



**KING'S**  
*College*  
**LONDON**

The North West London Hospitals **NHS**  
NHS Trust

Northwick Park Hospital  
Watford Road  
Harrow  
Middlesex  
HA1 3UJ

# Support for LTNC carers ...

1. With multiple caring roles
2. With replacement care needs

Diana Jackson  
Senior Research Fellow

Department of Palliative Care, Policy & Rehabilitation  
King's College London

diana.m.jackson@kcl.ac.uk

# Study 1

---

**Support for carers, particularly those with multiple caring roles:  
an investigation of support needs  
and cost of provision**

# Background

---

- Social services required to provide support to:
  - Sustain caring relationships
  - Promote independence, health, well-being
- Carers' support needs vary - not well understood
- Previous work in context of acquired brain injuries
- Particular needs for support in their own right for carers with multiple caring roles

# Research questions

---

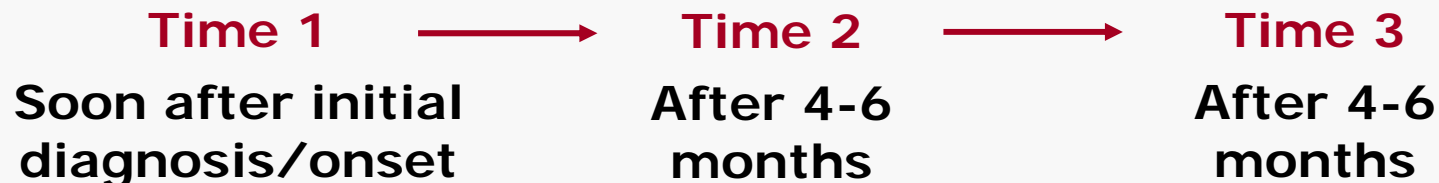
- How do support needs vary?
  - 'Lone' carers ..... Multiple caring roles
  - Sudden onset ..... Progressive conditions
- Do needs change over time?
  - Initial stages ..... Longer term
- How can needs be met cost effectively?
- Which organisations can answer unmet needs?

# Study design

---

Mixed methods: quantitative + qualitative

- Cross sectional questionnaire survey (target n=240)
  - Follow-up telephone interviews
  - Carers with diverse experiences
- Sub-set followed longitudinally (target n=60)



# Measures

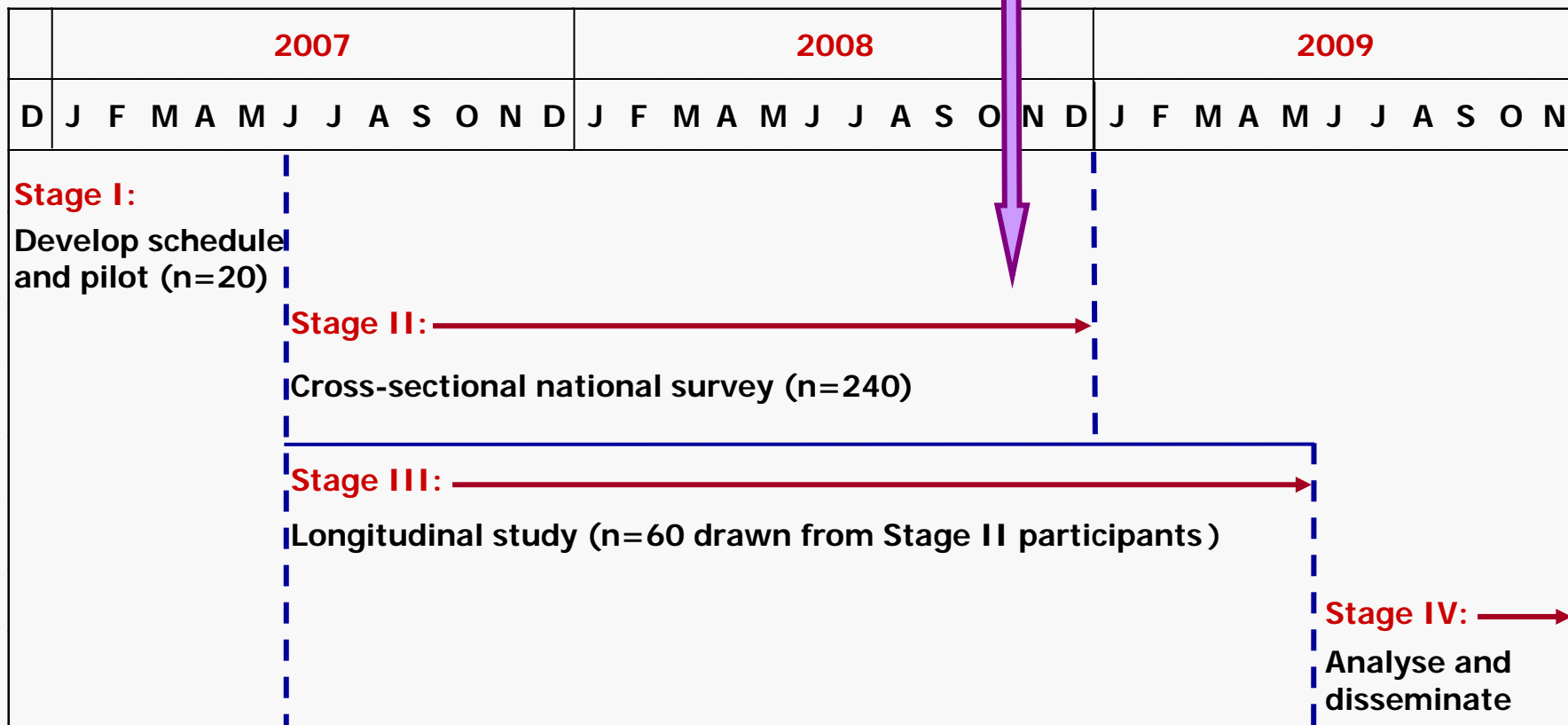
---

- Demographic data
- Impairments + care needs person cared for
- Time spent on care tasks
- Benefits and services
- Effects of caring ... health ... well-being
- What changes would help the most

# Timescale

← - - - - - 0.67 WTE Senior Research Fellow - - - - - →

← - - - Full-time Research Assistant - - - →



# Recruitment

---

- Voluntary organisations – national coverage
- Via web-sites, newsletters, carers' groups

## Progressive conditions

- MS Society
- Shane Project
- MND Association
- HD Association

## Sudden onset conditions

- Headway
- Encephalitis Society
- Epilepsy Action

## General

- Princess Royal Trust for Carers

# Recruitment

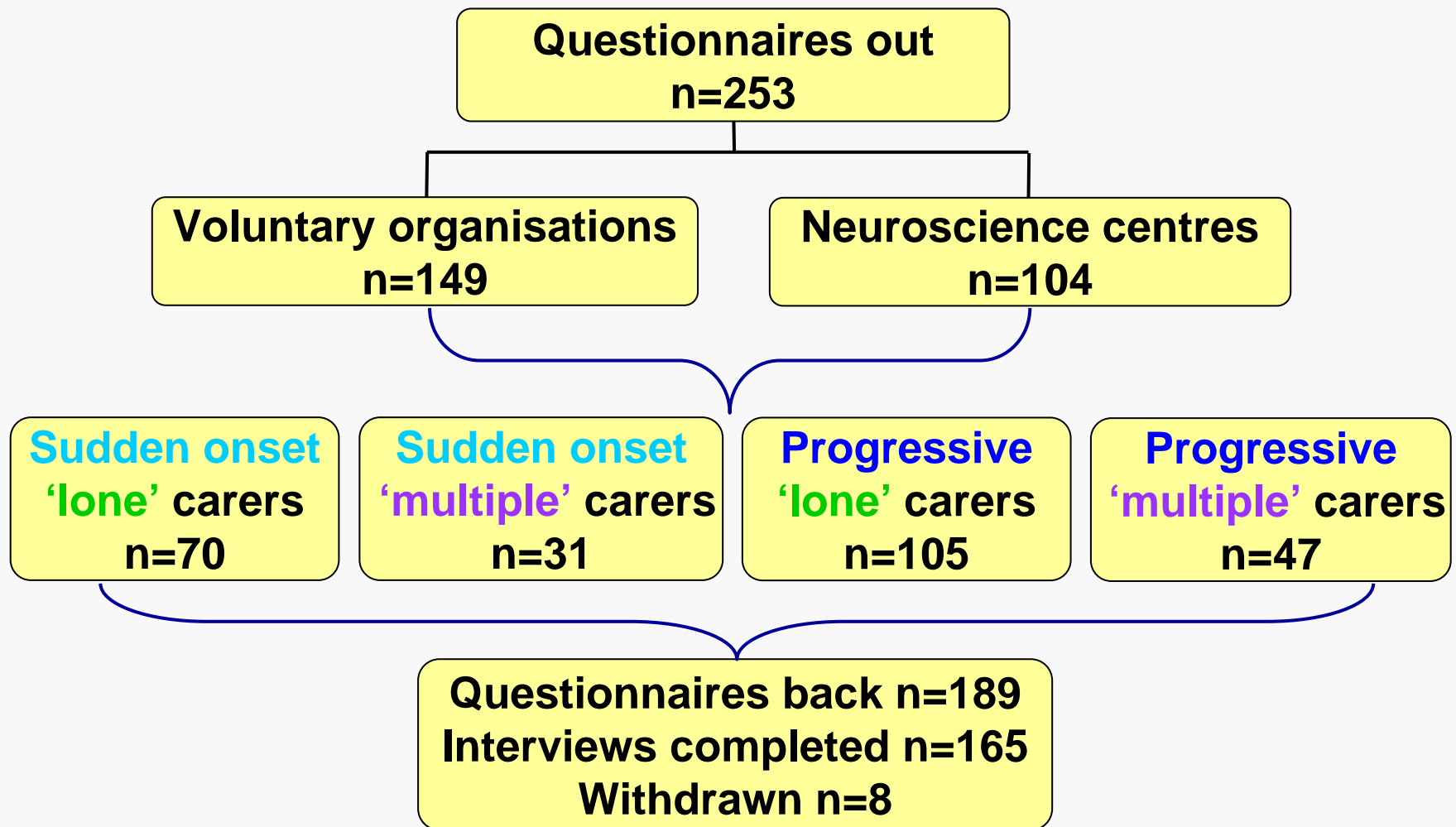
---

- Neuroscience Centres via research nurses
- Adoption by DeNDRoN
  - Increase in centres
- Co-adoption by Stroke Network
  - Underway



# Recruitment at 13.10.08

---



# Next six-months - targets

---

- December 31<sup>st</sup> 2008
  - Study closed to recruitment
  - T2 questionnaires sent to 60 carers
- March 31<sup>st</sup> 2008
  - 240 T1 questionnaires back
  - T1 data entered on database
  - Data cleaned and checked

# Study 2

---

**How do carers of people with long term neurological conditions experience the provision of replacement care?**

# Background

---

- Freedom for carers to participate in activities of their choosing outside the home a key issue in current Government strategy:
- **But ...** if person cared for cannot be left alone, replacement care is needed
- **Little is known ...** about access to replacement care services ... costs ... benefits

# Replacement care

---

- Temporary care in place of usual carer
- Carer can pursue outside activities
- Rest/respice ... Education ... Training ... Work
- Care away from home
  - Day care
  - Short residential stays
- Care in the home
  - A few hours or overnight
  - On a regular basis

# Research questions

---

- Existing replacement care services
  - Are LTNC carers *aware* and *informed* about services?
  - How *accessible* are services?
  - What *barriers* limit access?
- In general
  - What influences *use and non-use* of services?
  - What do *carers gain* from replacement care?
  - What are the *essential components* of *good quality* care?
- To inform future service planning
  - What *models of care* would serve different needs?
  - What are the *cost implications* of meeting needs?

# Study design

---

## Cross-sectional UK study

```
graph TD; A[Cross-sectional UK study] --- B[Questionnaire survey of LTNC carers  
Sample size n=300]; A --- C[Own language interviews/focus groups with BME carers  
Sample size n=50]
```

**Questionnaire survey of  
LTNC carers**

**Sample size n=300**

**Own language interviews/focus  
groups with BME carers**

**Sample size n=50**

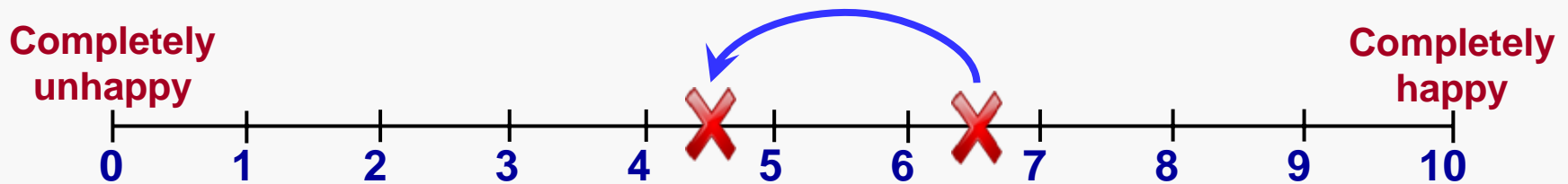
- **Inclusion criteria:**
  - Main carer of an adult with a LTNC
  - Live with person cared for or visit daily
  - Several hours every day in a caring role
- **Exclusion criteria:**
  - Carers of people with non-neurological conditions
  - Carers of children (aged 17 or under)

# Measures

---

- Demographic data
- Dependency of person cared for - input from carer
- Global impact of caring - carer well-being
- Process utility from providing informal care

Difference in how happy carer would feel if someone else took over their role in the home free of charge



- Current use of health and social services
- Reasons for use/non-use of replacement care
- Alternative use of freed time and gains

# Analysis

---

- Quantitative
  - Descriptive statistics
  - Replacement care needs
    - By condition type
    - By extent of caring role
  - Health economic modelling
    - Costs of providing unmet replacement care needs
    - Predictors of current costs + potential service costs
- Qualitative
  - Thematic analysis by bi/multi-lingual researchers

# Outputs

---

- Good practice guidelines
- Develop set of ‘concise guidance’
  - Evidence base for policy development
- Report to DH
- Academic dissemination
- Lay dissemination
  - Summary for participants
  - Voluntary organisations

# Applicants

1 Support for carers with multiple care roles  
2 Provision of replacement care

---

- **Lynne Turner-Stokes<sup>1,2</sup>** Professor of Rehabilitation, KCL
- **Jennifer Harris<sup>1,2</sup>** Director of IDRIS, Dundee University
- **Diana Jackson<sup>1,2</sup>** Senior Research Fellow, KCL
- **Paul McCrone<sup>1,2</sup>** Reader in Health Economics, IOP
- **Ava Easton<sup>1</sup>** Development Manager, Encephalitis Society
- **Nigel Leigh<sup>1</sup>** Professor of Clinical Neurology IOP
- **Jennifer Georgeson<sup>2</sup>** Senior Project Manager, CIO
- **Tariq Saleem<sup>2</sup>** Research Fellow, KCL
- **Irene Higginson<sup>2</sup>** Professor of Palliative Care & Policy, KCL

# Project advisory panel

---

- **Encephalitis Society**

**Ava Easton:** Development Manager

**Martin McLeish:** Past Carer

- **MS Society**

**Joanna Ridley:** National Carers Lead

**Caryl Reeves:** Carer

- **Headway**

**Norman Keen:** East London Branch and Carer

**Mary Porter:** Carer

- **MND Association**

**Ann Elfred:** SW London Regional Care Advisor

**Nancy Esterson:** Association Visitor

**Savita Jain:** Carer