></li> <li>▪ <b>LRNs</b></li> </ul>	<p>Patient and carer interpretations could add to validation of the results and the relevance (or otherwise) of results to patients and carers.</p> <p>Additional perspectives into the implications for further research.</p> <p>However, not really a core DeNDRoN issue.</p>	<p><b>MAINLY:</b>            (3) <b>Working with medical charities/patient representative bodies</b></p> <p><b>ALSO:</b>            (2) <b>Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)</b></p>

Potential impact of PPI is ... **LOW**

## FUNDER ENGAGEMENT

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>National DeNDRoN OSG and Coordinating Centre staff</b></li> <li>▪ <b>CSGs</b> (role in defining funding mechanisms)</li> </ul>	<p>Although DeNDRoN is not a funding body, authoritative PPI within DeNDRoN might potentially have a role in influencing funding decisions</p>	<p>(3) <b>Working with medical charities/patient representative bodies</b></p> <p>(7) <b>Joint PPI projects with other research networks</b></p>

Potential impact of PPI is ... **MEDIUM**

Comments:

*Beyond the important links with medical charities, the extent to which this is a priority for PPI is unclear; it may become a priority in the longer term, perhaps linking into the NIHR Central Commissioning Facility which aims for public involvement on all its commissioning panels.*

## TRAINING AND SUPPORT - INCLUDING PATIENTS AND PUBLIC

PPI within designing and delivering training to increase the knowledge and skills of DeNDRoN staff

DeNDRoN/UKCRN training days are also open and free to patients and the public who contribute to DeNDRoN PPI activity

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>All DeNDRoN groups in conjunction with UKCRN</b></li> <li>▪ <b>DeNDRoN PPI lead staff</b></li> </ul>	<p>Benefits of public access to DeNDRoN/UKCRN training are considerable. This will:</p> <ul style="list-style-type: none"> <li>▪ encourage more skilled and productive involvement by patients and carers within DeNDRoN</li> <li>▪ encourage wider variety of patients and carers to be involved</li> <li>▪ train staff around PPI</li> </ul>	<p>(2) <b>Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)</b></p> <p>(3) <b>Working with medical charities/patient representative bodies</b></p> <p>(7) <b>Joint PPI projects with other research networks</b></p>
Potential impact of PPI is ... <b><u>MEDIUM</u></b>		

Comments:

*Likely to become high priority in longer term.*

## COMMUNICATIONS ...WEBSITE

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>Lead PPI staff</b></li> </ul>	Increased relevance and clarity	(2) <b>Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)</b>

## ...ANNUAL REPORT

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>Coordinating Centre and LRN staff</b></li> </ul>	Increased relevance and clarity	(2) <b>Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)</b>

## ...LEAFLETS AND OTHER PRINTED MATERIAL

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>Coordinating Centre staff</b></li> <li>▪ <b>LRN staff</b></li> </ul>	<p>For studies, PPI will be valuable if the content of patient information is not fixed within the protocols.</p> <p>Increased relevance and clarity of general DeNDRoN information and publicity</p> <p>For studies, clearer information for patients may aid recruitment</p>	<p>MAINLY:</p> <p>(2) <b>Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)</b></p> <p>(3) <b>Working with medical charities/patient representative bodies</b></p> <p>ALSO occasionally:</p> <p>(5) <b>Focus groups and in-depth interviews</b></p>

...PLANNING OF OPEN EVENTS AND CONFERENCES		
Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>Project working teams</li> </ul>	Additional ideas and perspectives. Priority will depend on the event.	(1) <b>Representatives on committees</b> (2) <b>Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)</b>
Potential impact of PPI in certain aspects of communications will be ... <b><u>HIGH</u></b>		

Comments:

*Note: A general feedback option is needed for revamped DeNDRoN website*

(See also: 'Interpretation of results and dissemination' and 'Patient recruitment')

<b>STAFF RECRUITMENT</b> Developing job descriptions, selecting and interviewing applicants		
Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>Mainly LRN Managers</li> </ul>	Additional perspectives	(1) <b>Representatives on committees</b> i.e. sitting on interview panels
Potential impact of PPI likely to be ... <b><u>low / variable</u></b>		

## AD HOC TASKS AND PROJECT MANAGEMENT

Main groups or staff responsible	Potential added value	Main models
<ul style="list-style-type: none"> <li>▪ <b>Project teams</b></li> </ul>	<p>Additional ideas and perspectives</p>	<p>Occasional: (2) <b>Informal calls for views of individuals via wider forums and databases (e.g. circulating documents for review)</b></p> <p>ALSO: (4) <b>Surveys and consultations</b></p>
Potential impact of PPI likely to be ... <b><u>low / variable</u></b>		
<p><u>Comments:</u> <i>Priority will depend on the project.</i></p>		

### Finally: A note on evaluation

Evaluation was recognised by the Road Map Group as important within all of DeNDRoN's processes. In terms of formal patient/carer representatives on committees, identifying an individual's particular impact could be a challenge, because the various committees mentioned are collaborative in nature. Evaluation forms can be distributed to lay members surveying their experience in their roles, perceived benefits of lay membership, training and support issues, and what more can be done to strengthen the PPI thread throughout DeNDRoN. Chairs will also be asked for evaluations, not in terms of individuals, but about the effectiveness of PPI processes overall.

For patient/carer advisory panels and one-off focus groups, the breadth of membership and whether the groups function as planned can be evaluated. The extent to which their perspectives impact on process outcomes could be assessed by the group members themselves (in the case of ongoing reference panels), and the DeNDRoN groups or staff they relate to.

**This version was amended from an original draft by Terry McGrath and agreed by DeNDRoN Patient and Public Involvement Working Group (Feb 2008)**