

Notes of the Steering Group inaugural meeting held at the Post Graduate Education Centre, Llandough Hospital, Cardiff on Wednesday 22nd February 2006

Present

1. Introduction and welcome

2. Apologies

3. Work plan: Network Development

4. Work plan: Recruitment to research studies

5. Work plan: Links with DeNDRoN UK

6. Work plan: Links with CRCC Cymru and other networks

7. Brief title for the Network

8. Identification of others to be invited to participate

9. Any other business

10. Date of next meeting

Present

Mr Tom Woods	NHS Trusts in Wales
Dr Peter Hobson	Glan Clwyd Hospital
Professor Julie Williams	Cardiff University
Ms Jennie Powell	Cardiff & Vale NHS Trust
Dr John Gallacher	Cardiff University
Dr Tony Bayer	Cardiff University
Professor Johannes Thome	University of Wales Swansea
Professor Bob Woods (Chairman)	University of Wales Bangor
Mr Ian Thomas	Alzheimer's Society
Dr Jenny Naji	Cardiff University
Dr Olivia Handley	Cardiff University
Dr Huw Morris	Cardiff University
Professor Morton Warner	University of Glamorgan
Dr Linda Clare	University of Wales Bangor
Dr Charles Twining	Carers Wales
Dr Diane Seddon	University of Wales Bangor
Professor Richard Williams	University of Glamorgan
Mr Gareth Morgan	Wales Collaboration for Mental health

1. Introduction and welcome

Professor Woods gave a brief outline of the work which had led to the submission of the joint bid for the Wales Dementias and Neurodegenerative Diseases Research Network and the subsequent arrangements – including the 3 year work plan - which had been approved by the Welsh Office for Research & Development (WORD) in health and social care. A warm welcome was extended to all present at the inaugural meeting of the Steering Group and Dr Bayer was thanked for his help in organising the meeting, including arranging the venue and refreshments.

2. Apologies

J Meara, A Rosser, D Linden, C Thomas-Wylie, S Hatch, L Morgan, D Davies, C. Maciejewski

3. Work plan: Network Development

a) Executive group: The following nominations were approved: Professor Woods, Dr Bayer, Dr Meara, Professor J Williams, I Thomas, Professor Rosser, Professor Thome, Dr Morris, Dr Clare, Dr Seddon. The group would take the lead on the adoption of studies, provide direction for the work of dedicated employees within the research professional network (subject to their appointment), ensure close links with similar initiatives in other parts of the UK and elsewhere. It was noted that Gareth Morgan had been appointed as the Network Co-ordinator (1 day per week) to support implementation of the work plan.

Whilst the Executive Group would endeavour to conduct its business by communicating via e mail or by means of video conferencing, it was agreed that Steering Group meetings should be convened every six months. Members were informed that the well established Huntington's Research Network: UK and Europe had adopted a formal constitution and it was decided to consider its merits at the next meeting. **Action: GM**

b) User/carer involvement. It was noted that this would be contracted to the Alzheimer's Society in accordance with the submission which had been approved by WORD. **Action GM/IT**

The group supported the adoption of a twinned approach, as proposed by Dr Twining, in view of the fact that users and carers often have very different needs.

Professor Warner indicated that the Welsh Institute for Health and Social Care (WIHSC), University of Glamorgan was dedicated to applying the findings of research into practice and would be pleased to collaborate.

c) Web-site. Members were unanimous in support of developing a web site to include list of studies/current projects, publications data base, details of working groups/members/dates of meetings, regular newsletter, agenda and notes of Steering Group meetings, relevant links. There was some discussion about establishing different sites for researchers compared to others with a general interest, and chat

rooms. Finally it was decided to establish a relatively simple site, as soon as possible, which could easily be maintained and updated regularly. **Action: BW/GM**

d) Dissemination: It was agreed that suitable information about the network should be prepared and disseminated at the following events: **Action: BW/GM**

- "Building R & D in Health and Social Care in Wales", 21 June 2006, Dylan Thomas Centre Swansea, organised by AWARD (All Wales Alliance for Research and Development: mid and West Wales)

- Alzheimer's Conference UK, September 06

- British Society of Gerontology Conference, Bangor, Sept 06

- Carers Wales, Annual meeting, Sept 06

Similar information should also be sent to the R&D Directors, NHS Trusts in Wales.

Action: GM/TW

4. Work plan: Recruitment to research studies

a) Research Professional Network: Professor Woods explained that whilst WORD had identified funds for a RPN, which would be contracted to the Clinical Research Coordinating Centre Cymru, it had also acknowledged the need for a number of research practitioners (thought to be 6 posts) to have specialist knowledge and experience in order to support studies associated with dementias, neurodegenerative diseases, other mental health conditions affecting adults of working age and people with learning disability. Negotiations were ongoing and it was noted that Professor Woods, together with Professor Keith Lloyd (Mental Health Research Network) and Professor David Felce (Learning Disabilities Research Network) had agreed to attend a contracts meeting with CRCC Cymru on 20 March.

b) Protocol for opt-in scheme for permission to be approached regarding future research studies and requirements for database. Following discussion it was acknowledged there was a need to adopt a formal protocol, to be approved by the executive group in the first instance. **Action: GM/ExGp.**

c) Identify existing studies that would benefit from RPN input. It was acknowledged that a data base should be established at the earliest opportunity. Members agreed to send as much information as possible to Professor Woods about existing and proposed studies and trials, prior to the meeting with CCRC Cymru on 20 March. **Action: All.**

5. Work plan: Links with DeNDRoN UK

a) Local Research Networks in England: awaiting announcement of successful bids.

b) Executive Committee: Professor Woods had been invited to serve on the appointments panel for LRNs, which had also included a representative from the pharmaceutical industry and from user/carer groups. Hard copies of web page tabled for information.

c) Clinical Studies Groups: Seven CSGs were to be established to cover disease-specific and cross-cutting areas. Professor A Rosser was to lead on the Huntington's Disease CSG, and, as such, was an Associate Director of DeNDRoN UK. Huw Morris (Parkinson's) and Bob Woods (Primary and social care) had been cited in the successful DeNDRoN proposal.

d) Brain Tissue Banks: Cardiff University is associated with a UK wide initiative to develop an Alzheimer's Brain Bank through their link with the Institute of Psychiatry at the University of London; the initiative is sponsored jointly by the Alzheimer Research Trust and the Alzheimer's Society..

Professor Thome gave a brief account of recent developments in Swansea which involved close working with colleagues in pathology and, following discussion, it was suggested there may be scope in convening a Welsh group of researchers with an interest in brain tissues. **Action: JT**

6. Work plan: Links with CRCC Cymru and other networks

a) Research Professional Network – await outcome of contracts meeting, 20 March.

b) Mental Health Network: shared network co-ordinator with WDNDRN and close links established between academic leads.

c) Learning Disability Network: close links established between academic leads.

d) Older People Network: Dr Bayer serving on both network groups.

7. Brief title for the Network

Several suggestions were put forward including:

- DeNDRoN Cymru
- Wales DeNDRoN Cymru
- DemNet
- ??

It was acknowledged that a title would need to be adopted soon to facilitate communication with others and the web site development. Following discussion it was agreed to invite all members to vote (via e mail) on their preferred choice.

Action: BW

8. Identification of other interests / individuals to be invited to participate

The following was agreed:

Old Age Psychiatry – RCP Faculty to be invited to nominate representative.

Wales Industry Group – need to discuss representation with APBI.

Local Health Boards – to be invited to nominate representative.

Pathology – nominee proposed by Professor Thome to be invited to join the network. **Action: BW/GM**

9. Any other business

Jenni Naji and Olivia Handley gave a brief introduction to the work of the European Huntington's Research Network which is co-ordinated at Cardiff University under the Direction of Professor A Rosser. Members were impressed by the network's well developed data base of research subjects and it was decided to make enquiries about the implications of adopting a similar design and methodology for use across the WDNDNRN. **Action: BW/GM**

10. Date of next meeting

Tuesday, 3 October 2006, venue to be announced.