

Reflections

Martin Rossor, Director



POSTER PRIZE FOR NEW PROJECTS

Dementia: what are the real issues? Lessons learned during the development of a self-management programme for people with dementia

Claire Craig – Sheffield Hallam University

Movical vs Lactulose to treat Constipation in Parkinson's Disease

Camille Carroll – Peninsula Medical School

Vision

To provide all patients with a dementia or neurodegenerative disease the opportunity to participate in high quality clinical research

Workshop 1:

Primary Care Engagement

- Recruitment: not specific to Dendron
 - Need PC recruitment strategy in proposals
- Collaborate with other networks: centralised support for this
- Promote mutual benefit: “win-win-win” for Dendron, patients and practices
- Not just GP/Medical: multidisciplinary
- Learn from experience
 - Failures; levers; success

Workshop 2:

Expanding the network

- The interest & motivation is there, need the support: SpRs, whole team
- Creating research culture at all levels in the Trust is vital, from CEO down
- Encourage adoption of 'easier' trials to nurture new talent
- Shift burden of bureaucracy away from PI – it puts people off!

Workshop 3:

Patient, carer and public involvement

In what ways can DeNDRoN involve local patients, carers and the wider public in helping to include NEW sites?

- Develop ways to convince new sites to get involved
- Greater links with PCRN

In what ways can DeNDRoN involve local patients, carers and wider public in helping with recruitment to studies

- Very keen on more information from DeNDRoN and doctors/clinic staff on specific studies and about patient registers, perhaps RUN BY PATIENTS.
- Have more patient friendly study names

Workshop 4:

The NHS needs more regulation?!
The use of a regulation for geriatric medicines to stimulate markets and research

- Use the Paediatric medicines regulation as a model for extra patient protection for new products.
- Offer patent protection for older patients
- EU-wide consensus and lobbying for need

Reconstitute PIAG as a specialist Research Ethics
Committee to promote research with patient
data and new law for biomedical research

Researcher mobility in EU, researcher mobility in NHS

- No NHS-wide passport at present
- EU law to facilitate researcher mobility

Workshop 5:

Rehabilitation Research

Are LRNs currently configured appropriately to meet the needs of rehab trials?

- Yes – well placed to help with recruitment, ?whether able to help further than this
- Funding – a large proportion of rehab studies are small scale, therefore DeNDRoN will miss out on opportunities to be involved as not applicable for portfolio adoption (larger scale studies only)

What support will DeNDRoN provide to such studies

- Dependent on study type
- Dependent on backgrounds of LRN staff
- Definitely able to assist with recruitments

What are the key barriers to delivery?

- Funding – obtaining it – once funding is achieved it only pays for research, not treatment and therefore staff doing treatment have to come for alternative funding
- DeNDRoN endorsing RCT level studies only? Small studies (non RCTs) possibly do not qualify for adoption
- Lack of AHP being interested in research in the first place – need initial ideas/interest before research can be progressed further
- Those AHP interested in research lack of support and knowledge of how to develop their ideas further

How can better links between AHPs and DeNDRoN be made?

- DeNDRoN attending SIG – with regard to OT and physio
- Advertising in e-journals/paper journals (AHP magazines, eg, “Frontline”)
- Attending regular conferences for AHP, eg, ACPINs

Key Performance Indicators

	Specific measure
1	Overall accrual in UKCRN
2	Overall accrual in each TCRN/PCRN
3	Overall accrual in each LRN in each TCRN/PCRN
4	Overall accrual in CSGs/sub-topics
5	Accrual by type and complexity of study
6	Accrual into multi-centre/single centre/international studies
7	Percentage of UK participants recruited into international studies with UK sites
8	Accrual from primary care/secondary care/tertiary care into research studies
9	Accrual of a range of participants in terms of age, gender, ethnicity
10	Number and percentage of different types of industry studies in portfolio (overall and by TCRN/PCRN)
11	Accrual into industry vs non-commercial studies
12	Number of companies working with UKCRN
13	Performance of adoptions panels (wrt 2-week feasibility review and extended feasibility assessment)
14	LRNs' compliance with the national costing guidelines/template
15	% subjects recruited vs planned target
16	% recruiting centres/planned centres
17	Planned date vs actual date of last subject in
18	Audit findings: Critical findings per study
19	Audit findings : Significant findings per site
20	Audit findings :Significant findings per Site Master File
21	Time between protocol adoption and first participant recruited
22	Time between first participant recruited in study to first participant recruited in 50% of the number of sites planned at baseline
23	Time between first participant recruited in study to first participant recruited in 100% of the number of sites planned at baseline
24	Time between first and last participant recruited
25	Time between last participant recruited and all data cleaning activities completed for all subjects
26	Number of LRNs participating in UKCRN studies
27	Percentage of accrual from LRNs vs non-LRNs
28	Number of studies by type and complexity (e.g. commercial/non-commercial, interventional/ observational/RCT/screening/ prevention/process of care)
29	Timeliness of data provision
30	Completeness and quality of data provided
31	Number of studies developed by each Clinical Studies/Research Group, and proportion of studies that were funded
32	Number of studies that had patient/public involvement and the level of study involvement (user-led or user involvement)
33	Number of international trials in portfolio
34	Retention rates/loss to follow-up
35	Process measures in LRNs (e.g. numbers of screened patients, proportion of patients consenting)
36	Number of research support staff who have attended relevant UKCRN training courses

Real Key Performance Indicators

	Specific measure
1	Overall accrual in UKCRN
2	Overall accrual in each TCRN/PCRN
3	Overall accrual in each LRN in each TCRN/PCRN
4	Overall accrual in CSGs/sub-topics
5	Accrual by type and complexity of study
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8	Accrual from primary care/secondary care/tertiary care into research studies
9	Accrual of a range of participants in terms of age, gender, ethnicity
10	Number and percentage of different types of industry studies in portfolio (overall and by TCRN/PCRN)
11	Accrual into industry vs non-commercial studies
12	Number of companies working with UKCRN
13	Performance of add-ons panels (with 2-week feasibility review and extended feasibility assessment)
14	LRNs' compliance with the national costing guidelines/template
15	% subjects recruited vs planned target
16	% recruiting centres/planned centres
17	Planned date vs actual date of last subject in
18	Audit findings: Critical findings per study
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• Balance of portfolio

• Accrual of participants

• Speed of study conduct

Vision

To provide all patients with a dementia or neurodegenerative disease the opportunity to participate in high quality clinical research

Overview

- Vision
- Progress
- Feedback from workshops
- Key performance indicators
- Real key performance indicators
- Personal experience

Real Key Performance Indicators



National Dementia Strategy : Department of Health - Social care - Microsoft Internet

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Address http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrat

DH Department of Health


National Dementia Strategy

Health care | **Social care** | Public health | Managing your organisation | Publications

- ▶ Older people
 - ▶ NSF for Older People and system reform
 - ▶ Partnerships for Older People Projects (POPPs)
 - ▶ Older people's NSF standards
 - ▶ **National Dementia Strategy**

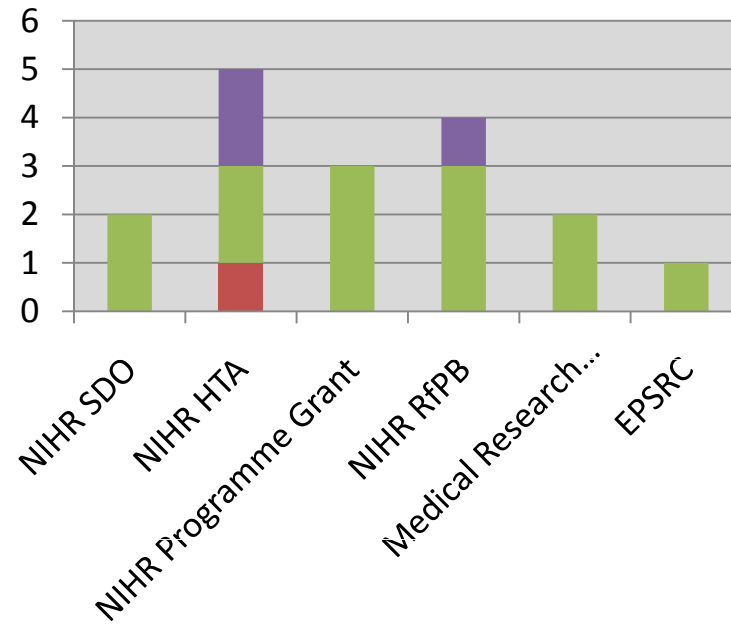
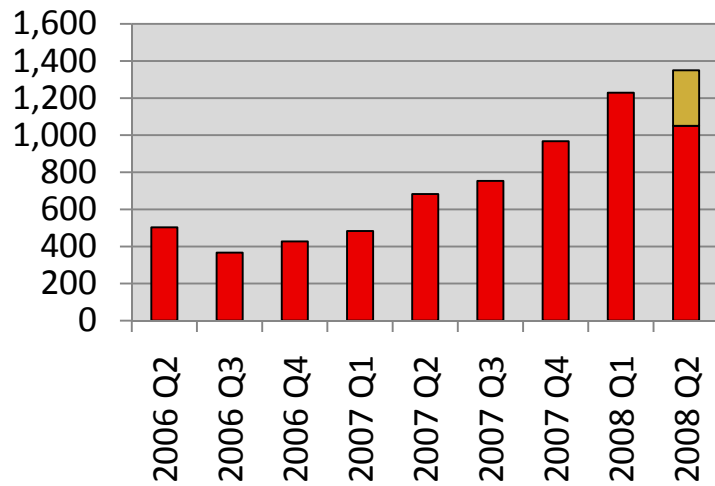
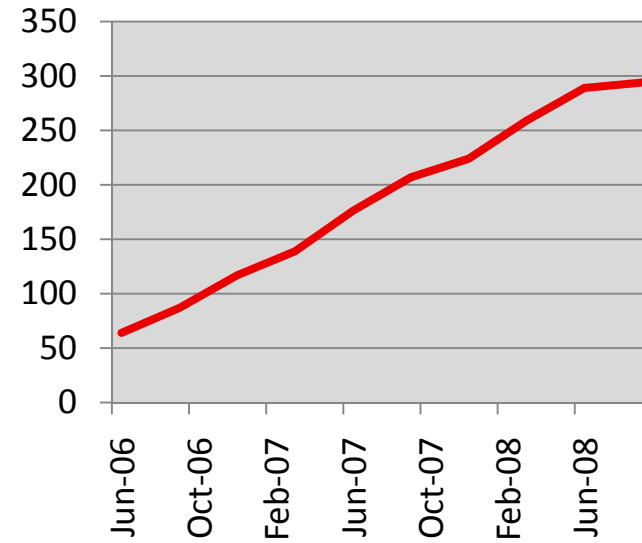
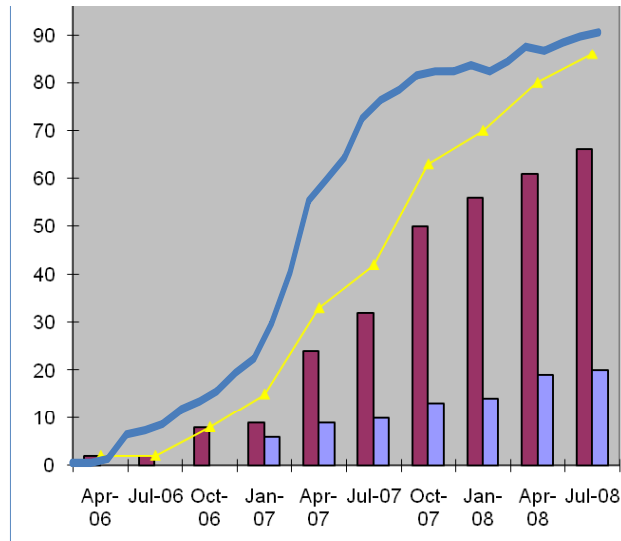
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National Dementia Strategy



The objectives of the pro implementation plan for themes – raising awareness of care.

Progress





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www.dendron.org.uk

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