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Guidance notes for reimbursing lay members on DeNDRoN LRN committees and in other LRN patient and public involvement (PPI) activities

Background

DeNDRoN is committed to supporting the involvement of lay representatives on its committees and in other PPI activities. At the national level, DeNDRoN follows an approved Expenses Policy, which was specifically written for national-level activities, such as Clinical Studies Groups, Special Interest Groups and Coordinating Centre business. This is in the Appendix of this document.

Aim of this document

The aim of this guidance is to outline the relationship between the national-level DeNDRoN Expenses Policy to Local Research Network/Supplementary Resources practices and procedures. Local Research Networks may choose to follow the DeNDRoN National Expenses Policy, using it as the basis for local policy. It should be considered alongside the relevant expenses policy and procedures of the host organisation for each Local Research Network or Supplementary Resource.

This guidance applies to reimbursement of expenses for:

- Lay member PPI representatives on DeNDRoN LRN committees, such as steering management groups
- Members of the public participating in other LRN patient and public involvement activities, such as one-off groups or activities which support the functioning of a DeNDRoN LRN or nationally

Whilst these guidance notes suggest good practice, any outstanding questions concerning local practices would need to be referred to the host organisation in the first instance.

Note concerning payment for time

DeNDRoN does reimburse for expenses, but we do not give payment for time. The DeNDRoN PPI Working Group has given very clear support for not giving payment for time. Therefore it is expected that LRNs will act in accordance with this.

Principles

Patient representation in a range of PPI activities, and formal participation as a lay member on committees, are on a voluntary basis, which is why DeNDRoN does not provide payment for time. However, lay members must not end up financially worse off for providing their services to DeNDRoN, and all reasonable out of pocket expenses will be reimbursed.

DeNDRoN is committed to:

- Principle 1.** Supporting the involvement of lay representatives on its committees and in other PPI activities.
- Principle 2.** Recognising patients and the public as equal partners in DeNDRoN processes.
- Principle 3.** Enabling all those involved in DeNDRoN's groups and processes to pursue the legitimate business of the Network in a manner which is fair, appropriate and acceptable from a personal and corporate point of view.
- Principle 4.** Acknowledging the wide range of health and social challenges which patients, carers, and others affected by dementias and neurodegenerative diseases face, and taking these into account in planning PPI.
- Principle 5.** Making best use of the budget available for this type of expenditure.

Roles

The role of the authorising signatory is to:

- Ensure that patients, carers and others involved in DeNDRoN PPI, both formally and informally, are aware of the processes for reimbursement of expenses
- Approve expense claims and ensure that they are correct.

The role of lay members and other patients/carers in PPI is to:

- Agree expenses in advance with the relevant chairperson of the group, the LRN Manager, or by other relevant DeNDRoN authorising signatories
- pre-arrange, wherever practically possible, any travel and accommodation and other expenses
- Alert DeNDRoN staff to any uncertainties over possible expenses, so that these can be sorted out on an agreeable basis.
- Follow the relevant procedures for claiming reimbursement

Guidance notes

Good relationship management

Excellent general relationship management with members of the public actively involved in DeNDRoN activities is of chief importance for success in smooth running of PPI reimbursement. It is as important as knowing the technical details of payments and expenses. Patients and carers face specific challenges which are different from those of paid DeNDRoN staff and professional representatives in DeNDRoN activities.

DeNDRoN should be flexible in meeting additional expenses for patients and carers (and ex-carers). Adopting this principle need not be seen as patronising, but rather as a realistic balance of Principles 2 and 4 above, acknowledging the pressures some patients and carers might face.

Other examples of flexibility:

- Arranging suitable times and locations to enable participants to attend easily, such as arranging meetings in a town centre or patient-friendly area, rather than out of town,
- Providing good quality refreshments,
- Printing and physically posting out relevant documents,
- Supplying stationery equipment and stamped addressed envelopes
- Pre-booking train tickets, and accommodation if needed
- Informing people about training opportunities, including UKCRN training,
- Reducing the bureaucracy by pre-filling the necessary forms,
- Being clear upfront that reimbursement can take a very long time (with an estimate of how long the institute's system takes), and keeping photocopies of claims.

Travel

Flexibility is helpful for patients/carers when there are health problems, or carer demands, for example, patients with unpredictable symptoms might not know in advance whether they will be well enough to manage a specific train. Patients or carers might therefore prefer to arrange a costlier open ticket - or even prefer to book into a hotel the night before or after a meeting or event. If a person is expected to attend a DeNDRoN event or meeting that requires travel, any necessary travel should be booked in advance wherever possible to obtain discounted fares with reimbursement of expenditure at the most cost effective rate as per the national DeNDRoN Expenses Policy.

Carers

Patients should be able to bring a carer if needed, and there should be reasonable financial support for such cases. However, members of the public acting in a PPI capacity need to negotiate and agree their plans with relevant DeNDRoN managers in advance, which might, for example result in DeNDRoN offering to pay a portion of the carer's costs. Reimbursement of expenses will only be available for those directly participating

Replacement carers' costs

It is fully recognised that some carers might not be able to participate in PPI activities unless they can arrange for replacement care for their relative. Replacement carer costs, including childcare, would always need to be agreed in advance as bona fide with proper receipts to be supplied. It is also important to be aware of the policies and procedures of the relevant host organisation's Finance Office. DeNDRoN cannot pay for neighbours or relatives undertaking this. Neither should DeNDRoN in any way become involved in arranging or recommending specific replacement carers, or recommending agencies.

Meals and subsistence

Plans should be made in advance by DeNDRoN staff to provide refreshments and food when necessary for events with PPI input. This is particularly relevant to patients in view of the health considerations.

Overnight accommodation

Depending on the particular local policies, a nominal sum may possibly be agreed in advance as a gift for hosts (e.g. a family member) supplying free accommodation. A letter written by the host confirming the arrangement is required.

Kitty

For some people, the obstacle stopping people agreeing to be involved would be the delay getting even very small costs reimbursed, such as a bus fare.

To include people in financial difficulties, a kitty for reimbursement of smallish costs would be good practice. Inevitably, protracted negotiations would be needed with specific Finance Offices to agree practicalities for providing a general petty cash kitty specifically for PPI expenses.

Teleconferences

Teleconference calls may be arranged for meetings of some groups, aiming to save group members having to travel. Users dial into a central number and enter an access code. The current charge to the bill-payer is roughly 14 pence per minute, including VAT.

When a lay member incurs call costs, then following the teleconference a copy showing the specific itemised cost on their statement will be required. It is possible to arrange for a toll-free access number for teleconferencing to be supplied to a lay member if necessary, but the resulting charge to DeNDRoN is higher, so this should be avoided where possible.

Effects on benefits and tax

For all one-off payments, tax and National Insurance contributions will not be deducted by the Institute's finance office. However, Income Tax and National Insurance are payable on any income classed as earnings over a given amount over a year. Income Support levels might also be reduced.

It remains the responsibility of the individual to clarify their own circumstances with respect to any relevant income support, tax office, or with Jobcentre Plus. Income support and tax are complex areas and individuals must be aware that it is their own responsibility to deal with those issues.

Reimbursement Procedure

DeNDRoN LRN staff should be able to provide patients and carers with information on the specific policies, procedures and requirements of the local host Institution's Finance Office, to make as clear as possible the relevant avenues and processes for claiming expenses. Patients and carers should be made aware of specific working practices which evolve as circumstances arise, particularly if there are problems in practice like a Finance Office rejecting a claim, or taking a very long time to reimburse claims.

Appendix: DeNDRoN Expenses Policy specifically covering national groups, including CSGs, and DeNDRoN Coordinating Centre activities

Dementias & Neurodegenerative Diseases Research Network

Expenses Policy

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Aims

The aims of this policy are:

- To enable Directors of DeNDRoN and members of its key task groups, Clinical Studies Groups, Special Interest Groups and Coordinating Centre staff to pursue the legitimate business of the Network in a manner which is fair, appropriate and acceptable to the Inland Revenue from a personal and corporate point of view
- To make best use of the budget available for this type of expenditure

The policy is adapted from the Expenses Policy of the Newcastle University, one of the host organisations for the DeNDRoN Coordinating Centre. Any issue not covered in this policy will be referred to the University policy in the first instance.

Roles

The role of the authorising signatory is to approve expense claims and ensure that they are correct in every way.

The role of the DeNDRoN Coordinating Centre is to act as budget holder and authorised signatory for expense claims and to process claims for payment through the Newcastle University Finance Office.

The role of Directors of the Network and Chairs of Clinical Studies Groups and Special Interest Groups is to manage the expenses incurred by their groups within their budget allocation.

Introduction

It is expected that all claimants will recognise the need to ensure economy and cost-effectiveness in the manner in which expenses are incurred, the level of those expenses and the effective use of Network members' time.

In principle, expenditure should be approved in advance by the Director or Group Chair or, where the Director or Group Chair is the claimant, by the Coordinating Centre. Reimbursement of expenses will only be available for Directors of the Network, Chairs and official members of Clinical Studies Groups and Special Interest Groups and Coordinating Centre staff.

Reimbursement Procedure

For all claims, it is important that:

- a. All claims are submitted on the Newcastle University Claim Form.
- b. Original receipts or travel tickets are provided, except where it would be impossible, for example, tube fares and parking meters. If receipts are not available, this

should be noted on the claim form. In the case of a 'shared' bill, a photocopy should be provided, signed by the Director or Group Chair. Credit card vouchers are not receipts and will not be accepted in lieu of receipts.

- c. Where receipts or tickets are lost, refunds will be made at the discretion of the Newcastle University Finance Office, and only where this is explained in writing by the Director or Group Chair and the written explanation attached to the claim form.
- d. For web-based purchases and telephone ordered items, claims must be supported by suitable documentation, for example, a copy of the web page describing the item(s) with the price and confirmation of purchase.
- e. Items claimed must be described fully and accurately, for example, details of the journey (means of transport and location of event) and purpose of the journey (to attend a conference on x date).
- f. Claimants must always sign and date claim forms. Electronic or 'pp' signatures will not be accepted.
- g. No person can authorise their own expenses. Only employees of Newcastle University may be authorising or verifying signatories for expense claim forms and must be included on the list of approved signatories held within the Coordinating Centre.
- h. Claims should be submitted within one month of the expense being incurred.
- i. Following meetings of any groups, Chairs should forward a list of attendees to the Coordinating Centre to tally with any expense claims received.

Once completed, claim forms should be submitted to the Coordinating Centre, together with all supporting documentation (receipts, etc). Any attempt to submit a false claim will be treated as a serious matter.

Meetings

Teleconference accounts have been arranged for the Coordinating Centre-led meetings and each of the Clinical Studies Groups and Special Interest Groups. It is expected that these accounts will be used wherever possible to save group members the time and expense of attending face-to-face meetings.

Where meetings are arranged at venues where room hire, refreshments or teleconference facilities will incur costs, these should be agreed in advance with the Chair of the meeting, and if necessary, the Assistant Director at the Coordinating Centre. These costs will be set against the budget allocation of the relevant Group.

Wherever possible, face-to-face meetings should be arranged at suitable times and locations to enable participants to travel to and from meetings within the same day. Directors and Chairs of Groups are encouraged to coordinate face-to-face meetings with other national meetings which members are likely to be attending also, for example,

national DeNDRoN conferences. Where it is not possible for a group member to travel to and from a meeting in one day, consideration will be given to reimbursing accommodation costs. This must be agreed with the Coordinating Centre in advance. For further information, see section on Overnight Accommodation.

Where a meeting is sponsored by an organisation other than the Network, or a meeting is held in parallel with other national meetings, members of Network groups already attending the meeting or having expenses paid by another organisation will not have those expenses reimbursed. Only additional expenses incurred as a direct result of attending the Network meeting will be reimbursed. Again, this must be agreed with the Coordinating Centre.

Travel Expenses

Expenditure on necessary business travel should be booked in advance wherever possible to obtain discounted fares. Reimbursement of expenditure on necessary business travel will be at the most cost effective rate:

- For rail travel, this will generally be standard class. Members of the Network are expected to take advantage of all types of 'saver' tickets and discounts. Members are alerted to the fact that two single tickets may be considerably cheaper than a return, and that first class travel, if booked far enough in advance, can be a permissible alternative. Rail travel will be reimbursed only up to the value of an open standard class ticket for any particular journey.
- For air travel within the UK, this should be economy class with scheduled services, or budget airlines
- For car travel, this will be at the Newcastle University mileage rates of £0.40 per mile for the first 200 miles of the journey and £0.20 for every subsequent mile
- Taxis should only be used for short journeys, if cheaper transport is not available or practicable. Fares will be reimbursed only when circumstances justify the expense incurred.

Only in exceptional circumstances will more expensive travel be considered for reimbursement, and this must be agreed with the Assistant Director of the Coordinating Centre in advance of travel. A copy of the approval should be attached to the claim form.

Where mileage is claimed, the vehicle must be insured for business use (this is the responsibility of the individual and will not be reimbursed). Claimants should keep notes of their cumulative mileage claimed for Inland Revenue Purposes.

Car Parking

While parking costs incurred in the course of travelling or attending meetings may be claimed, the cost of parking at the normal place of work may not be claimed.

Overnight Accommodation

Only in exceptional circumstances will overnight accommodation, in addition to travel, be funded. All accommodation must be authorised in advance by the Coordinating Centre.

Reimbursement will be made only for the cost of the room and subsistence as shown above, up to a maximum of £80 per night (£100 London). Where meals are not taken in the hotel, separate restaurant receipts must be obtained. Failure to provide a receipt in respect of accommodation will result in the reimbursement being reported to the Inland Revenue as a taxable benefit.

Items of a personal nature such as mini-bar items, video hire, newspapers etc will not be reimbursed by the Network. Where these are included on the bill, the costs must be deducted before submitting the bill for reimbursement.

Subsistence

The Network will reimburse subsistence only in relation to an overnight stay i.e. breakfast if not included in the accommodation costs. When members are away from their normal place of work for a period of over 10 hours and incur out of pocket expenses over and above the cost of a normal working day, one meal (eg breakfast where an unusually early start is required) will be subsidised with a contribution of up to £5. Expenditure on alcohol will not be reimbursed.

Incidental Expenses

The sum of £25 is allowed for a gift for hosts supplying free accommodation.