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**DeNDRoN Coordinating Centre  
Wolfson Centre, Mecklenburgh Square  
LONDON WC1N 2AP  
Tel: +44 (0)20 7905 2960  
E-mail: [terry.mcgrath@dendron.org.uk](mailto:terry.mcgrath@dendron.org.uk)**

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To All **Lay** Members of the following DeNDRoN groups:

- All the Clinical Studies Groups, (Primary Care, Dementias, Huntington's Disease, Parkinson's Disease, Motor Neurone Disease, Neuropathology & Brain Banking)
- The Methodology Special Interest Group
- DeNDRoN PPI Working Group

Dear colleague,

This is to notify you that DeNDRoN is introducing 'Payment For Time' for formal lay member attendance at certain meetings (as listed above). This is because we are required to work in line with Department of Health guidance.

Most activity involving patients/carers will stay entirely unpaid as at present (only reimbursing costs incurred). People's views will differ on this, but the payments are optional, and only for these "formal" committees, not other PPI contributions, meetings and events. Also it is worth underlining that every current lay member on these committees undertook these roles voluntarily before there was any question whatsoever of offering 'Payment For Time'.

Yours respectfully,

Terry McGrath  
Patient and Public Involvement Co-ordinator  
DeNDRoN  
Ground Floor, The Wolfson Centre, Mecklenburgh Square, London WC1N 2AP  
Telephone: (020) 7905 2995      [www.dendron.org.uk](http://www.dendron.org.uk)

## GUIDANCE ON 'PAYMENT FOR TIME' FOR LAY MEMBERS

### ***What is changing?***

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The NIHR has long supported the principle of offering payment for time for lay members on Clinical Research Network committees. Now, the DH National Institute for Health Research (NIHR) has made available additional funds to the DeNDRoN Coordinating Centre (CC), as well as to the other Topic-specific Clinical Research Networks to support payment for time. Until now, DeNDRoN has **NOT** offered payment for time, but DeNDRoN is now expected to start to adopt this practice. The extra funding is for DeNDRoN formal national level activity, not DeNDRoN's Local Research Networks.

### ***What are the tax and revenue circumstances?***

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It is the responsibility of the individual to investigate any legal or tax and revenue implications. It is the responsibility of the individual, not DeNDRoN, to tell Inland Revenue and/or their local Job Centre Plus office of any payments they are formally offered, whether accepted or not. This income may be taxed and may affect levels of benefit payments received. Nothing in the payment for time constitutes any legal financial engagement nor an employment relationship of any kind nor a contractual agreement of any kind.

There are a number of important factors to consider when offering payment to patients and carers, in addition to setting rates, and familiarisation with the INVOLVE publication 'A Guide to reimbursing and paying members of the public who are actively involved in research' is recommended.

See [http://www.invo.org.uk/pdfs/Payment\\_Guidefinal240806.pdf](http://www.invo.org.uk/pdfs/Payment_Guidefinal240806.pdf)

In all cases, it is the responsibility of the individual to tell Inland Revenue and/or their local Job Centre Plus office of any payments they are formally offered.

### ***How might it affect Local Research Networks (LRNs)?***

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The funding is for DeNDRoN CC level activity, not LRNs. There is at present no additional payment for rolling this out to LRN level.

### ***Can lay members decline to accept payments?***

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Yes. It is important to note that if a lay member is in receipt of benefits, formal offers of payment can be classed as notional income, even if declined.

### ***Can DeNDRoN give the money to charity?***

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DeNDRoN **can't** donate the money to charity instead. Also, whether or not any individual donates their payments to charity, it will still be considered as their income for benefit purposes.

### ***Might some lay people involved in medical charities shift more towards DeNDRoN and away from charities which don't pay for time?***

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No. Many will informally or formally decline any offer of payment anyway. Many DeNDRoN committees (e.g., Clinical Studies Groups and Local Research Network steering committees) are only formally expected to meet twice a year, and many other categories of involvement will not be paid for at all.

Anyway, for those who accept payment, a lot could be taken away in tax and reduced benefits. The amount of paid time per person per year will not be large enough to result in any significant changes to their level of activity in medical charities.

### ***How much are the payments?***

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The 'Payments For Time' are for attending formal national meetings & involvement only, as follows.

#### **FACE-TO-FACE MEETINGS**

£150 per meeting for attending any of the following face-to-face meetings:

- Dementias Clinical Studies Group
- Primary Care Clinical Studies Group
- Huntington's Disease Clinical Studies Group
- Parkinson's Disease Clinical Studies Group
- Motor Neurone Disease Clinical Studies Group
- Neuropathology & Brain Banking Clinical Studies Group
- Methodology Special Interest Group
- DeNDRoN PPI Working Group
- Future formal national groups, such as the Operational Steering Group, and Industry Adoption Panels

Ad hoc committees or consultation activity will be decided case-by-case, based on whether the involvement is classified as a formal national responsibility. Also, if unusually high levels of considerable preparatory work and effort are required, the overall rate would be £200 rather than £150.

#### **TELECONFERENCES**

On the rare occasions where formal full-length face-to-face meetings as above are replaced by full-length teleconferences, (e.g. a few hours), the 'Payment For Time' will be £150 per meeting.

Where a teleconference is a shorter additional meeting, such as the monthly MND CSG teleconferences, the 'Payment For Time' will be £50.

Ad hoc teleconferences will be decided on a case-by-case basis, based on whether they are classified as a formal national responsibility, where the 'Payment For Time' would typically be £50.

#### **OTHER MEETINGS AND EVENTS**

Most activity involving patients/carers will stay entirely voluntary - without 'Payment For Time' - as at present. For example, attending and participating in an open DeNDRoN national meeting or chairing a session at a DeNDRoN conference, will not normally be reimbursed. Neither will any informal meetings, focus groups, visits to research sites, consultations, training days or public events attended. The excellent work done will continue as before.

Ad hoc one-off activities will be decided on a case-by-case basis, based on whether they are classified as a formalised responsibility. Significant formal contributions, such as co-chairing a whole day would however mean an offer of 'Payment For Time' of £150.

#### ***So, how might it affect income benefits?***

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There is no authoritative national guidance, but there is a growing governmental recognition that the benefits system should acknowledge the positive value of involvement activities, and not prevent people on benefits from contributing to PPI.

It is the responsibility of the individual to tell Inland Revenue and/or their local Job Centre Plus office of any payments they are formally offered. This income may be taxed and may affect levels of benefit payments received. For example, those who are in receipt of benefits could have the equivalent amount deducted from their income, except for a "discounted" £20 or so. There is considerable scope for differences in what individual JobCentre Plus offices decide to deduct from benefits.

#### ***Other practicalities***

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Payment for time will be paid in arrears and may unfortunately take a couple of months to process. The payment – at the same rates – is also to be offered to the person officially agreed as accompanying the lay member as their carer.

#### ***Will claiming expenses e.g., travel and accommodation, be affected?***

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If an individual lay member decides to accept offers of payment for time, then any train fares, hotel costs, meals or other expenses reimbursed directly to those lay members could officially become classed as income, not reimbursement. It may then lawfully be subject to tax or reduction in benefits.

It is therefore important that DeNDRoN should consider booking hotels and travel directly, rather than the lay member doing this. Also any expenses reimbursed to individuals must continue to be for exact amounts, not rounded up or estimated.

However, an important note is that, for the foreseeable future, the 'Payment For Time', if you decide to claim for it, will be processed by University College London (UCL), whilst all other expenses will continue to be processed entirely separately, by Newcastle University.

### ***Questions and comments***

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If you have any questions, please contact Terry McGrath, PPI Co-ordinator, DeNDRoN Co-ordinating Centre. Email: [terry.mcgrath@dendron.org.uk](mailto:terry.mcgrath@dendron.org.uk) or telephone (020) 7905 2995.

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This version was written on June 10, 2009 by Terry McGrath, PPI Coordinator,  
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