



Long-term Neurological Conditions Survey University of Oxford

14 October 2008



Aims

- To develop two questionnaires (one for individuals with conditions and one for carers) on experiences of health and social care for individuals with particular disabling neurological conditions (MND, MS, PD)
- Carry out benchmarking survey

Questionnaire Development

- Qualitative interviews
- Literature review
 - National Service Framework on long-term neurological conditions
 - Scientific literature
- Research advisory group
- Expert input (Health Care Commission and Commission for Social Care Inspection)
- Pilot interviews

Qualitative interviews

- 46 interviews in total (34 patients and 12 carers)
 - MND (26)
 - 16 patients
 - 10 carers
 - PD (9)
 - 8 patients
 - 1 carer
 - MS (11)
 - 10 patients
 - 1 carer

Qualitative interviews

Analysis

- Coding grid according to the NSF to code all interviews
- Printed out themes
- Each theme examined by 2 researchers for missing question topics/ response options and identify most appropriate wording
- Changes were made accordingly e.g. wording of equipment questions

Pre-pilot Interviews

- Patients
 - 2 PD
 - 1 MND
 - 4 MS
- Carers
 - 1 PD
 - 3 MND
 - 2 MS
- Sent questionnaire
- Telephone or face to face interviews
- Changes: deleted question (symptoms), added response options ('I am not sure'), equipment questions (different questions)

Pilot questionnaires

- Experiences of health and social care (patient)
 - MND
 - with and without QoL
 - PD
 - with and without QoL
 - MS
 - with and without QoL
- Experiences of caring for someone with a neurological condition (carer)
 - MND
 - with and without QoL
 - PD
 - with and without QoL
 - MS
 - with and without QoL

Quality of life

- Patient
 - SF-36v2
 - MND- ALSAQ40
 - PD- PDQ-39
 - MS- MSIS (version 2)
- Carer
 - SF-36
 - Carer strain index (modified version)

Mailing Process

- Pre-packed envelopes
- Carer questionnaire sent out with patient questionnaire
- Questionnaires numbered to be able to match patient and carer questionnaires
- Questionnaires
 - Half the sample was sent our questionnaire
 - Second half of sample was sent our questionnaire plus QoL questionnaires
- Reminder

Pilot mailing

- Worked together with charities
- Groups
 - MND Association (160)
 - MS societies (165)
 - Newbury and District (90)
 - High Wycombe (75)
 - PD societies (total 170)
 - Oxford (90)
 - Portsmouth (80)

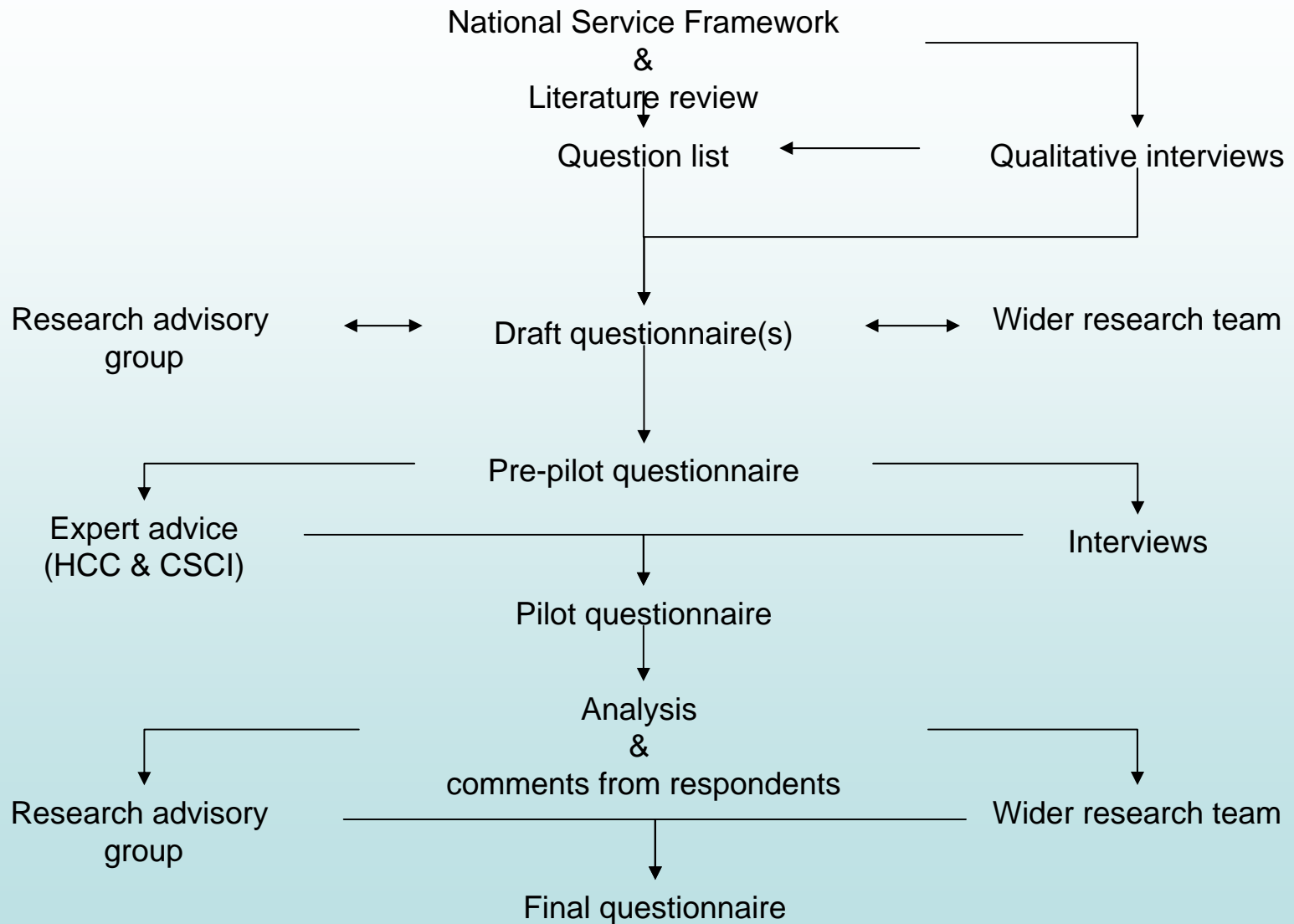
Responses to pilot survey

- 271 individuals with a neurological condition (116 MND, 67 MS and 88 PD)
- 211 carers (104 MND, 38 MS and 69 PD)

Developments since pilot survey

- **Discussion of results and modifications to survey questionnaires with Research Advisory Group**
- **Some changes to questionnaires (mainly shortening)**
- **Liased with the three charities to publish a short article in one of their newsletters (local or national) to publicize the study and encourage members to take part, if they receive a questionnaire**
- **Web/internet based delivery an option for some individuals with MND**
- **Main survey being carried out over October '08 – receiving responses**
- **Development of MND and PD modules for DiPEX website**

LTNC questionnaire development



Content of questionnaire for individuals with neurological conditions

- Receiving diagnosis 6 items
- Medication 7 items
- Health and social care 13 items
- Hospital 4 items
- Community care and support 17 items
- Information sources 2 items

Total 49 items

Content of questionnaire for carers

- Caring role 3 items
 - Health and well-being 3 items
 - Carer assessment 4 items
 - Help and support received 8 items
 - Training and information 4 items
 - Employment 7 items
 - Financial support as carer 3 items
- Total 32 items