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KING'S College LONDON

Patient wellbeing and caregiver burden in long-term neurological conditions: Baseline results from the OPTCARE Neuro trial

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Background

- Approx. 10 million people in UK are affected by long-term neurological conditions (LTNCs)
- People with LTNCs often have poor symptom control, poor social support with high **carer burden and distress**
- Palliative care is recommended but should it be 'end of life' (if so when?) or earlier?

- **OPTCARE Neuro:** NIHR funded Phase III multicentre RCT in patients with MS, MND, IPD, PSP & MSA
- To evaluate the clinical- and cost-effectiveness of Short-term Integrated Palliative Care (SIPC) Services to OPTimise CARE for people with LTNCs

Inclusion criteria

Adults severely affected by:

Multiple Sclerosis (MS), Idiopathic Parkinson's Disease (IPD), Progressive Supranuclear Palsy (PSP), **Multiple System Atrophy (MSA)**, **Motor Neurone Disease (MND)**

AND who are deemed (by referring/usual care clinicians) to have an unresolved symptom (e.g. pain or another symptom) which has not responded to usual care

AND at least one of: unresolved other symptom (e.g. breathlessness, nausea / vomiting, spasticity, fatigue); cognitive problems; complex psychological (depression, anxiety, loss, family concerns) and/or complex social needs

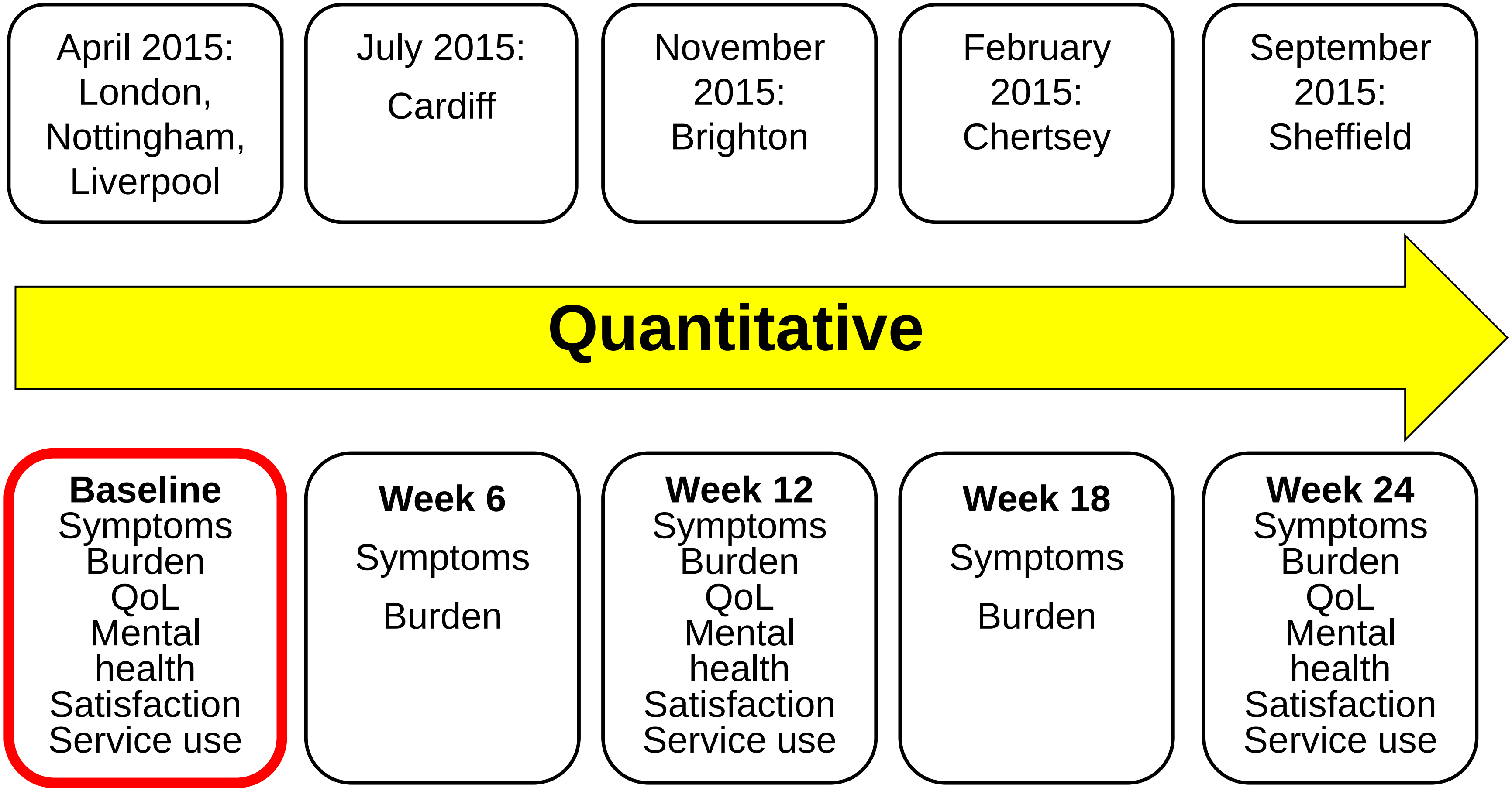
Exclusion Criteria: patients already receiving specialist palliative care (or have done so in the last 6 months) or patients who lack mental capacity and have no consultee to assent on their behalf and provide proxy data

Short-term integrated palliative care (SIPC) – what is it?

- Offered when patients are: severely affected, highly complex, at high risk of hospital admissions, high need of care
- Patients do not have to be actively dying
- Delivered by multi-professional palliative care teams and consist of approx. 3 visits over 6-8 weeks:
  - 1st comprehensive assessment, agree plan, make recommendations, treatment, liaison
  - 2nd review response, assess further actions needed, possible advanced care plan
  - 3rd final review/actions/liaison, discharge plan (small % need ongoing palliative care)

Progress so far…..

Target=356; Recruited: 215 patients & 149 carers (IPD=88, MS=83, PSP=19, MND=16, MSA=8)



April 2015: London, Nottingham, Liverpool

July 2015: Cardiff

November 2015: Brighton

February 2015: Chertsey

September 2015: Sheffield

Quantitative

Baseline
Symptoms
Burden
QoL
Mental health
Satisfaction
Service use

Week 6
Symptoms
Burden

Week 12
Symptoms
Burden
QoL
Mental health
Satisfaction
Service use

Week 18
Symptoms
Burden

Week 24
Symptoms
Burden
QoL
Mental health
Satisfaction
Service use

Aim & Methods

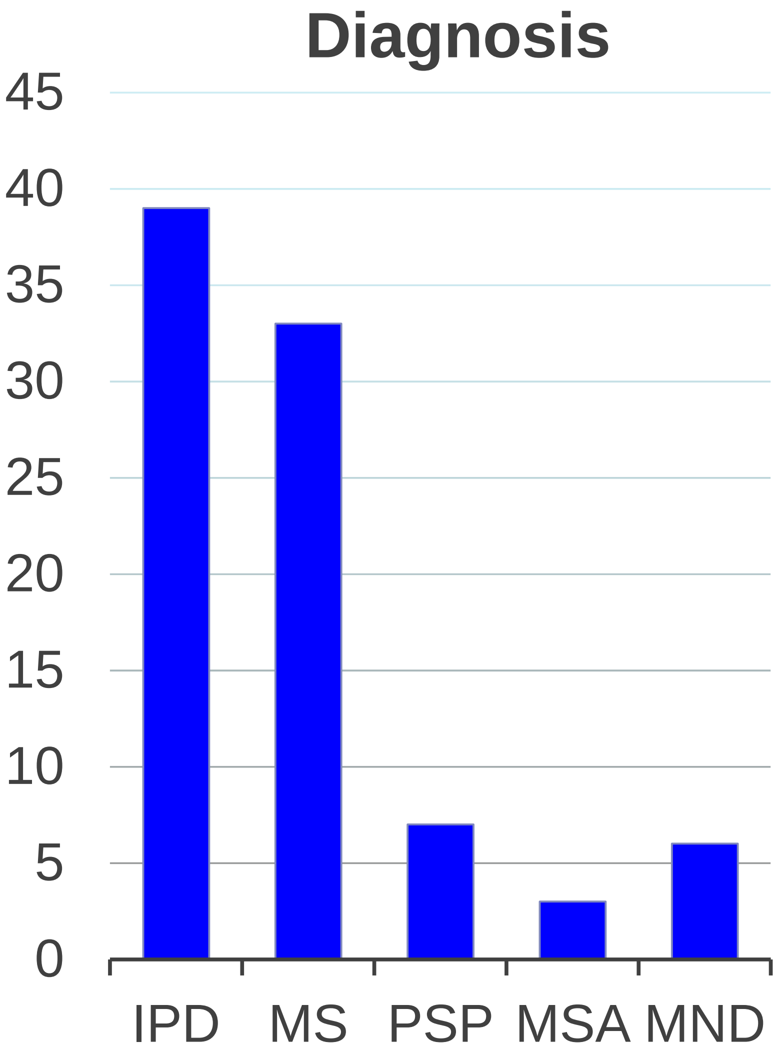
- **To test the association between caregiver burden and patient quality of life (QoL) and mental health**

- Patient Quality of life: EQ5D
- Patient mental health: Hospital Anxiety and Depression Scale (HADS)
- Caregiver burden: Zarit Burden Inventory (ZBI-12)
- Data analysis: Linear regression (STATA)

Demographics (n=88)

Patients
- Age: mean 68, SD=10.9
- Gender: 37.5% female
- Time since diagnosis
  <10 years: 46.6%

Caregivers
- Age: mean 64.5, SD=12.8
- Gender: 68.2% female
- Carer illness: 62.5% Yes
- Carer employment: 33% Yes
- Carer Education
  Primary/lower secondary: 34.1%
  Upper secondary: 31.8%
  Tertiary: 34.1%



Results

N = 88	Bivariate (unadjusted) models *B*	Multivariable adjusted model[1] *B*
EQ5D	0.86 (p<0.001)	0.92 (p<0.001)
HADS Anxiety	0.33 (p=0.20)	
HADS Depression	0.61 (p=0.049)	-0.06 (p=0.77)

[1] Model included EQ5D, depression, carer age, carer illness, carer gender, carer education, carer employment, patient diagnosis and time since diagnosis.

Conclusions & Future work

- Our results support the idea that patient QoL is associated with caregiver burden
- Improvements in patient QoL through the provision of palliative care, may have associated benefits for caregivers
- The ongoing OPTCARE Neuro trial will provide further evidence to explore the impact of early palliative care in this population
- Embedded qualitative component will allow for in depth exploration of the impact of palliative care

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Follow the progress of OPTCARE Neuro via twitter @OPTCARENeuro

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Department of Health Disclaimer:

- The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR, NIHR, NHS or the Department of Health

OPTCARE Neuro

NHS
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thank you!