#### Appendix 1 Electronic search strategies

The following databases were searched on OVID using the search strategy shown below:

- Medline 1996–24.5.06
- Amed 1985–7.6.06
- British Nursing Index 1985–7.6.06
- Cinahl 1982–7.6.06
- Embase 1980-7.6.06
- Medline 1966–7.6.06
- HMIC-7.6.06
- PsycINFO (previously PscyhLit) 1985

#### Search strategy

- 1 "service delivery".mp
- 2 limit 1 to (humans and english language)
- 3 "service organization".mp
- 4 limit 3 to (humans and english language)
- 5 "rehabilitation".mp
- 6 limit 5 to (humans and english language)
- 7 "neurological rehabilitation".mp
- 8 limit 7 to (humans and english language)
- 9 neurological.mp
- 10 limit 9 to (humans and english language)
- 11 10 and 6
- 12 approach.mp
- 13 limit 12 to (humans and english language)
- 14 10 and 13
- 15 specialist.mp or Specialist/
- 16 limit 15 to (humans and english language)
- 17 16 and 6
- 18 multiple sclerosis.mp or Multiple Sclerosis/
- 19 limit 18 to (humans and english language)
- 20 Parkinsons.mp or Parkinson Disease/
- 21 limit 20 to (humans and english language)
- 22 stroke.mp or Cerebrovascular Accident/
- 23 limit 22 to (humans and english language)
- 24 "brain injury".mp or Brain Injuries/
- 25 limit 24 to (humans and english language)
- 26 Motor Neuron Disease/ or "motor neurone disease".mp

- 27 limit 26 to (humans and english language)
- 28 muscular dystrophy.mp or Muscular Dystrophies/
- 29 limit 28 to (humans and english language)
- 30 "spinal cord injury".mp or Spinal Cord Injuries/
- 31 limit 30 to (humans and english language)
- 32 Epilepsy/ or epilepsy.mp
- 33 limit 32 to (humans and english language)
- 34 "huntington's disease".mp or Huntington Disease/
- 35 limit 34 to (humans and english language)
- 36 2 or 4 or 8 or 11 or 14 or 17
- 37 36 and 19
- 38 36 and 21
- 39 36 and 23
- 40 36 and 25
- 41 36 and 27
- 42 36 and 29
- 43 36 and 31
- 44 36 and 33
- 45 36 and 35
- 46 service model. mp
- 47 limit 46 to (humans and english language)
- 48 48 and 19
- 49 48 and 21
- 50 48 and 23
- 51 48 and 25
- 52 48 and 27
- 53 48 and 29
- 54 48 and 31
- 55 48 and 33
- 56 48 and 35

The following databases were searched on OVID using the search strategy shown below:

Cochrane Library:

Central Register of Controlled Trials

Specialised registers following the Cochrane Review Groups:

Consumers and Communication

Dementia and Cognitive Improvement Group

Effective Practice and Organisation of Care Group

**Epilepsy Group** 

**Movement Disorders** 

Multiple Sclerosis Group

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Neuromuscular Disease

Stroke Group

- Physiotherapy Evidence Database (PEDro)
- OT Seeker
- Centre for Dissemination & Reviews
- Database of Abstracts of Reviews of Effectiveness (DARE)
- NHS Economic Evaluation Database (NHS EED)
- Health Technology Assessment (HTA)
- National Research Register, MRC Register, CRD

#### Search terms

- Service delivery
- Service organisation
- Service organization
- Neurological rehabilitation
- Neurological approach
- Specialist rehabilitation
- Service model

## Appendix 2 Qualitative review proforma

Paper No: Reviewer's initials:

Full reference of paper:

#### Guidance notes:

Some columns give multiple choice answers. Please highlight appropriate answer(s) in yellow. NB You may need to add further details in free text below. NB It may be appropriate to highlight more than one answer. Please include page numbers from the paper for all quotes

| Type of publication  | Methodology<br>Include approach if<br>stated, or clearly<br>inferable   | Type(s) of data collection used Include details such as: Number of interviews; hours observed; hours/sessions recorded; type of documents collected   |
|--|---|---|
| a Original qualitative research b Comment by user(s) (e.g. opinion piece, commentary, etc.) c Comment by professional(s) (e.g. opinion piece, commentary etc) d Policy document – government e Policy document – professional body f Policy document – other body – Please give details of the body g Other, please give details | Only for original research: a Grounded theory b Content analysis c Phenomenology d Critical e Empowerment f Ethnographic g Anthropology h Delphi Other, please give details | i Original Research a Observation and fieldnotes b Video/audio recording (naturalistic) c Interview (specify type of interview if stated e.g. vignette/semi- structured/narrative) d Questionnaire/survey e Documents f Other, please give details ii Reviews a Meta analysis b Systematic review c Cochrane review d Unsystematic 'personal' review e Descriptive/ synthesis f Other, please give details iii Policy documents a Literature review b Professional/expert opinion c User views d Other, please give details |

#### Paper No:

| Participants/subjects Numbers of participants, and descriptive details, such as: conditions; service experience; clinicians; users, carers | Type of service/setting(s) involved E.g. stroke unit, community rehabilitation service, specialist clinic, etc. | Type of intervention provided to participants E.g. suicide prevention, counselling, multidisciplinary (MDT) stroke rehabilitation | Stated research question                                   | Stated summary of findings Include short summary from the abstract and also more detailed findings from text of paper Give page numbers |
|--|---|---|--|---|
|  |   |   | For original research and reviews but not policy documents |   |

#### Paper No:

| Any stated implications for SDO specialist neurorehabilitation | Reviewer's comments on implications for SDO of specialist neurorehabilitation | Stated category(s) (from SDO brief)   | Category(s) relating to SDO themes<br>(would expect to pick several for most<br>publications)  | Any other comments |
|--|---|---|--|--------------------|
|  |   | a Model of<br>specialist<br>neurological<br>service<br>b Organisation<br>and delivery of<br>service | a Survey of current services (e.g. across a region) b Proposal, model of service/role/intervention – ie 'what should happen' (*often includes what is wrong with what is provided now) (only highlight where the paper concerns or includes proposals, not just description of current services) |                    |

| d Effectiveness d Expert opinion/commentary user (carer,   |  |
|--|--|
| of service patient)  |  |
| e Cost- effectiveness of service f Other, please give details  e Outcome evaluation – primary qualitative research f Observational study – primary qualitative research g Other, please give details |  |

# Appendix 3 Services in the South Central SHA

| No | Model                           | Name of service  | Town          | Brain Injury | Spinal | Stroke | Prog |
|----|---------------------------------|--|---------------|--------------|--------|--------|------|
| 1  | Specialist inpatient acute unit | Southampton University Hospitals NHS Trust (Southampton General Hospital) SU | Southampton   |              |        | ✓      |      |
| 2  | Non-specialist acute unit       |  |               |              |        |        |      |
| 3  | Surgical acute unit             |  |               |              |        |        |      |
| 4  | Specialist inpatient rehab unit | Acquired Brain Injury Rehabilitation (H5)                                    | Portsmouth    | ✓            |        | ✓      | ✓    |
|    |                                 | Southampton Stroke Service (H6)  | Southampton   |              |        | ✓      |      |
|    |                                 | Rayners Hedge (TV14)   | Aylesbury     | ✓            |        | ✓      | ✓    |
|    |                                 | SRU Victoria House (H8)  | Southampton   |              |        | ✓      |      |
|    |                                 | Southampton Rehab Unit (H9)  | Southampton   | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Portsmouth Rehabilitation Unit (PB/SC/02)                                    | Gosport       | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Milton Keynes General NHS Trust SU   | Milton Keynes |              |        | ✓      |      |

|   |  | Milford Stroke Unit (New Forest PCT) SU  | Milford on sea            |   |   | ✓ |   |
|---|--|--|---------------------------|---|---|---|---|
| 5 | Specialist inpatient combined (acute and | Oxford Centre for Enablement (TV4, 5, 11)  | Oxford                    | ✓ | ✓ | ✓ | ✓ |
|   | rehab) unit                              | Neurorehabilitation Unit, Royal Berks (TV7)                                      | Reading                   | ✓ | ✓ | ✓ | ✓ |
|   |  | National Spinal Injuries Centre (TV9)  | Aylesbury                 |   | ✓ |   |   |
|   |  | International Spinal Injuries and<br>Rehabilitation Centre                       | Aylesbury                 | ✓ | ✓ | ✓ | ✓ |
|   |  | Oakley Stroke Rehab Unit (H1, 7)   | Basingstoke               | ✓ |   | ✓ |   |
|   |  | St Mary's Stroke Unit (PB/SC/03)   | Newport, Isle of<br>Wight |   |   | ✓ |   |
|   |  | Oxford Radcliffe Hospitals NHS Trust (Oxford Radcliffe Hospitals NHS Trust) SU   | Oxford                    |   |   | ✓ |   |
|   |  | Winchester and Eastleigh Healthcare NHS<br>Trust SU                              | Winchester                |   |   | ✓ |   |
|   |  | Buckinghamshire Hospitals NHS Trust SU   | Aylesbury                 |   |   | ✓ |   |
|   |  | Royal Berkshire & Battle Hospitals NHS Trust<br>SU                               | Reading                   |   |   | ✓ |   |
|   |  | East Hampshire Primary Care Trust jointly with Portsmouth Hospitals NHS Trust SU | Isle of Wight             |   |   | ✓ |   |

|    |  | Heatherwood & Wexham Park Hospitals SU                                      | Slough                        | ~        | /        |        |
|----|--|---|-------------------------------|----------|----------|--------|
|    |  | Buckinghamshire Hospitals NHS Trust SU                                      | Amersham                      | <b>✓</b> |          |        |
| 6  | Inpatient services                                 |   |                               |          |          |        |
| 7  | Condition-specific specialist nurse                | Specialist Nurse Rare Neuro Conds (TV21)                                    | Reading                       |          |          | ✓      |
| 8  | Condition-specific specialist therapist            |   |                               |          |          |        |
| 9  | Case management                                    |   |                               |          |          |        |
| 10 | Third sector condition-specific nurse              |   |                               |          |          |        |
| 11 | Third sector condition-specific therapist          | MS Society-funded posts   | Amersham                      |          |          | ✓      |
|    |  | MS Society-funded posts   | Aylesbury                     |          |          | ✓      |
|    |  | MS Society-funded posts   | Newbury                       |          |          | ✓      |
|    |  | MS Society-funded posts   | Oxford                        |          |          | ✓      |
|    |  | MS Society-funded posts   | Reading                       |          |          | ✓      |
|    |  | MS Society-funded posts   | Southampton                   |          |          | ✓      |
|    |  | MS Society-funded posts   | Milton Keynes                 |          |          | ✓      |
| 12 | Outreach rehabilitation (NHS/PCT) team             | MS Team (TV1)   | Amersham                      |          |          | ✓      |
| 13 | Outpatient services – statutory sector             |   |                               |          |          |        |
| 14 | Specialist community rehabilitation (NHS/PCT) team | Bletchley Therapy Unit (TV3, 8, 15)<br>Community Head Injury Service (TV12) | Milton Keynes ✓ ✓ Aylesbury ✓ | · •      | <i>(</i> | ✓<br>✓ |
|    |  |   |                               |          |          |        |

|         |  | Newbury Day Centre (PB/SC/01)                  | Newbury       |              |   |              | ✓ |
|---------|--|--|---------------|--------------|---|--------------|---|
|         |  | Rayners Hedge (TV14)                           | Aylesbury     | ✓            | ✓ | $\checkmark$ | ✓ |
|         |  | Snowdon Neuro Rehab Team                       | Southampton   | ✓            | ✓ | ✓            | ✓ |
| 15      | Specialist community rehabilitation –                        | Rehab Without Walls                            | Milton Keynes | ✓            | ✓ |              |   |
|         | private sector   | Peartree House Rehabilitation                  | Southampton   | ✓            |   |              |   |
|         |  | Team Medical Solutions                         | Southampton   | ✓            |   |              |   |
|         |  | Cornerstone Service Support                    | Southampton   | ✓            |   |              |   |
| 16      | New innovative models  |  |               |              |   |              |   |
| 17 Regi | Regional specialist centre (driving,                         | MAVIS  | Crowthorne    | ✓            | ✓ | ✓            | ✓ |
|         | communication, assistive devices)                            | ACE centre (Communication)                     | Oxford        | ✓            | ✓ | $\checkmark$ | ✓ |
|         | devices)   | Mary Marlborough Specialist Disability Service | Oxford        | ✓            | ✓ | $\checkmark$ | ✓ |
|         |  | Communication aid service                      |               |              |   |              |   |
|         |  |  | Southampton   | ✓            | ✓ | ✓            | ✓ |
| 18      | Statutory residential facility for respite or long-term care | St Mary's Rehab Medicine                       | Isle of Wight | ✓            |   |              | ✓ |
| 19      | Private or third sector residential rehab                    | Peartree House Rehabilitation                  | Southampton   | ✓            |   |              |   |
|         | facilities, respite or long-term care                        | Brain Injury Rehabilitation Trust, Aylesbury   | Aylesbury     | $\checkmark$ |   |              |   |
|         | curc   | Cornerstone Service Support                    | Southampton   | $\checkmark$ |   |              |   |
|         |  | Brunel Unit (SCQ1)                             | Milton Keynes | ✓            |   | ✓            | ✓ |
| 20      | Multi-disciplinary clinic                                    |  |               |              |   |              |   |

| 21 | Outpatient services – private sector              |   |                                    |             |          |             |        |
|----|---|---|------------------------------------|-------------|----------|-------------|--------|
| 22 | Specialist outpatient services – statutory sector | Bletchley Therapy Unit (TV3, 8, 15)  Oxford Centre for Enablement (TV4, 5, 11)  Neurorehabilitation Unit, Royal Berks (TV7) | Milton Keynes<br>Oxford<br>Reading | ✓<br>✓<br>✓ | <b>√</b> | ✓<br>✓<br>✓ | ✓      |
|    |   | Acquired Brain Injury Rehabilitation (H5) St Mary's Rehab Medicine  | Portsmouth  Isle of Wight          | ✓<br>✓      |          | ✓           | ✓<br>✓ |
| 23 | Specialist outpatient services – private sector   | ACE Centre Advisory Trust   | Oxford                             | ✓           |          |             |        |
| 24 | Third sector rehabilitation                       | Dysphasia Service (TV2)   | Appleton                           |             |          | ✓           |        |
|    |   | Muscular Dystrophy Campaign RCA (TV6)   | Oxford                             |             |          |             | ✓      |
|    |   | MS Therapy Centre (TV19)  | Reading                            |             |          |             | ✓      |
|    |   | South Bucks Hospice (TV20) (SCQ2)   | High Wycombe                       |             |          | ✓           | ✓      |
|    |   | MND Regional Care Advisor (TV13)  | Oxford                             |             |          |             | ✓      |
|    |   | Headway (H2)  | Portsmouth                         | ✓           |          |             |        |
|    |   | Brain Injury Rehabilitation Trust, Thomas<br>Edward Mitton House  | Milton Keynes                      | ✓           |          |             |        |
|    |   | Headway branch  | Oxford                             | ✓           |          |             |        |
|    |   | Headway branch  | Aylesbury                          | ✓           |          |             |        |
|    |   |   |                                    |             |          |             |        |

| Headway branch                       | Basingstoke          | ✓ |   |   |
|--------------------------------------|----------------------|---|---|---|
| Headway branch                       | Milton Keynes        | ✓ |   |   |
| Headway branch                       | Marlow               | ✓ |   |   |
| Headway branch                       | Southampton          | ✓ |   |   |
| Headway branch                       | Henley on<br>Thames  | ✓ |   |   |
| Headway branch                       | Isle of Wight        | ✓ |   |   |
| Stroke Association dysphasia support | Oxford               |   | ✓ |   |
| Stroke Association dysphasia support | Winchester           |   | ✓ |   |
| Stroke Association dysphasia support | Basingstoke          |   | ✓ |   |
| Stroke Association dysphasia support | Portsmouth           |   | ✓ |   |
| Stroke Association dysphasia support | Blackwater<br>Valley |   | ✓ |   |
| Stroke Association family support    | Oxford               |   | ✓ |   |
| MS Therapy Centre                    | Aylesbury            |   |   | ✓ |
| MS Therapy Centre                    | Portsmouth           |   |   | ✓ |
| MS Therapy Centre                    | Oxford               |   |   | ✓ |

MNDA regional care centre

MNDA regional care centre

Southampton

HDA regional care advisory service

Oxford

25 Third sector social, patient and carer support

TV10 (national voluntary service) and TV22 (Neuro alliance) have not been included on the maps as they are both information services not rehabilitation services.

# Appendix 4 Services in the East Midlands SHA

| No | Model                           | Name of service   | Town         | Brain Injury | Spinal | Stroke | Prog |
|----|---------------------------------|---|--------------|--------------|--------|--------|------|
| 1  | Specialist inpatient acute unit | Neuro Rehab Unit, LRI   | Leicester    |              |        |        | ✓    |
|    |                                 | Chesterfield Royal Hospital NHS Foundation<br>Trust SU        | Chesterfield |              |        | ✓      |      |
| 2  | Non-specialist acute unit       |   |              |              |        |        |      |
| 3  | Surgical acute unit             | Neurosurgery, QMC (EM/M/10)                                   | Nottingham   | ✓            | ✓      | ✓      | ✓    |
| 4  | Specialist inpatient rehab unit | Kings Lodge (EM/D/2, EM/D/6)                                  | Derby        | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Portland College  | Mansfield    | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Linden Lodge (EM/N/6)   | Nottingham   | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Neuro Rehab Unit, LRI   | Leicester    |              |        |        | ✓    |
|    |                                 | Wakerley Lodge, Leicester General                             | Leicester    | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Rehabilitation Medicine Service, Ashby Unit (EM/L/8, EM/L/10) | Lincoln      | ✓            | ✓      | ✓      | ✓    |

|  | Chatsworth Rehab Centre (EM/NN/1)  | Mansfield   | ✓ | ✓ | ✓ | ✓ |
|--|--|-------------|---|---|---|---|
|  | United Lincolnshire Hospitals NHS Trust<br>(Louth County Hospital) SU          | Louth       |   |   | ✓ |   |
|  | Sherwood Rehab Unit  | Mansfield   | ✓ | ✓ | ✓ | ✓ |
| 5 Specialist inpatient combined (acute | Neurology Centre, QMC (EM/N/7, EM/N/9)   | Nottingham  | ✓ | ✓ | ✓ | ✓ |
| and rehab) unit                        | Neurology Dept, DRI  | Derby       |   |   |   | ✓ |
|  | MS Prescribing Centre  | Lincoln     | ✓ | ✓ | ✓ | ✓ |
|  | MS Prescribing Centre  | Boston      | ✓ | ✓ | ✓ | ✓ |
|  | MS Prescribing Centre  | Brigg       | ✓ | ✓ | ✓ | ✓ |
|  | United Lincs Hospitals (EM/L/9)  | Lincoln     | ✓ | ✓ | ✓ | ✓ |
|  | Nottingham University Hospital NHS Trust<br>(Nottingham City Hospital) SU      | Nottingham  |   |   | ✓ |   |
|  | University Hospitals of Leicester NHS Trust SU                                 | Leicester   |   |   | ✓ |   |
|  | Northampton General Hospital NHS Trust<br>SU                                   | Northampton |   |   | ✓ |   |
|  | United Lincolnshire Hospitals NHS Trust<br>(Grantham and District Hospital) SU | Grantham    |   |   | ✓ |   |
|  | Sherwood Forest Hospitals NHS Trust SU   | Mansfield   |   |   | ✓ |   |

|   |                                     | United Lincolnshire Hospitals NHS Trust<br>(Pilgrim Hospital) SU                   | Boston       |   |   | ✓ |   |
|---|-------------------------------------|--|--------------|---|---|---|---|
|   |                                     | Derby Hospitals NHS Foundation Trust SU  | Derby        |   |   | ✓ |   |
|   |                                     | United Lincolnshire Hospitals NHS Trust<br>(Lincoln County) SU                     | Lincoln      |   |   | ✓ |   |
|   |                                     | Doncaster & Bassetlaw Hospitals NHS<br>Foundation Trust (Bassetlaw<br>Hospital) SU | Worksop      |   |   | ✓ |   |
|   |                                     | Coalville Community Hospital<br>(EM/LE/COAL/OT)                                    | Coalville    | ✓ |   | ✓ | ✓ |
| 6 | Inpatient services                  | Day Hospital, Bolsover   | Bolsover     | ✓ | ✓ | ✓ | ✓ |
|   |                                     | Chesterfield Royal Hospital  | Chesterfield | ✓ | ✓ | ✓ | ✓ |
|   |                                     | Social Services Derby City   | Derby        | ✓ | ✓ | ✓ | ✓ |
|   |                                     | Pilgrim Hospital (EM/L/4)  | Boston       | ✓ | ✓ | ✓ | ✓ |
|   |                                     | Orthoptic Dept, DRI  | Derby        | ✓ | ✓ | ✓ | ✓ |
|   |                                     | Loughborough Hospital  | Loughborough | ✓ | ✓ | ✓ | ✓ |
|   |                                     | Walton Hospital  | Chesterfield | ✓ | ✓ | ✓ | ✓ |
| 7 | Condition-specific specialist nurse | Clinical nurse specialist  | Derby        |   |   |   | ✓ |
|   |                                     | MS nurses, QMC   | Nottingham   |   |   |   | ✓ |

|    |   | Neurology specialist nurse (EM/D/7)                                   | Erewash      | ✓ | ✓ |   | ✓ |
|----|---|---|--------------|---|---|---|---|
|    |   | MND nurse, QMC  | Nottingham   |   |   |   | ✓ |
|    |   | Neurosciences nurse   | Nottingham   | ✓ | ✓ | ✓ | ✓ |
|    |   | MS Nurses   | Leicester    |   |   |   | ✓ |
|    |   | MS Nurses   | Northampton  |   |   |   | ✓ |
|    |   | HD nurse (EM/N/13)  | Nottingham   |   |   |   | ✓ |
|    |   | Brain Injury clinical specialist                                      | Chesterfield | ✓ |   |   |   |
| 8  | Condition-specific specialist therapist | Specialist Therapist (PD Leengate Clinic)                             | Nottingham   |   |   |   | ✓ |
|    |   | Specialist Therapist (PD) AHP in Physical Disability, Walton Hospital | Chesterfield |   |   |   | ✓ |
|    |   | Neurophysiotherapist, Ripley Hospital                                 | Ripley       | ✓ | ✓ | ✓ | ✓ |
|    |   | Neuropsychologist NUH   | Nottingham   | ✓ | ✓ | ✓ | ✓ |
|    |   | Neurophysiotherapist, Ilkeston Community<br>Hospital                  | Ilkeston     | ✓ | ✓ | ✓ | ✓ |
| 9  | Case management                         | N Derby BI Service (EM/ND/1)  | Bolsover     | ✓ |   |   |   |
|    |   | BI Case Management  | Derby        | ✓ |   |   |   |
| 10 | Third sector condition-specific nurse   |   |              |   |   |   |   |

| 11 | Third sector condition-specific therapist | MS Society-funded specialists                    | Leciester      |   |   |   | ✓ |
|----|---|--|----------------|---|---|---|---|
|    | τη ει αριδί                               | MS Society-funded specialists                    | Leciester      |   |   |   | ✓ |
|    |   | MS Society-funded specialists                    | Nottingham     |   |   |   | ✓ |
| 12 | Outreach rehabilitation (NHS/PCT)         | Social Services Derby City                       | Derby          | ✓ | ✓ | ✓ | ✓ |
|    | team                                      | Nottingham Traumatic BI Service (EM/N/4, EM/N/8) | Nottingham     | ✓ |   |   |   |
|    |   | TBI Outreach Service (EM/D/1)                    | Derby          | ✓ |   |   |   |
|    |   | Community Outreach Team                          | Grantham       | ✓ | ✓ | ✓ | ✓ |
|    |   | St Mary's Hospital                               | Melton Mowbray | ✓ | ✓ | ✓ | ✓ |
| 13 | Outpatient services – statutory sector    | Day Hospital, DRI                                | Derby          | ✓ | ✓ | ✓ | ✓ |
|    |   | Day Hospital, Bolsover                           | Bolsover       | ✓ | ✓ | ✓ | ✓ |
|    |   | Newholme Hospital                                | Bakewell       | ✓ | ✓ | ✓ | ✓ |
|    |   | Claycross Community Hospital                     | Clay Cross     | ✓ | ✓ | ✓ | ✓ |
|    |   | Chesterfield Royal Hospital                      | Chesterfield   | ✓ | ✓ | ✓ | ✓ |
|    |   | Outpatient service, Ropewalk,                    | Nottingham     | ✓ | ✓ | ✓ | ✓ |
|    |   | Day Ward, LRI                                    | Leicester      |   |   |   | ✓ |
|    |   | Social Services Disability Team (EM/D/8)         | Derby          | ✓ | ✓ | ✓ | ✓ |
|    |   |  |                |   |   |   |   |

| Social Services Disability Team (EM/N/12) | Nottingham   | ✓ | ✓ | ✓ | ✓ |
|---|--------------|---|---|---|---|
| Social Services Disability Team           | Swadlincote  | ✓ | ✓ | ✓ | ✓ |
| Social Services Disability Team           | Ripley       | ✓ | ✓ | ✓ | ✓ |
| Social Services Disability Team           | Matlock Bath | ✓ | ✓ | ✓ | ✓ |
| Social Services Disability Team           | Ilkeston     | ✓ | ✓ | ✓ | ✓ |
| Social Services Disability Team           | Leicester    | ✓ | ✓ | ✓ | ✓ |
| Social Services Disability Team           | Hinckley     | ✓ | ✓ | ✓ | ✓ |
| Social Services Disability Team           | Coalville    | ✓ | ✓ | ✓ | ✓ |
| Social Services Disability Team           | Loughborough | ✓ | ✓ | ✓ | ✓ |
| Continence Advisory Service               | Brigg        |   |   |   | ✓ |
| Continence Advisory Service               | Grantham     |   |   |   | ✓ |
| Continence Advisory Service               | Lincoln      |   |   |   | ✓ |
| Continence Advisory Service               | Derby        |   |   |   | ✓ |
| Continence Advisory Service               | Mansfield    |   |   |   | ✓ |
| British Medicine Rehabilitation Team      | Brigg        | ✓ | ✓ | ✓ | ✓ |
| Loughborough Hospital                     | Loughborough | ✓ | ✓ | ✓ | ✓ |

|    |  | Walton Hospital                                     | Chesterfield | ✓ | ✓ | ✓ | ✓ |
|----|--|---|--------------|---|---|---|---|
|    |  | Disability Resource Team                            | Chesterfield | ✓ | ✓ | ✓ | ✓ |
|    |  | Adult Social Care and Health (EM/N/10)              | Nottingham   | ✓ | ✓ | ✓ | ✓ |
| 14 | Specialist community rehabilitation (NHS/PCT) team | High Peak and Dales Rehabilitation Service (EM/D/9) | Buxton       | ✓ | ✓ | ✓ | ✓ |
|    |  | Independent Living Team (EM/N/2)                    | Nottingham   | ✓ | ✓ | ✓ | ✓ |
|    |  | Intermediate Care Team (EM/N/11)                    | Nottingham   | ✓ | ✓ | ✓ | ✓ |
|    |  | County Community Stroke Team                        | Nottingham   |   |   | ✓ |   |
|    |  | City Community Stroke Team                          | Nottingham   |   |   | ✓ |   |
|    |  | Rehab Medicine community Outreach Team (EM/L/5)     | Lincoln      | ✓ | ✓ | ✓ | ✓ |
|    |  | Physical Disability Team                            | Boston       | ✓ | ✓ | ✓ | ✓ |
|    |  | Physical Disability Team                            | Gainsborugh  | ✓ | ✓ | ✓ | ✓ |
|    |  | Physical Disability Team                            | Grantham     | ✓ | ✓ | ✓ | ✓ |
|    |  | Physical Disability Team                            | Horncaslte   | ✓ | ✓ | ✓ | ✓ |
|    |  | Physical Disability Team (EM/L/3)                   | Lincoln      | ✓ | ✓ | ✓ | ✓ |
|    |  | Physical Disability Team                            | Louth        | ✓ | ✓ | ✓ | ✓ |

|    |   | Physical Disability Team                         | Market Rasen  | ✓ | ✓ | ✓ | ✓ |
|----|---|--|---------------|---|---|---|---|
|    |   | Physical Disability Team                         | North Hykeham | ✓ | ✓ | ✓ | ✓ |
|    |   | Physical Disability Team                         | Skegness      | ✓ | ✓ | ✓ | ✓ |
|    |   | Physical Disability Team                         | Sleaford      | ✓ | ✓ | ✓ | ✓ |
|    |   | Physical Disability Team                         | Spalding      | ✓ | ✓ | ✓ | ✓ |
| 15 | Specialist community rehabilitation – private sector          | Athena Care Ltd                                  | Leicester     | ✓ | ✓ | ✓ | ✓ |
|    |   | Berkley Close, St Andrews Hospital               | Northampton   | ✓ |   |   |   |
| 16 | New innovative models   |  |               |   |   |   |   |
| 17 | Regional specialist centre (driving, communication, assistive | Nottingham Traumatic BI Service (EM/N/4, EM/N/8) | Nottingham    | ✓ |   |   |   |
|    | devices)  | Derby Drivability                                | Derby         | ✓ | ✓ | ✓ | ✓ |
|    |   | Disablement Services Centre                      | Leicester     | ✓ | ✓ | ✓ | ✓ |
|    |   | Communication Aid Centre                         | Leicester     | ✓ | ✓ | ✓ | ✓ |
|    |   | Communication Aid Resource Centre                | Lincoln       | ✓ | ✓ | ✓ | ✓ |
|    |   | Communication Aid Resource Centre                | Lincoln       | ✓ | ✓ | ✓ | ✓ |
| 18 | Statutory residential facility for respite or long-term care  |  |               |   |   |   |   |

| 10 | Private or third sector residential  | Nottingham DI Dahahilitation Contro               | Uualmall            | , |   |   |   |
|----|--------------------------------------|---|---------------------|---|---|---|---|
| 19 | rehab facilities, respite or long-   | Nottingham BI Rehabilitation Centre               | Hucknall            | ✓ |   |   |   |
|    | term care                            | Christchurch Court                                | Abington, Northants | ✓ | ✓ | ✓ | ✓ |
|    |                                      | Grafton Manor                                     | Towcester           | ✓ |   |   |   |
|    |                                      | Kemsley Unit, St Andrews Hospital                 | Northampton         | ✓ |   |   |   |
|    |                                      | BI Rehabilitation Care, Richardson<br>Partnership | Northampton         | ✓ |   |   |   |
|    |                                      | Oakleaf Care                                      | Northampton         | ✓ |   |   |   |
|    |                                      | Matthews Neuro and Rehabilitation Services        | Loughborough        | ✓ | ✓ | ✓ | ✓ |
|    |                                      | Aspley Neuro Disability Services (EM/N/3)         | Nottingham          | ✓ |   |   | ✓ |
|    |                                      | White Rose  | Nottingham          | ✓ | ✓ | ✓ | ✓ |
| 20 | Multi-disciplinary clinic            | Neurology Centre, QMC (EM/N/7, EM/N/9)            | Nottingham          | ✓ | ✓ | ✓ | ✓ |
|    |                                      | Derby City General Hospital (EM/D/3)              | Derby               | ✓ | ✓ | ✓ | ✓ |
| 21 | Outpatient services – private sector |   |                     |   |   |   |   |
| 22 | Specialist outpatient services –     | Neurology Centre, QMC                             | Nottingham          | ✓ | ✓ | ✓ | ✓ |
|    | statutory sector                     | Derby City General Hospital (EM/D/3)              | Derby               | ✓ | ✓ | ✓ | ✓ |
|    |                                      | Nottingham Traumatic BI Service                   | Nottingham          | ✓ |   |   |   |
|    |                                      | TBI Outreach Service                              | Derby               | ✓ |   |   |   |
|    |                                      |   |                     |   |   |   |   |

|  | Disabled Living Centre                       | Nottingham | ✓ | ✓ | ✓ | ✓ |
|--|--|------------|---|---|---|---|
|  | Portland College                             | Mansfield  | ✓ | ✓ | ✓ | ✓ |
|  | Cedars Rehabilitation Service (EM/N/5)       | Nottingham | ✓ | ✓ | ✓ | ✓ |
|  | Coalville Community Hospital (EM/LE/COAL/OT) | Coalville  | ✓ |   | ✓ | ✓ |
|  | Leicester BI Team (EM/LE/2)                  | Leicester  | ✓ |   |   |   |
|  | MS Prescribing Centre                        | Lincoln    | ✓ | ✓ | ✓ | ✓ |
|  | MS Prescribing Centre                        | Boston     | ✓ | ✓ | ✓ | ✓ |
|  | MS Prescribing Centre                        | Brigg      | ✓ | ✓ | ✓ | ✓ |
|  | Pilgrim Hospital (EM/L/4)                    | Boston     | ✓ | ✓ | ✓ | ✓ |
|  | Rehabilitation Medicine Service (EM/L/8)     | Lincoln    | ✓ | ✓ | ✓ | ✓ |
|  | United Lincs Hospitals (EM/L/9)              | Lincoln    | ✓ | ✓ | ✓ | ✓ |
|  | Neuro Outpatient Department                  | Newark     | ✓ | ✓ | ✓ | ✓ |
|  | Rosehill Business Centre                     | Derby      | ✓ |   | ✓ | ✓ |
|  | Orthoptic Dept, DRI (PB/EM/01)               | Derby      | ✓ | ✓ | ✓ | ✓ |
| Specialist outpatient services – private | Neurophysiotherapist                         | Eggington  | ✓ | ✓ | ✓ | ✓ |
| sector                                   | Psychology service                           | Alfreton   | ✓ |   | ✓ |   |
|  |  |            |   |   |   |   |

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|    |                             | Psychology service                   | Hathersage     | ✓ |   |   |
|----|-----------------------------|--------------------------------------|----------------|---|---|---|
| 24 | Third sector rehabilitation | MS Therapy Centre                    | Nottingham     |   |   | ✓ |
|    |                             | MDC Care Advisor (EM/N/6)            | Nottingham     |   |   | ✓ |
|    |                             | MS Therapy Centre                    | Leicester      |   |   | ✓ |
|    |                             | MS Therapy Centre                    | Lincoln        |   |   | ✓ |
|    |                             | MNDA Regional Care Centre            | Nottingham     |   |   | ✓ |
|    |                             | MNDA Regional Care Advisor           | Northampton    |   |   | ✓ |
|    |                             | HDA Regional Care Advisor            | Northampton    |   |   | ✓ |
|    |                             | Headway branch                       | Leicester      | ✓ |   |   |
|    |                             | Headway branch                       | Nottingham     | ✓ |   |   |
|    |                             | Headway branch                       | Derby          | ✓ |   |   |
|    |                             | Headway branch                       | Northampton    | ✓ |   |   |
|    |                             | Headway branch                       | Wellingborough | ✓ |   |   |
|    |                             | Headway branch                       | Lincoln        | ✓ |   |   |
|    |                             | Headway branch                       | Chesterfield   | ✓ |   |   |
|    |                             | Stroke Association Dysphasia Support | S Derbys       |   | ✓ |   |

Stroke Association Family Support

Stroke Association Family Support

Leicester

Stroke Association Family Support

Mansfield

25 Third sector social, patient and carer support

Code 6 or 13 services have not been included on the maps as they are not specialist services.

# Appendix 5 Services in the North East SHA

| No | Model                           | Name of service  | Town          | Brain injury | Spinal | Stroke | Prog |
|----|---------------------------------|--|---------------|--------------|--------|--------|------|
| 1  | Specialist inpatient acute unit |  |               |              |        |        |      |
| 2  | Non-specialist acute unit       |  |               |              |        |        |      |
| 3  | Surgical acute unit             |  |               |              |        |        |      |
| 4  | Specialist inpatient rehab unit | Neuro rehabilitation units – (Hume) (NEQ1)                                 | Sunderland    | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Neuro rehabilitation units - (JC) (NEQ13)                                  | Middlesbrough | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Neuro rehabilitation units - Newcastle<br>General                          | Newcastle     | ✓            | ✓      | ✓      | ✓    |
|    |                                 | Hunters Moor (BI)  | Newcastle     | ✓            |        |        |      |
|    |                                 | North Tees and Hartlepool NHS Trust SU (University Hospital of Hartlepool) | Hartlepool    | ✓            |        | ✓      |      |
|    |                                 | North Tees and Hartlepool NHS Trust (North<br>Tees Hospital) SU            | Peterlee      |              |        | ✓      |      |

|   |  | County Durham and Darlington Acute<br>Hospitals NHS Trust (Darlington<br>Memorial) SU | Darlington    |   |   | ✓ |   |
|---|--|---|---------------|---|---|---|---|
|   |  | Hartside Unit – Neuro Behavioural Unit  | Newcastle     | ✓ |   |   | ✓ |
|   |  | Janie Hepple Unit, Prudhoe Hospital   | Prudhoe       | ✓ |   |   |   |
|   |  | MND team – James Cook   | Middlesbrough |   |   |   | ✓ |
|   |  | Neuro Rehab team  | Sunderland    | ✓ | ✓ | ✓ | ✓ |
|   |  | Neuro Rehab wards   | N Tyneside    | ✓ | ✓ | ✓ | ✓ |
| 5 | Specialist inpatient combined (acute and rehab) unit | Northumbria Healthcare NHS Trust (North<br>Tyneside District General Hospital)<br>SU  | North Shields |   |   | ✓ |   |
|   |  | Newcastle upon Tyne Hospitals NHS Trust<br>SU   | Newcastle     |   |   | ✓ |   |
|   |  | Northumbria Healthcare NHS Trust<br>(Wansbeck General Hospital) SU                    | Wansbeck      |   |   | ✓ |   |
|   |  | Northumbria Healthcare NHS Trust<br>(Hexham General Hospital) SU                      | Hexham        |   |   | ✓ |   |
|   |  | South Tees Hospitals NHS Trust (The James<br>Cook University Hospital) SU             | Middlesbrough |   |   | ✓ |   |
|   |  | Gateshead SU (NEQ6)   | Gateshead     |   |   | ✓ |   |

|    |   | South Tyneside NHS Foundation Trust SU   | South Shields    | ✓ |   |
|----|---|--|------------------|---|---|
|    |   | County Durham and Darlington Acute<br>Hospitals NHS Trust (Bishop<br>Auckland) SU                  | Bishop Auckland  | ✓ |   |
|    |   | City Hospitals Sunderland NHS Foundation<br>Trust SU   | Sunderland       | ✓ |   |
|    |   | County Durham and Darlington Acute<br>Hospitals NHS Trust (University<br>Hospital North Durham) SU | Durham           | ✓ |   |
|    |   | Spinal cord injury unit – (JC) (NEQ12,<br>NEQ17)   | Middlesbrough 🗸  |   |   |
| 6  | Inpatient services                      |  |                  |   |   |
| 7  | Condition-specific specialist nurse     | MS nurses  | Newcastle        |   | ✓ |
|    |   | MS nurses  | Middlesbrough    |   | ✓ |
|    |   | PD nurses  | Middlesbrough    |   | ✓ |
| 8  | Condition-specific specialist therapist |  |                  |   |   |
| 9  | Case management                         |  |                  |   |   |
| 10 | Third sector condition-specific nurse   |  |                  |   |   |
| 11 | Third sector condition-specific         | MS Society PT service  | Stockton on Tees |   | ✓ |
|    | therapist                               | MS Society-funded posts  | Durham           |   | ✓ |

|    |  | MS Society-funded posts                                       | Sunderland           |   |   |   | ✓ |
|----|--|---|----------------------|---|---|---|---|
| 12 | Outreach rehabilitation (NHS/PCT) team               | Discharge Stroke Team (St Nicholas)                           | Newcastle            |   |   | ✓ |   |
| 13 | Outpatient services – statutory sector               |   |                      |   |   |   |   |
| 14 | Specialist community rehabilitation                  | Regional Disability Team, Hunters Moor                        | Newcastle            | ✓ | ✓ | ✓ | ✓ |
|    | (NHS/PCT) team                                       | Community MS Team, Hunters Moor                               | Newcastle            |   |   |   | ✓ |
|    |  | Northumberland Head Injury Service                            | Morpeth              | ✓ |   |   |   |
|    |  | (NEQ5)  | Chester le Street    | ✓ | ✓ | ✓ | ✓ |
|    |  | Neuro rehab community team (NEQ11)                            | Gateshead            | ✓ |   |   |   |
|    |  | Community ABI team (NEQ3)                                     | Gateshead            |   |   | ✓ |   |
|    |  | Community Stroke team (NEQ4)                                  | Peterlee (Easington) |   |   | ✓ |   |
|    |  | Community stroke team (NEQ16)                                 | Wallsend             | ✓ | ✓ | ✓ | ✓ |
|    |  | Wallsend community neuro rehab team                           | Transcina .          |   |   |   |   |
| 15 | Specialist community rehabilitation – private sector | Neuro Partners (BI comm. Rehab) (NEQ8)                        | Newcastle            | ✓ |   |   |   |
|    |  | Strategic Property Solutions (BI accommodation + comm. rehab) | Newcastle            | ✓ |   |   |   |
|    |  | JS Parker and Associates (BI case management + voc rehab)     | Newcastle            | ✓ |   |   |   |
|    |  | Physio Works (incl SCI rehab)                                 |                      | , | , |   |   |
|    |  | Rehab UK (BI comm + voc rehab)                                | Newcastle            | ✓ | ✓ |   |   |
|    |  |   | Newcastle            | ✓ |   |   |   |

| 16 | New innovative models  | Neural Pathways (UK) Ltd (NEQ10)   | Newcastle | ✓ |   | ✓        |   |
|----|--|--|-----------|---|---|----------|---|
|    |  | MND hub & spoke service (NEQ14) with Carlisle and Whitehaven (CLSP05)        | Newcastle |   |   |          | ✓ |
|    |  | MND clinic exchange (consultant with MS                                      | Durhan    |   |   |          | ✓ |
|    |  | nurse)   | Newcastle |   |   |          | ✓ |
|    |  | One-stop nurse-lead BI clinic  | Newcastle | ✓ |   |          |   |
| 17 | Regional specialist centre (driving, communication, assistive devices) | Regional mobility centre - (Hunters Moor)                                    | Newcastle | ✓ | ✓ | ✓        | ✓ |
|    |  | Regional environmental controls service -<br>Newcastle (Hunters Moor)        | Newcastle | ✓ | ✓ | ✓        | ✓ |
|    |  | Regional technical aids centre - (Hunters Moor)                              | Newcastle | ✓ | ✓ | ✓        | ✓ |
|    |  | Regional (Northern) communication aids centre (Communicate) - (Hunters Moor) | Newcastle | ✓ | ✓ | ✓        | ✓ |
|    |  | Regional Medical Physics Department<br>(Technical aids) – Newcastle General  | Newcastle | ✓ | ✓ | <b>√</b> | ✓ |
| 18 | Statutory residential facility for respite or long-term care           |  |           |   |   |          |   |
| 19 | Private or third sector residential                                    | Whickham Villa (BI IP rehab)   | Newcastle | ✓ |   |          |   |
|    | rehab facilities, respite or long-term care                            | Hawthorns Nursing Home   | Peterlee  | ✓ |   |          |   |

| 20 | Multi-disciplinary clinic                       |  |                |              |              |   |   |
|----|---|--|----------------|--------------|--------------|---|---|
| 21 | Outpatient services – private sector            |  |                |              |              |   |   |
| 22 | Specialist outpatient services –                | Hartside Unit  | Newcastle      | ✓            |              |   | ✓ |
|    | statutory sector                                | Regional Disability Team, Hunters (NEQ2)                   | Newcastle      | $\checkmark$ | $\checkmark$ | ✓ | ✓ |
|    |   | Neuro outpatient Physiotherapists (NEQ15)                  | Gateshead      | ✓            | ✓            | ✓ | ✓ |
| 23 | Specialist outpatient services – private sector |  |                |              |              |   |   |
| 24 | Third sector rehabilitation                     | MND Care Centre (NEQ14)                                    | Newcastle      |              |              |   | ✓ |
|    |   | Stroke Association communication aids centre - Dene Centre | Newcastle      |              |              | ✓ |   |
|    |   | MS Therapy Centre  | Middlesbrough  |              |              |   | ✓ |
|    |   | Stroke Association dysphasia support                       | Sunderland     |              |              | ✓ |   |
|    |   | Stroke Association dysphasia support                       | Blyth Valley   |              |              | ✓ |   |
|    |   | Stroke Association family support                          | Gateshead      |              |              | ✓ |   |
|    |   | Stroke Association family support                          | Easington      |              |              | ✓ |   |
|    |   | Stroke Association family support                          | Guisborough    |              |              | ✓ |   |
|    |   | Stroke Association family support                          | Middlesbrough  |              |              | ✓ |   |
|    |   | Headway branch   | Northumberland | ✓            |              |   |   |
|    |   |  |                |              |              |   |   |

| Headway branch   | Teesside   | <b>√</b> |   |
|--|------------|----------|---|
| Headway branch   | Gateshead  | ✓        |   |
| BIRT supported housing   | Sunderland | ✓        |   |
| Muscular Dystrophy Assocation - MDA Care<br>Advisor, Newcastle covers region | Newcastle  |          | ✓ |
| MND Assocation - MND Care Centre<br>coordinator, Royal Victoria<br>Informary | Newcastle  |          | ✓ |
| MND Care Advisors cover Northumberland,<br>Tyne and Wear, Durham, Cleveland, | Newcastle  |          | ✓ |
| Huntingtons Disease Association - regional care advisory service             | Newcastle  |          | ✓ |

25 Third sector social, patient and carer support

# Appendix 6 Services in the North West SHA

| No | Model                           | Name of service  | Town        | Brain Injury | Spinal | Stroke   | Prog |
|----|---------------------------------|--|-------------|--------------|--------|----------|------|
| 1  | Specialist inpatient acute unit | Inpatient neuro rehab ward (CLSP03)  | Ormskirk    | ✓            | ✓      | ✓        | ✓    |
|    |                                 | Morecambe Bay Hospitals NHS Trust<br>(Westmorland General Hospital) SU                 | Kendal      |              |        | ✓        |      |
| 2  | Non-specialist acute unit       |  |             |              |        |          |      |
| 3  | Surgical acute unit             |  |             |              |        |          |      |
| 4  | Specialist inpatient rehab unit | Bolton Hospitals NHS Trust SU  | Bolton      |              |        | ✓        |      |
|    |                                 | Lancashire Teaching Hospitals NHS<br>Foundation Trust (Chorley and South<br>Ribble) SU | Chorley     |              |        | ✓        |      |
|    |                                 | Morecambe Bay Hospitals NHS Trust (Royal<br>Lancaster Infirmary) SU                    | Lancaster   |              |        | ✓        |      |
|    |                                 | Isle of Man Department of Health and Social<br>Security SU                             | Isle of Man |              |        | <b>√</b> |      |
|    |                                 | Brain Injury Rehabilitation Centre   |             |              |        |          |      |

|  |  | Liverpool   | ✓  |  |  |  |
|--|--|---|--|--|--|--|
| Specialist inpatient combined (acute and | Devonshire Centre for Rehabilitation   | Stockport   | ✓  | ✓  | ✓  | ✓  |
| renab) unit                              | Rakehead Rehabilitation Centre   | Burnley   | ✓  | ✓  | ✓  | ✓  |
|  | Floyd Unit for Neurological Rehabilitation                                       | Rochdale  | ✓  | ✓  | ✓  | ✓  |
|  | Talyor Rehabilitation, Leigh Infirmary   | Leigh   | ✓  | ✓  | ✓  | ✓  |
|  | Clatterbridge Hospitals  | Wirral  | ✓  | ✓  | ✓  | ✓  |
|  | Preston Neuro Rehab Unit (CLSP04)  | Preston   | ✓  | ✓  | ✓  | ✓  |
|  | Neuro Rehab Unit, West Cumb (CLSP05)   | Carlisle  | ✓  |  | ✓  | ✓  |
|  | YDU, Whitehaven (CLSP05)   | Whitehaven  | ✓  |  | ✓  | ✓  |
|  | Regional Spinal Injuries Centre (CLSP20)   | Southport   |  | ✓  |  |  |
|  | Walton Centre (CMSP17)   | Liverpool   | ✓  |  | ✓  | ✓  |
|  | Central Manchester and Manchester Children's<br>University Hospital NHS Trust SU | Manchester  |  |  | ✓  |  |
|  | Salford Royal Hospitals NHS Trust SU   | Salford   |  |  | ✓  |  |
|  | Aintree Hospitals NHS Trust SU   | Liverpool   |  |  | ✓  |  |
|  | North Cumbria Acute Hospitals NHS Trust<br>(West Cumberland Hospital) SU         | Whitehaven  |  |  | ✓  |  |
|  | Pennine Acute Hospitals NHS Trust (Rochdale                                      | Rochdale  |  |  | ✓  |  |
|  | Specialist inpatient combined (acute and rehab) unit                             | rehab) unit  Rakehead Rehabilitation Centre  Floyd Unit for Neurological Rehabilitation  Talyor Rehabilitation, Leigh Infirmary  Clatterbridge Hospitals  Preston Neuro Rehab Unit (CLSP04)  Neuro Rehab Unit, West Cumb (CLSP05)  YDU, Whitehaven (CLSP05)  Regional Spinal Injuries Centre (CLSP20)  Walton Centre (CMSP17)  Central Manchester and Manchester Children's University Hospital NHS Trust SU  Salford Royal Hospitals NHS Trust SU  Aintree Hospitals NHS Trust SU  North Cumbria Acute Hospitals NHS Trust (West Cumberland Hospital) SU | Specialist inpatient combined (acute and rehab) unit  Rakehead Rehabilitation Centre  Rakehead Rehabilitation Centre  Floyd Unit for Neurological Rehabilitation  Rochdale  Talyor Rehabilitation, Leigh Infirmary  Leigh  Clatterbridge Hospitals  Wirral  Preston Neuro Rehab Unit (CLSP04)  Neuro Rehab Unit, West Cumb (CLSP05)  Carlisle  YDU, Whitehaven (CLSP05)  Regional Spinal Injuries Centre (CLSP20)  Southport  Walton Centre (CMSP17)  Liverpool  Central Manchester and Manchester Children's  University Hospital NHS Trust SU  Salford Royal Hospitals NHS Trust SU  Aintree Hospitals NHS Trust SU  North Cumbria Acute Hospitals NHS Trust  (West Cumberland Hospital) SU  North Cumbria Acute Hospitals NHS Trust  Whitehaven | Specialist inpatient combined (acute and rehab) unit  Rakehead Rehabilitation Centre  Rakehead Rehabilitation Centre  Floyd Unit for Neurological Rehabilitation  Rochdale  Talyor Rehabilitation, Leigh Infirmary  Leigh  Clatterbridge Hospitals  Wirral  Preston Neuro Rehab Unit (CLSP04)  Neuro Rehab Unit, West Cumb (CLSP05)  Carlisle  YDU, Whitehaven (CLSP05)  Regional Spinal Injuries Centre (CLSP20)  Southport  Walton Centre (CMSP17)  Liverpool  Valiversity Hospital NHS Trust SU  Salford Royal Hospitals NHS Trust SU  Aintree Hospitals NHS Trust SU  North Cumbria Acute Hospitals NHS Trust  (West Cumberland Hospital) SU  Viewpool | Specialist inpatient combined (acute and rehab) unit  Rakehead Rehabilitation Centre  Rakehead Rehabilitation Centre  Burnley  Floyd Unit for Neurological Rehabilitation  Rochdale  Talyor Rehabilitation, Leigh Infirmary  Leigh  Clatterbridge Hospitals  Wirral  Preston Neuro Rehab Unit (CLSP04)  Neuro Rehab Unit, West Cumb (CLSP05)  Regional Spinal Injuries Centre (CLSP05)  Whitehaven  YDU, Whitehaven (CLSP05)  Regional Spinal Injuries Centre (CLSP20)  Southport  Walton Centre (CMSP17)  Liverpool  Y  Salford Royal Hospitals NHS Trust SU  Salford  Aintree Hospitals NHS Trust SU  North Cumbria Acute Hospitals NHS Trust  (West Cumberland Hospital) SU  Whitehaven  Whitehaven  Whitehaven  Whitehaven | Specialist inpatient combined (acute and rehab) unit  Rakehead Rehabilitation Centre  Rakehead Rehabilitation Centre  Floyd Unit for Neurological Rehabilitation  Rochdale  Talyor Rehabilitation, Leigh Infirmary  Leigh  Clatterbridge Hospitals  Wirral  Preston Neuro Rehab Unit (CLSP04)  Neuro Rehab Unit, West Cumb (CLSP05)  Regional Spinal Injuries Centre (CLSP20)  Whitehaven  Central Manchester and Manchester Children's University Hospital NHS Trust SU  Salford Royal Hospitals NHS Trust SU  North Cumbria Acute Hospitals NHS Trust (West Cumberland Hospital) SU  V V V V V V V V V V V V V V V V V V V |

#### Infirmary) SU

| Pennine Acute Hospitals NHS Trust (Fairfield<br>General Hospital) SU | Bury         | ✓        |
|--|--------------|----------|
| Royal Liverpool & Broadgreen University<br>Hospitals NHS Trust SU    | Liverpool    | ✓        |
| Pennine Acute Hospitals NHS Trust (Royal<br>Oldham Hospital) SU      | Salford      | ✓        |
| North Cheshire Hospitals NHS Trust<br>(Warrington Hospital) SU       | Warrington   | ✓        |
| South Manchester University Hospitals NHS<br>Trust SU                | Manchester   | ✓        |
| North Cheshire Hospitals NHS Trust (Halton<br>General Hospital) SU   | Runcorn      | <b>✓</b> |
| North Cumbria Acute Hospitals NHS Trust<br>(Cumberland Infirmary) SU | Carlisle     | <b>✓</b> |
| Pennine Acute Hospitals NHS Trust (North<br>Manchester General) SU   | Manchester   | <b>✓</b> |
| Countess of Chester Hospital NHS Foundation<br>Trust SU              | Chester      | ✓        |
| East Cheshire NHS Trust SU   | Macclesfield | ✓        |
| Stockport NHS Foundation Trust SU                                    | Stockport    | ✓        |

|   |                                     | Wirral Hospital NHS Trust SU  | Upton, Wirral        | ✓ |   |
|---|-------------------------------------|---|----------------------|---|---|
|   |                                     | Southport and Ormskirk Hospital NHS Trust<br>SU                                   | Southport            | ✓ |   |
|   |                                     | Wrightington, Wigan and Leigh NHS Trust SU  | Wigan                | ✓ |   |
|   |                                     | Lancashire Teaching Hospitals NHS<br>Foundation Trust SU                          | Preston              | ✓ |   |
|   |                                     | Morecambe Bay Hospitals NHS Trust (Furness<br>General Hospital) SU                | Barrow in<br>Furness | ✓ |   |
|   |                                     | East Lancashire Hospitals NHS Trust (Burnley<br>Health Care NHS Trust) SU         | Burnley              | ✓ |   |
|   |                                     | Mid Cheshire Hospitals NHS Trust SU   | Crewe                | ✓ |   |
|   |                                     | St Helens & Knowsley Hospitals NHS Trust SU                                       | St Helens            | ✓ |   |
|   |                                     | Blackpool, Fylde & Wyre Hospitals NHS Trust<br>(Blackpool Victoria Hospital) SU   | Blackpool            | ✓ |   |
|   |                                     | East Lancashire Hospitals NHS Trust<br>(Blackburn Hyndburn & Ribble Valley)<br>SU | Blackburn            | ✓ |   |
| 6 | Inpatient services                  |   |                      |   |   |
| 7 | Condition-specific specialist nurse | PD Nurse  | Liverpool            |   | ✓ |
|   |                                     | PD Nurse  | Carlisle             |   | ✓ |
|   |                                     |   |                      |   |   |

|    |  | MS Nurse  | Carlisle     |   |   |   | ✓ |
|----|--|---|--------------|---|---|---|---|
| 8  | Condition-specific specialist therapist              |   |              |   |   |   |   |
| 9  | Case management                                      |   |              |   |   |   |   |
| 10 | Third sector condition-specific nurse                |   |              |   |   |   |   |
| 11 | Third sector condition-specific therapist            | MS Society-funded posts                                       | Isle of Man  |   |   |   | ✓ |
|    |  | MS Society-funded posts                                       | Liverpool    |   |   |   | ✓ |
|    |  | MS Society-funded posts                                       | Stockport    |   |   |   | ✓ |
|    |  | MS Society-funded posts                                       | Carlisle     |   |   |   | ✓ |
|    |  | MS Society physio service                                     | West Cumbria |   |   |   | ✓ |
|    |  | MS Society physio service                                     | Liverpool    |   |   |   | ✓ |
| 12 | Outreach rehabilitation (NHS/PCT) team               |   |              |   |   |   |   |
| 13 | Outpatient services – statutory sector               |   |              |   |   |   |   |
| 14 | Specialist community rehabilitation                  | Community ABI rehab team (CLSP08)                             | Chorley      | ✓ |   |   |   |
|    | (NHS/PCT) team                                       | Community MS team (CMSP07)                                    | Liverpool    |   |   |   | ✓ |
|    |  | Warrington ABI Team (CMSP16)                                  | Warrington   | ✓ |   |   |   |
|    |  | Community neuro rehab team (CMSP25)                           | Southport    | ✓ | ✓ | ✓ | ✓ |
|    |  | South Cheshire ABI Service                                    | Chester      | ✓ |   |   |   |
| 15 | Specialist community rehabilitation – private sector | Susan Pattison Chartered Neurological<br>Physiotherapists Ltd | Bury         | ✓ | ✓ | ✓ | ✓ |

|    |   | Physio Matters  | Oldham                 | ✓ |   |   |              |
|----|---|---|------------------------|---|---|---|--------------|
|    |   | JPS Machester Ltd                                       | Manchester             | ✓ | ✓ |   |              |
|    |   | Physiotherapy   | Manchester             | ✓ | ✓ | ✓ | $\checkmark$ |
| 16 | New innovative models   | MND hub & spoke service (CLSP05) with Newcastle (NEQ14) | Whitehaven<br>Carlisle |   |   |   | ✓<br>✓       |
| 17 | Regional specialist centre (driving,  | Driving assessment centre (CLSP18)                      | Wigan                  | ✓ | ✓ | ✓ | ✓            |
|    | communication, assistive devices)   | ACE Centre-North (communication)                        | Saddleworth            | ✓ | ✓ | ✓ | ✓            |
| 18 | Statutory residential facility for respite or long-term care                    |   |                        |   |   |   |              |
| 19 | Private or third sector residential rehab facilities, respite or long-term care | Priory Highbank Neuro-Rehabilitation Service (CLSP23)   | Bury                   | ✓ | ✓ | ✓ | ✓            |
|    |   | Voyage Residential Care Home, Burnley                   | Burnley                | ✓ |   |   |              |
|    |   | Stephenson Unit   | ,<br>Warrington        | ✓ | ✓ | ✓ | ✓            |
|    |   | David Lewis Centre                                      | Alderley Edge          |   |   |   | ✓            |
| 20 | Multi-disciplinary clinic   | Movement Disorder Service (CMSP06)                      | St Helens              |   |   |   | ✓            |
| 21 | Outpatient services – private sector  | Community PT team (CLSP21)                              | Bury                   | ✓ | ✓ | ✓ |              |
| 22 | Specialist outpatient services – statutory                                      | Walton Centre (CMSP17)                                  | Liverpool              | ✓ | ✓ | ✓ | ✓            |
|    | sector  | Talyor Rehabilitation, Leigh Infirmary                  | Leigh                  | ✓ | ✓ | ✓ | ✓            |
|    |   | Brain Injury Rehabilitation Centre                      | Liverpool              | ✓ |   |   |              |

23 Specialist outpatient services – private sector

| 24 | Third sector rehabilitation | MND Care Centre (CLVO22)                                  | Preston    |   |   | ✓ |
|----|-----------------------------|---|------------|---|---|---|
|    |                             | MND Care Centre   | Liverpool  |   |   | ✓ |
|    |                             | MND Care Centre   | Manchester |   |   | ✓ |
|    |                             | MND Care advisor  | Cumbria    |   |   | ✓ |
|    |                             | MND Care advisor  | Lancashire |   |   | ✓ |
|    |                             | MND Care advisor  | Cheshire   |   |   | ✓ |
|    |                             | Neuromuscular Centre (CMVO09, CMV024)                     | Winsford   |   |   | ✓ |
|    |                             | Brain Injury Rehabilitation Trust, Redford<br>Court       | Liverpool  | ✓ |   |   |
|    |                             | Brain Injury Rehabilitation Trust, Redford<br>Court Lodge | Liverpool  | ✓ |   |   |
|    |                             | Brain and Spinal Injuries Centre                          | Salford    | ✓ | ✓ |   |
|    |                             | Headwayhouse  | Manchester | ✓ |   |   |
|    |                             | Headway branch  | Workington | ✓ |   |   |
|    |                             | Headway branch  | Burnley    | ✓ |   |   |
|    |                             | Headway branch  | Preston    | ✓ |   |   |
|    |                             |   |            |   |   |   |

| Headway branch                       | Salford                 | ✓ |   |
|--------------------------------------|-------------------------|---|---|
| Headway branch                       | Stockport               | ✓ |   |
| Headway branch                       | Wirral                  | ✓ |   |
| Headway branch                       | Lancaster               | ✓ |   |
| Headway branch                       | Carlisle                | ✓ |   |
| Headway branch                       | Blackburn               | ✓ |   |
| Headway branch                       | Halton                  | ✓ |   |
| Headway branch                       | Warrington              | ✓ |   |
| Stroke Association dysphasia support | Salford                 |   | ✓ |
| Stroke Association dysphasia support | Stockport               |   | ✓ |
| Stroke Association dysphasia support | South<br>Manches<br>ter |   | ✓ |
| Stroke Association dysphasia support | Tameside                |   | ✓ |
| Stroke Association dysphasia support | Trafford                |   | ✓ |
| Stroke Association dysphasia support | Oldham                  |   | ✓ |
| Stroke Association dysphasia support | South Cumbria           |   | ✓ |

| Stroke Association dysphasia support | Morecambe Bay | ✓ |
|--------------------------------------|---------------|---|
| Stroke Association dysphasia support | Rochdale      | ✓ |
| Stroke Association dysphasia support | Blackpool     | ✓ |
| Stroke Association dysphasia support | Burnley       | ✓ |
| Stroke Association dysphasia support | Southport     | ✓ |
| Stroke Association dysphasia support | South Sefton  | ✓ |
| Stroke Association dysphasia support | St Helens     | ✓ |
| Stroke Association dysphasia support | Liverpool     | ✓ |
| Stroke Association dysphasia support | Liverpool     | ✓ |
| Stroke Association dysphasia support | Wirral        | ✓ |
| Stroke Association dysphasia support | Wirral        | ✓ |
| Stroke Association dysphasia support | Halton        | ✓ |
| Stroke Association dysphasia support | Warrington    | ✓ |
| Stroke Association dysphasia support | Crewe         | ✓ |
| Stroke Association dysphasia support | Vale Royal    | ✓ |
| Stroke Association dysphasia support | Macclesfield  | ✓ |

| Stroke Association dysphasia support | Chester      | ✓ |
|--------------------------------------|--------------|---|
| Stroke Association family support    | Salford      | ✓ |
| Stroke Association family support    | Salford      | ✓ |
| Stroke Association family support    | Bolton       | ✓ |
| Stroke Association family support    | Bolton       | ✓ |
| Stroke Association family support    | Bolton       | ✓ |
| Stroke Association family support    | Blackburn    | ✓ |
| Stroke Association family support    | Blackburn    | ✓ |
| Stroke Association family support    | Chester      | ✓ |
| Stroke Association family support    | Chester      | ✓ |
| Stroke Association family support    | Crewe        | ✓ |
| Stroke Association family support    | Halton       | ✓ |
| Stroke Association family support    | Liverpool    | ✓ |
| Stroke Association family support    | Liverpool    | ✓ |
| Stroke Association family support    | Macclesfield | ✓ |
| Stroke Association family support    | South Sefton | ✓ |

| Stroke Association family support | St Helens     | ✓ |   |
|-----------------------------------|---------------|---|---|
| Stroke Association family support | Southport     | ✓ |   |
| MS Therapy centre                 | Manchester    |   | ✓ |
| MS Therapy centre                 | Chester       |   | ✓ |
| HDA care advisor                  | Manchester    |   | ✓ |
| HDA care advisor                  | Lancs/Cumbria |   | ✓ |
| MDC care advisor                  | Liverpool     |   | ✓ |

25 Third sector social, patient and carer support

# Appendix 7 Details of primary qualitative research papers

| Authors           | Main aims of study   | Research design and method of data collection   | Sample  | Type of service/setting(s) involved   | Type of intervention provided to participants            | Category(s) from SDO brief       |
|-------------------|--|---|---|---|--|----------------------------------|
| Low et al. (2004) | To explore the impact of two methods of post-hospital stroke rehabilitation (domiciliary or day hospital) on both carers' perceptions of the health services offered and their quality of life | Qualitative methods: Semi structured Interviews with 40 out of 106 informal carers identified from 140 stroke patients taking part in the Dorset Stroke Study (an RCT)  I | 40 informal carers of patients who were participating in an RCT. Mean age 68.7 yrs. Mainly spouses or partners. Mainly female (72%) Wives the majority (with daughters and daughters in laws acting as the main carer if no spouse available) Mainly nonmanual background (63%) | The people the carers were helping were receiving Either . Domiciliary or Day hospital Post-hospital Rehab. As part of an RCT | Day hospital rehabilitation or home based rehabilitation | Commentary user (carer, patient) |

| Finlayson<br>(2004)         | To describe health related concerns and service needs in older people with multiple sclerosis (MS)   | Qualitative: Phenomenological approach. In depth interviews. "Issue focussed qualitative analysis" using Atlas software.   | 27 older adults<br>with MS<br>recruited<br>through<br>support groups                             | N/A   |   | Effectiveness of service                                      |
|-----------------------------|--|--|--|---|---|---|
| Scheer <i>et al.</i> (2003) | To examine access barriers to primary, specialist and rehabilitative care and their consequences for individuals' health, functioning and well-being and health services' utilisation. | Qualitative: "Thematic coding" using Nvivo (p223) Original Research Interview semi structured Part of national (US) survey of 537 working adults.  | 30 working age individuals with spinal cord injury, cerebral palsy or MS                         | Primary, specialist<br>and rehabilitative<br>care | N/A   | Organisation and delivery of service Acceptability of service |
| Warner,<br>et al.<br>(2005) | Can you improve<br>the quality of<br>service to people<br>experiencing a<br>relapse of MS?   | Qualitative: Action research, Carried out initial audit of treatment times, type of treatment (day or inpatient) and discharge times. Repeated after intervention. Also interviewed patients for their experience. | People experiencing a relapse of MS. 46 in initial audit but no numbers mentioned for follow up. | District general<br>hospital                      | Relocation to neurology department; develop treatment protocol; specialist nurse telephone helpline and relapse review clinic. More day case management. For original research and reviews but not policy documents | Proposal, model of service/role/intervention Action research  |

| Brown <i>et al.</i> (2006)       | To investigate whether health and social care services met the needs of patients with MND and their carers. To explore their preferences for service delivery and to compare with services provided locally | Qualitative:<br>Structured interview<br>with patients and<br>carers. Questionnaire<br>to commissioners.  | 11 patients and<br>9 family carers<br>living in 3<br>counties in S.<br>England<br>17<br>commissioners<br>from PCTs and<br>social care | NHS and social services for people with motor neurone disease. | N/A  | Organisation and delivery of service  |
|----------------------------------|---|--|---|--|--|---|
| Pound <i>et al.</i> (1999)       | i) Were there any differences in the process of care between the three settings ii) Could these differences be explained by differences in the type of patients admitted to each setting                    | Qualitative: Non-<br>participant<br>observation of 12<br>patients in each of<br>the three settings<br>(stroke unit, Elderly<br>care unit and<br>General medical<br>ward)             | 36 patients in 3 settings   | Stroke unit; Elderly<br>care unit; General<br>medical ward     | Stroke patients<br>referred to<br>therapists, but no<br>interdisciplinary<br>team meetings | Organisation and delivery of service  |
| Corben<br>and<br>Rosen<br>(2005) | The experience of living with a long-term condition   | Qualitative: Interview and Literature review - focus on patients perspectives about self management. 'E- reference group' - members working in policy and service development around | 9 people living with different (long-term) conditions Represent ' a range of conditions, ages, ethnic groups and geographical         | Not specified  | Not specified  | Organisation and delivery of service Acceptability of service Effectiveness of service Patient selfmanagement |

|                             |   | long-term conditions  | spread'.<br>Long-term<br>conditions from<br>2–40 years   |  |   |  |
|-----------------------------|---|---|--|--|---|--|
| Dowswell et al. (2000)      | To capture details about support provided by the specialist nurses, to gain further insight into the process of care and enhance understanding of the principal problems facing stroke patients and their carers in the first year following stroke' (p161) Also to improve understanding of the process of the intervention for future development of the approach for stroke rehabilitation | Qualitative: Diaries (specialist nurses) review                         | Specialist nurses providing support in the year following stroke. Comprehensive written records of involvement with all patients and their carers in randomized controlled trial. 101 complete records | Community - patients' own homes  | Specialist nurse support - information, advice. Support and monitoring - flexible, individualised approach (p160) | Organisation and delivery of service Effectiveness of service  |
| Neri and<br>Kroll<br>(2003) | Exploration of: 1. Scope and nature of consequences that adults with disabilities perceive  | Grounded theory<br>Interview semi<br>structured<br>Telephone interviews | 30 participants,<br>with spinal<br>cord injury,<br>cerebral palsy<br>or MS   | Difficulties in accessing at least 3/5 health service areas (Primary care, specialist care, rehabilitative | N/A   | Organisation and<br>delivery of service<br>Acceptability of service<br>Effectiveness of service<br>Cost-effectiveness of |

|                               | as a result of inappropriate access to health care services 2. Variability of consequences by demographic attributes 3. Interrelatedness and multidimensionality of these consequences |  |                         | services, mental<br>health, durable<br>medical equipment)  |  | service   |
|-------------------------------|--|--|-------------------------|--|--|---|
| von Koch<br>et al.<br>(2000b) | To describe the content of a programme involving early hospital discharge and continued rehabilitation at home after stroke  | Original Research: Observation and fieldnotes Quantitative and qualitative descriptive study of an intervention within the context of a RCT; Frequency of visits, duration, content. | 41 patients post stroke | University Hospital<br>Sweden  | Rehabilitation<br>team of six<br>occupational,<br>physical and<br>speech and<br>language<br>therapists         | Organisation and delivery of service                          |
| Dennis <i>et al.</i> (1997)   | Contact with a family care worker  | Original Research; RCT, Barthel, Frenchay (patients and carers), GHQ (patients and carers), HADS (patients and carers), Social adjustment scale (patients and carers), mental        |                         | Inpatient or<br>outpatient attenders<br>with stroke 210<br>(187 successfully<br>followed up) for<br>intervention, 207<br>for control (185<br>successfully<br>followed up). | "A well-organised<br>stroke service in<br>an Edinburgh<br>teaching hospital"<br>(abstract) – good<br>for them! | Great study but shame that intervention wasn't more effective |

|   |   | adjustment to stroke<br>scale, patient and<br>carer satisfaction,<br>caregiver hassle<br>scale |   |   |                  |  |
|---|---|--|---|---|------------------|--|
| von Koch<br>and<br>Widen<br>Holmqvist<br>(2001) | For original research and reviews but not policy documents  "To explore possible differences between a rehabilitation session in the home environment and the hospital, and to study the implementation of the program from the service deliverer's perspective" (Page 123) | Observation and fieldnotes, semistructured Interviews Medical records consulted                | 2 therapists<br>observed<br>In 2 different<br>settings (home<br>and hospital)<br>providing<br>rehabilitation<br>as part of a<br>MDT | Patients in the control group received routine rehabilitation (RRG) Stroke unit until discharge and, if required, in the Geriatrics or Rehabilitation departments as inpatients and/or in day-care or Home rehabilitation (HRG) | MDT stroke rehab | c. Acceptability of service d. Effectiveness of service e. Cost-effectiveness of service |

| Lewinter<br>and<br>Mikkelsen<br>(1995) | For original research and reviews but not policy documents Not specified clearly. Patients interviewed concerning their experience of rehabilitation in an experimental stroke unit. | Interviews coded using successive inductive coding as described by Strauss (Ref 19).  Interview - Semistructured - 45 mins to 2 hours Audio recorded and transcribed.  Transcripts examined to see whether people and events were described in a consistent manner; to consider the extent to which there were internal contradictions; and, by triangulation, to compare the information in the interview with other sources, primarily medical chart data and other interviews. Interviews coded using successive inductive coding as described by Strauss (Ref 19). | 21 stroke patients First time stroke Stroke would be categorised as severe using McCann's categorization (Ref 16). Ages ranged from 36-77 | Kommunehospital's rheumatology department receives patients from the city's hospitals. 8 beds in the wing of the department were set aside for the Experimental stroke unit | Bobath method of rehabilitation (Ref 1) MDT comprising OTs, PTs, nurses and physicians. Additional personnel called in as needed (e.g., speech therapist, social worker and neuropsychologist) |  |
|--|--|--|---|---|--|--|
|--|--|--|---|---|--|--|

| Larsson<br>Lund and<br>Tamm<br>(2001) | For original research and reviews but not policy documents  The purpose of the study was to describe how a group of mainly elderly disabled persons experienced their rehabilitation over a period of time focusing on their interactions with professionals, relatives and the community. | Approach described as "an inductive approach, to allow the informants to describe their experiences in their own words" (Page 97) Interview (specify type of interview if stated e.g. vignette/semi-structured/narrative) Interviews carried out in the informants' own homes by the first author. Interviews started with an open-ended question in which the informants were asked to describe their experiences from the time of the onset of the illness. Interviews lasted from 1 – 2.5 hours and were tape recorded. | N=15 9 men From North Sweden Mean age 58 yrs (30-84) 9 had a stroke 3 had a SCI 3 other diseases | Participants at home Rehab provided in hospital, at home and in the community. | N/A | Acceptability. Description of 3 rehabilitation themes (or chains) – medical, psychological and social. Some aspects of 'acceptability' are considered, but primarily a description of the participants' response (and adaptation) to disability. |
|---------------------------------------|--|--|--|--|-----|--|
|---------------------------------------|--|--|--|--|-----|--|

# Appendix 8 Details of expert-opinion papers based on high-level, sound-basis guidance

| Authors                                 | Type of publication        | Type(s) of data collection used            | Type of service/setting(s) involved | Type of intervention provided to participants | Stated summary of findings  | Any stated implications for SDO specialist neurorehabilitation   | Category(<br>from SDO<br>brief   |
|---|----------------------------|--|-------------------------------------|---|---|--|--|
| NICE Clinical<br>Guideline 35<br>(2006) | NICE Clinical<br>Guideline | Policy Documents - NICE Clinical Guideline | N/A                                 | N/A   | Key priorities for implementation (p4) Regular access for specialist nursing care Access to physiotherapy Access to occupational therapy Access to speech and language therapy Palliative care            | No   | Organisation and deliver service Acceptability of service Effectivene of service   |
| NICE Clinical<br>Guideline 8<br>(2003)  | NICE Clinical<br>Guideline | Policy Documents - NICE Clinical Guideline | N/A                                 | N/A   | Key priorities for implementation (p5) 1. Specialised services 2. Rapid diagnosis 3. Seamless Services 4. Responsive Service 5. Sensitive but thorough problem assessment 6. Self referral unit discharge | 1. Should be available to everyone with MS when needed 2. Every health commissioning organisation should ensure that all orgs. in local health area agree and publish protocols for sharing and transferring responsibility for, | Model of<br>specialist<br>neurologica<br>service<br>Organisatio<br>and deliver<br>service<br>Acceptabilit<br>of service<br>Effectivene<br>of service |

|                                       |   |  |  |  |  | and information about, people with MS 3. Information re contact when no longer under treatment or review. Guidance regards when such contact is appropriate  |   |
|---------------------------------------|---|--|--|--|--|--|---|
| Multiple<br>Sclerosis<br>Trust (2006) | Overview of role of therapists in delivering the quality requirements of the NSF for long-term conditions | Examples of evidence - based good practice; case studies | Outpatient clinic;<br>Rehabilitation service;<br>Community<br>rehabilitation and<br>support; Vocational<br>rehab; social care<br>services. | MS Specialist Team; self- referral; Emergency and acute management; Inpatient rehabilitation; Community based rehabilitation; Vocational rehabilitation; Social services; Palliative care; Families and carers support | Benefits of specialist<br>therapist skills (p11)<br>'Hub and Spoke'<br>model (p11) | Proposals (p05) 1. Commissioners should work with service users and specialist therapists to develop service models providing users with access to specialist therapists in community hospitals and multi agency settings. An expansion of suitably qualified therapists will be required to achieve such services 2. All inter disciplinary teams should have specialist therapy input 3. Models of service delivery should fit local need but 'hub & | Organisation and deliver service Acceptability of service Effectiveners of service Case Studies |

|  |  |   |               |     | spoke' fits well for MS. Department of Health risk sharing scheme - development of MS services should be undertaken in conjunction with these centres 4. Specialist therapists - should provide a bridge between health and social care settings 5. Research should be funded further to develop the evidence base for specialist therapy interventions 6. Studies should be commissioned for local populations that model these proposals |     |
|--|--|---|---------------|-----|--|-----|
| Prime<br>Minister's<br>Strategy Unit<br>(2005) | Policy<br>document -<br>professional<br>body | N/A Professional/expert opinion - Prime Minister's Strategy Group. Representation from DWP, SEU, etc. Early Years Expert Group Independent Living | Not specified | N/A | Not specified -<br>General Department<br>of Health guidelines  | N/A |

|  |  | Expert Group   |     |  |  |   |
|--|--|--|-----|--|--|---|
| National<br>Collaborating<br>Centre for<br>Chronic<br>Conditions<br>(2004) | Policy<br>document -<br>professional<br>body | N/A Systematic review - Titles/abstracts screened for relevance Literature review Professional/expert opinion User views - Study to identify key issues for people with MS in separate document. Key findings summarised in Appendix B of this document (p146) | N/A | From Summary (pxi) Specialist neuro and neuro rehabilitation services 'should be available to every person with MS when they need them' (requirement for appropriate expertise)  Rapid diagnosis important  Need for 'seamless service' - all organisations should agree and publish protocols for sharing and transferring responsibility for information about people with MS.  Responsive service - actively involving service users (pxii) | (pxii) A good service for people with MS would mean a good service to all people with long-term conditions - implications for other services | Model of specialist neurologica service Organisation and deliver service Acceptability of service Effectivene of service Costeffectivene of service |

|  |  |  |                     |     | Advice/Info/availability<br>for self - referral of<br>service user after<br>discharge  |                                     |  |
|--|--|--|---------------------|-----|--|-------------------------------------|--|
| Motor<br>Neurone<br>Disease<br>Association<br>(2003) | Policy<br>document -<br>Motor<br>Neurone<br>Disease<br>Association | Summary of<br>evidence from<br>relevant literature<br>Unsystematic<br>'personal' review -<br>no evidence of<br>systematic review<br>Literature review -<br>recommendations | Specialist Services | N/A | Importance of early diagnosis (para 2) 1 Importance of coordinated specialist services 2 - impact on quality of life for patients with MND if needs not anticipated (para 3) Access to clinical interventions (para 4) 3 Support - needs of informal carers (para 5) 4 | Interventions palliative not rehab. | a. Model of specialist neurologica service b.Organisat and deliver service c. Acceptab of service d. Effectivenes of service b. & d. of k importance |

| Turner-<br>Stokes<br>(2003) | Policy<br>document -<br>professional<br>body | Systematic review, Cochrane review, Other - Pre existing reviews for national stroke and MS guidelines. Literature review, Professional/expert opinion, Users view - representatives of users views Guidelines based on evidence 'so far as resources allow' (p4) Guidelines necessarily rely to a significant degree on expert opinion and consensus - based documents (p5) | Guidelines refer to all these | N/A | Principal themes: pix 1. Coordination and communication between services for ABI 'paramount' 2. Services should be planned in coordinated networks across a geographical area - joint health, social services, liaise with statutory and voluntary services 3. Staffing in rehab and support - adequacy in 'terms of number and experience' 4.Rehab 'should be goal oriented and planned on individual basis' | Improved access to appropriate rehab. services (p6) Long-term nature of some services - need for recognition of |  |
|-----------------------------|--|--|-------------------------------|-----|---|---|--|
|-----------------------------|--|--|-------------------------------|-----|---|---|--|

| Department<br>for Work and<br>Pensions<br>(2006) | Policy<br>Document<br>Department<br>for Work and<br>Pension | Policy document Welfare Reform (relevant section chapter 2) Proposals aim to: 1. Increase the number of people who remain in work when they fall sick or become disabled 2. Increase the number leaving benefits and finding employment 3. Better address the needs of all those who need extra help and support (p24) | All health care professionals                          | N/A | Main relevant proposal: To work more proactively with incapacity benefit claimants with potentially manageable conditions 'balancing their responsibilities to prepare for a return to work with the need to treat them fairly' (p7 - para 23) | None specifically stated, but all health care professionals are expected to engage with and support patients to promote/support policy aims - to improve the 'workfocused' message. (p34-35) Also proposed 'strong links' between GPs, healthcare professionals and direct employment advice | Cost- effectivenes of service Policy document - Cost- effectivenes relates to proposed reduction ir incapacity benefit claimants |
|--|---|--|--|-----|--|--|--|
| Department<br>of Health<br>(2000)                | Policy<br>Document<br>Department<br>of Health               | Context: Response to the Royal Commission on long-term care - 'Set up to examine short and long-term options for a sustainable system of funding long-term care for older people' (at home and in other settings) (p6) To make   | Own home; residential setting; supported accommodation | N/A | NHS nursing care free in all settings (p10) Reform of charging arrangements for residential care (p12) Introduction of national care standards commission (p20)  | None   | Cost-<br>effectivenes<br>of service  |

|  |            | recommendations about cost of care (public/private funding) Also to examine the numbers of people likely to need long-term care, older peoples' expectations and need for cost effectiveness (constraints on public funding) This document represents Government response to 24 recommendations made by the Royal Commission |  |     |     |   |  |
|--|------------|--|--|-----|-----|---|--|
| Inter-agency<br>Advisory<br>Group on<br>Vocational<br>Rehabilitation<br>after Brain<br>Injury (2004) | Guidelines | Executive<br>summary of<br>document  | 1. Specialist brain injury vocational rehab; 2. Occupational Health; 3. Jobcentre Plus 4. 'Other' occupational/educational provision | N/A | N/A | Implementation of guidelines: Key recommendation; staff from local brain injury services, Jobcentre Plus, local councils and independent vocational, occupational and educational providers should: | Organisatio<br>and deliver<br>service<br>Effectivenes<br>of service<br>Cost-<br>effectivenes<br>of service |

|  | <br><u> </u>                          |
|--|---------------------------------------|
|  | <ul> <li>Undertake a joint</li> </ul> |
|  | review of services for                |
|  | people with brain                     |
|  | injury - facilitate                   |
|  | working together,                     |
|  | 'appropriate and                      |
|  | timely access' to                     |
|  | services and identify                 |
|  | gaps in local                         |
|  | provision                             |
|  | • Establish ongoing                   |
|  | service links -                       |
|  | discuss vocational                    |
|  | needs of people with                  |
|  | brain injuries                        |
|  | Adopt a joint                         |
|  | approach to 1.                        |
|  | increasing awareness                  |
|  | of vocational needs                   |
|  | and 2. 'development                   |
|  | of specialist skills                  |
|  | training for all                      |
|  | providers of                          |
|  | vocational                            |
|  | assessment and                        |
|  | rehabilitation                        |
|  |                                       |
|  | services for people                   |
|  | with brain injury'                    |
|  | (pviii)                               |

| Department | Policy   | Quality          | All settings | N/A | 11 quality        | Evidence-based         | Organisatio |
|------------|----------|------------------|--------------|-----|-------------------|------------------------|-------------|
| of Health  | Document | requirements for |              |     | requirements, for | markers of good        | and deliver |
| (2005a)    |          | National Service |              |     | implementation by | practice               | service     |
|            |          | Framework, with  |              |     | 2015              | QR1 - 'Core'           | Acceptabili |
|            |          | 'evidence-based  |              |     |                   | requirement (p19)      | of service  |
|            |          | markers of good  |              |     |                   | QR3 - 'Local ``´       | Effectivene |
|            |          | practice' (p7)   |              |     |                   | hospitals admit        | of service  |
|            |          |                  |              |     |                   | people transferred     |             |
|            |          |                  |              |     |                   | from specialist and    |             |
|            |          |                  |              |     |                   | neuroscience centres   |             |
|            |          |                  |              |     |                   | to suitable wards or   |             |
|            |          |                  |              |     |                   | facilities where any   |             |
|            |          |                  |              |     |                   | necessary ongoing      |             |
|            |          |                  |              |     |                   | neurological care,     |             |
|            |          |                  |              |     |                   | supervision or         |             |
|            |          |                  |              |     |                   | rehabilitation can be  |             |
|            |          |                  |              |     |                   | appropriately          |             |
|            |          |                  |              |     |                   | provided Qr3.5         |             |
|            |          |                  |              |     |                   | (Expert opinion not    |             |
|            |          |                  |              |     |                   | evidence based)        |             |
|            |          |                  |              |     |                   | (p30)                  |             |
|            |          |                  |              |     |                   | QR4 - Improved         |             |
|            |          |                  |              |     |                   | access to              |             |
|            |          |                  |              |     |                   | rehabilitation QR4.2   |             |
|            |          |                  |              |     |                   | - Seamless             |             |
|            |          |                  |              |     |                   | transition of care     |             |
|            |          |                  |              |     |                   | QR4.3 (Research        |             |
|            |          |                  |              |     |                   | based evidence)        |             |
|            |          |                  |              |     |                   | (p34)                  |             |
|            |          |                  |              |     |                   | QR5 - Local            |             |
|            |          |                  |              |     |                   | multidisiplinary       |             |
|            |          |                  |              |     |                   | rehabilitation and     |             |
|            |          |                  |              |     |                   | support are provided   |             |
|            |          |                  |              |     |                   | in the community by    |             |
|            |          |                  |              |     |                   | professionals with     |             |
|            |          |                  |              |     |                   | the right skills and   |             |
|            |          |                  | 1            | 1   |                   | i the right skills and |             |

| F | • |   |   |                       |  |
|---|---|---|---|-----------------------|--|
|   |   |   |   | experience (include   |  |
|   |   |   |   | access to specialist  |  |
|   |   |   |   | neurological          |  |
|   |   |   |   | evidence, eg neuro-   |  |
|   |   |   |   | rehabilitation)QR5.2  |  |
|   |   |   |   | (Research based       |  |
|   |   |   |   | evidence) (p38)       |  |
|   |   |   |   | QR6 - Refer people    |  |
|   |   |   |   | with neurological     |  |
|   |   |   |   | conditions who have   |  |
|   |   |   |   | more complex          |  |
|   |   |   |   | occupational need to  |  |
|   |   |   |   | specialist vocational |  |
|   |   |   |   | services (QR6.2)      |  |
|   |   |   |   | (Research based       |  |
|   |   |   |   | evidence) (p42)       |  |
|   |   |   |   | QR7 - Assistive       |  |
|   |   |   |   | technology, work      |  |
|   |   |   |   | closely with neuro    |  |
|   |   |   |   | and rehabilitation    |  |
|   |   |   |   | services QR7.2        |  |
|   |   |   |   | (Research based       |  |
|   |   |   |   | evidence) (p46)       |  |
|   |   |   |   | QR8 - Care in all     |  |
|   |   |   |   | settings -            |  |
|   |   |   |   | appropriately trained |  |
|   |   |   |   | nursing, therapy and  |  |
|   |   |   |   | care staff with       |  |
|   |   |   |   | experience in         |  |
|   |   |   |   | managing long-term    |  |
|   |   |   |   | neurological          |  |
|   |   |   |   | conditions (Expert    |  |
|   |   |   |   | opinion) (p50)        |  |
|   |   |   |   | QR9 - Specialised     |  |
|   |   |   |   | neurology,            |  |
|   |   |   |   | rehabilitation and    |  |
|   | 1 | 1 | ı |                       |  |

|                                    |                                  |   |  |  | palliative care multidisciplinary teams work together to provide care for people with advanced long-term neuro conditions QR9.1 (Evidence based) - Specialised neurological and community rehabilitation services provide support, advice and training for all staff providing palliative care in the community (QR9.2) (Research based evidence) (p54) QR11 - Specialist neurosciences, rehabilitation and spinal cord injury services are involved in providing advice and training for staff in general hospital and other care setting QR11.4 (Research based |                                       |
|------------------------------------|----------------------------------|---|--|--|---|---------------------------------------|
| Department<br>of Health<br>(2006a) | Government<br>Policy<br>Document | Document: 'Explains how health and social | All Local Strategic<br>Partnerships,<br>Partnerships Building, | Positive benefits for patients of self care (p7) | evidence) (p61)  None explicit but: Multidisciplinary teams; Use of   | Organisatio<br>and deliver<br>service |

|                                    |   |  | -                        |     | -  | _  |  |
|------------------------------------|---|--|--------------------------|-----|--|--|--|
|                                    | Department<br>of Health                                     | care services can support self care through an integrated package consisting of a range of elements at a local level' Includes self care information, self monitoring devices, self care skills education and training and self care support networks (p7)                                 | Expert Patient Programme |     | Positive benefits to the health service (p8)   | information to<br>support self care (for<br>patients and<br>professionals)<br>Partnership building | Acceptability of service Effectiveness of service Costeffectiveness of service   |
| Department<br>of Health<br>(2005b) | Government<br>Policy<br>Document<br>Department<br>of Health | Proposals for reducing dependency where possible; empowering service users, involving in assessment and increasing choice; improving access to services; shift focus of delivery to more proactive and preventative model; supporting carers; social care workforce training and standards | Community                | N/A | Key role for Local Authorities and social services. Local Authorities must 'give high priority to the inclusion of all sections of the community and other agencies, including the NHS, recognise their own contribution to the agenda' (p9). Also direct payments, individual budgets, service improvement and delivery, workforce training, performance management, and working with the | None   | Organisatio<br>and deliver<br>service<br>Acceptabilit<br>of service<br>Effectivenes<br>of service<br>Cost-<br>effectivenes<br>of service |

|                                    |  |                |                                       |  | voluntary sector (p10-14) |  |   |
|------------------------------------|--|----------------|---------------------------------------|--|---------------------------|--|---|
| Department<br>of Health<br>(2002a) | Policy<br>document<br>Specialised<br>services<br>national<br>definition<br>Department<br>of Health | Definition set | Specialist Rehabilitation<br>Services | Nor<br>prescriptive<br>(p1)<br>Definitions<br>set (2nd<br>edition) | Basis for service review  | Close integration of<br>services that do exist<br>is necessary to leave<br>as few gaps as<br>possible' (p11) | Organisatio<br>and deliver<br>service<br>Effectivenes<br>of service<br>Commission<br>- Policy and<br>Guidance |

# Appendix 9 Details of expert-opinion papers, clinical and academic

| Authors                | Aims | Methodology<br>Type(s) of data<br>collection used  | Sample  | Type of service/setting(s) involved                                | Type of intervention provided to participants  | Category (s) relating to SDO themes |
|------------------------|------|--|---|--|--|-------------------------------------|
| Cadilhac et al. (2006) |      | I assume descriptions were either written up concurrently with the process of development of concept, or retrospectively gathered from records and reflection. | National public health programme in Australia Stroke care experts, state and federal government and consumer representatives (pp111) Staff (n=12) from 4 demonstration hospitals which did have stroke units already Then for feasibility study Two sites in Victoria and two sites in Queensland consulted about perceptions | Integrated stroke model covering geographically spread client base | Developing a model of practice using literature evidence, expert opinion and collection of data from stroke units already up and running Also collect perceptions of facilitators and barriers to an integrated stroke model. Also collect perceptions of facilitators and barriers to an integrated stroke model. |                                     |

| Das Gupta<br>and Turner-<br>Stokes<br>(2002) | For original research and reviews but not policy documents n/a   | Unsystematic 'personal' review; An educational article outlining the principles of management of severe traumatic brain injury (TBI) from a practical clinical viewpoint also includes a brief review of evidence for effectiveness of rehabilitation in severe TBI                             | TBI                    | Acute post-acute and long-term rehabilitation and support for TBI  | Interdisciplinary<br>team<br>rehabilitation<br>and support | Expert opinion/commentary - academic/clinician  |
|--|--|---|------------------------|--|--|---|
| Hale (2004)                                  | Claims p131 to review "current literature on stroke rehabilitation in the community and debates the issue as to whether it is truly community-based or just merely an extension of institutionalised care" | Unsystematic 'personal' review, Descriptive overview of research to date, both trials and qualitative and grey literature on different forms of stroke rehabilitation delivery that is outside hospitals. they raise issues of patient and carer perspectives, as well as effectiveness studies | Context is New Zealand | p132 Discusses the WHO definitions round community based rehabilitation that involves the idea that community based rehabilitation involves community development, social integration for people with disabilities, and delivered through combined efforts of users carers and services in health, education, vocation and social services |  | Proposal, model of service/not just description of current services Expert opinion/commentary - academic/clinician, review. Outcome evaluation - primary qualitative research |

| Watson and<br>Quinn (1998)      | To describe a model for stroke rehabilitation (holistic, multidisciplinary, integrated) that helps all those involved with stroke rehab to feel more in control of treatment choices and gain a sense of future. | Professional/expert opinion  | N/A   | Stroke rehabilitation                                       | Multidisciplinary<br>with carers and<br>patients | Proposal, model of service/role/intervention  |
|---------------------------------|--|--|---|---|--|---|
| Mackay <i>et al.</i> (1995)     | "Reviews the literature and draws on the experience of local innovations in South London to suggest alternative models of care that could be evaluated." p502  | Unsystematic<br>'personal' review  | Stroke<br>review<br>authored by<br>people from a<br>number of<br>different<br>clinical<br>backgrounds | Stroke units<br>stroke community<br>rehabilitation          | Stroke<br>rehabilitation                         | Expert opinion/commentary - academic/clinician  |
| Stuart and<br>Zafonte<br>(2004) | Not stated   | Description by someone from a Department of Sociology and Anthropology! Observation and fieldnotes; Description of planning, funding | N/A   | Statewide program in<br>Florida for individuals<br>with TBI | Case management?                                 | Proposal, model of<br>service/role/intervention<br>Expert<br>opinion/commentary -<br>academic/clinician |

|                           |   | stream, organisation, management of information, etc. No outcome or evaluative information  |     |  |  |   |
|---------------------------|---|---|-----|--|--|---|
| Ward <i>et al.</i> (2003) | N/A   | Professional/expert opinion, Three rehabilitation specialists and someone from social services critically review service provision from their perspective                                       | N/A | Multidisciplinary<br>services for<br>progressive<br>neurological<br>conditions | Multidisciplinary!<br>(includes<br>psychiatry and<br>genetics) | Proposal, model of service/role/intervention Expert opinion/commentary - academic/clinician |
| Wade (2003)               | N/A   | a. Professional/expert opinion, Supported by evidence from published literature   | N/A | Community<br>rehabilitation<br>services  |  | Expert opinion/commentary - academic/clinician  |
| Holmes<br>(2005)          | Tries to illustrate how the 11 QRs from the NSF apply to the support and practical care of people with MND. | Professional/expert opinion, Tries to illustrate how the 11 QRs from the NSF apply to the support and practical care of people with MND. Uses hypothetical cases demonstrating typical problems | N/A | Rehabilitation<br>services for people<br>with MND                              | N/A  | Expert opinion/commentary - academic/clinician  |

|                    |  | (eg Dysphagia) to<br>do so.                           |   |  |   |  |
|--------------------|--|---|---|--|---|--|
| Shue (1993)        | For original research and reviews but not policy documents Not research but the object of the model is to 'facilitate the return of braininjured individuals from US rehab facilities to their home communities in Ontario. The purpose of the paper is to describe the collaborative model of service delivery. | N/A   | N/A – not participants  10 people with brain injuries were selected to pilot the collaborative model of service delivery. | US rehabilitation facilities           | The model described incorporates inpatient rehabilitation, long-term community-based care | Expert opinion/commentary - academic/clinician |
| Bakheit<br>(1995). | N/A  | Unsystematic 'personal' review Descriptive/ synthesis | N/A   | An integrated hospital-community model | An integrated hospital-community model  | Expert opinion/commentary - academic/clinician |
| Burke (1995)       | "A range of  | Unsystematic  | N/A   | Several models are                     | Brain injury  | Expert   |

|  | models of specialised brain injury rehabilitation programmes has evolved. It is the purpose of this review to describe these, and to discuss their relationship with each other" (p736) | 'personal' review<br>Descriptive/<br>synthesis   |   | described and compared, including:  The comprehensive centre Cognitive rehabilitation Behaviour rehabilitation Slow-stream rehabilitation Coma arousal programme Acute rehabilitation Outpatient rehabilitation Transitional rehabilitation Vocational rehabilitation Children's' services | rehabilitation   | opinion/commentary -<br>academic/clinician  |
|--|---|--|---|--|--|---|
| Department<br>of Health<br>(2003)<br>NHS<br>Changing<br>Workforce<br>Programme,<br>2nd edn | N/A   | Grey area - review of services for stroke victims and their carers under NHS Changing Workforce Programme. Examples of education and work across healthcare disciplines and in different contexts (e.g. hospital, community) sharing | Pilot site for<br>NHS Changing<br>Workforce<br>Programme<br>(stroke care) | All healthcare settings: Emergency, hospital, community, voluntary sector Dysphasia and Dysphasia specialist support; Emotional support family support Mental health; Younger stroke patients; Advocacy; Health information and prevention   | Specialist stroke<br>services;<br>Community<br>follow up and<br>rehabilitation | Organisation and delivery of service Acceptability of service Effectiveness of service None explicit re cost effectiveness but implications re commissioning tasks/roles and use of specialist staff to inform/train other groups |

|                                     |  | expertise                         |   |                          |   |
|-------------------------------------|--|-----------------------------------|---|--------------------------|---|
| Barnes and<br>Radermacher<br>(2001) | p244 "This review article summarizes some of the models of community rehabilitation and the evidence for their effectiveness." | a. Unsystematic 'personal' review | Disabled persons in the community across a range of countries | Community rehabilitation | Models reviewed include Multidisciplinary teams in terms of early discharge schemes, hospital at home Care management (p246) The individual therapist in the community (p246) Nursing intervention (p246-7) Other interventions (p247) Notes two other services – referrals facilitator working between primary care and voluntary sector (p247), specialist care attendants on discharge of elderly people from hospital and providing |

|                 |   |  |  |           | care for two<br>weeks (p247)  |  |
|-----------------|---|--|--|-----------|---|--|
| Inman<br>(1999) | "Current research is aimed at teasing apart the aspects of different care models that are most effective, or the evidence for the usefulness of interventions for control of symptoms such as spasticity and pain. This evidence is reviewed and discussed"  (Page 25 – Abstract) | Unsystematic literature review – publication dates from 1965-1997). Findings of previous studies, surveys, hospital statistics and/or databases summarised in connection with the following topics: • incidence of SCI (source – hospital stats from Midlands Centre for Spinal Injuries) • impact of early admission on . pressure sores (source – hosp | Spinal Cord Injury Patients (SCI). Sample size variable As a review of literature. | SCI Units | SCI Unit delivered rehab and * ambulatory devices * neural stimulators * spasticity and pain mgt (intrathecal phenol, medication, electrical stimulation) | Expert opinion and discussion of findings obtained in other studies (i.e., review) |

|                                   |  | stats from Univ of Alabama SCI System) • contractures • impairment (source – National SCI database for the USA) • disability • impact of age on outcome • discharge venue • outcome in the community • transport • vocational outcome social relationships |     |   |                |   |
|-----------------------------------|--|--|-----|---|----------------|---|
| Johnson and<br>Thompson<br>(1996) | For original<br>research and<br>reviews but not<br>policy documents<br>N/A | N/A Results reported from an earlier audit of 135 admissions – neurorehabilitation unit Patients (Freeman et al., 1995) Number/% admitted from: Nursing/residential home/other rehab unit Acute hospital Home Number/%                                     | N/A | Neurorehabilitaiton<br>unit<br>(National Hospital for<br>Neurology and<br>Neurosurgery) | MDT Neurorehab | x. Expert opinion/commentary - academic/clinician |

|  | discharged to: |  |  |
|--|----------------|--|--|
|  | As above       |  |  |

# Appendix 10 Details of surveys of provision papers

| Authors                    | Aim   | Methodology<br>Type(s) of data<br>collection used  | Sample   | Type of service setting(s) involved                              | Type of service provision   | Category(s)<br>from SDO brief                                 |
|----------------------------|---|--|--|--|---|---|
| Deane <i>et al.</i> (2003) | to discover information pertaining to 'standard' occupational therapy for Parkinson's disease (PD)  | Mixed methods:<br>Postal survey Content<br>analysis and<br>descriptive stats.  | Occupational<br>therapists (160)<br>working with<br>people with PD       | Outpatient, social services and inpatient settings across the UK | Occupational Therapy<br>for PD, mostly in NHS<br>and some in social<br>services | Organisation and delivery of service                          |
| Scheer et al. (2003)       | To examine access barriers to primary, specialist and rehabilitative care and their consequences for individuals' health, functioning and wellbeing and health services' utilisation. | Qualitative: Semi-structured Interviews as Part of national (US) survey of 537 working adults. Thematic coding". using Nvivo. Thematic coding" using Nvivo | 30 working age individuals with spinal cord injury, cerebral palsy or MS | Primary, specialist<br>and rehabilitative<br>care in the US      | primary, specialist and rehabilitative care                                     | Organisation and delivery of service Acceptability of service |
| Barnes<br>(1997b)          | To produce report on<br>the state of<br>neurological rehab in<br>Europe<br>to recommend<br>standards for<br>provision of neuro<br>services for disabled<br>people                     | Qualitative:<br>Questionnaire Survey<br>of each European<br>member country   | Replies received from 18 countries                                       | Neurological<br>rehabilitation<br>services in Europe             | N/A   | Organisation and delivery of service                          |

| Botterell<br>et al.<br>(1975)        | Review of past experience in order to develop model of care. Most questions applied to acute phase but for rehabilitation:  a. What is the course for all patients?  b. how successful? | Interview, Questionnaire, available ambulance records, interviews with patients and physicians, review of patients' hospital records. All data entered on to questionnaire. Total hospital costs. | 244 injuries   | Everything from<br>time of incident<br>(ie ambulance,<br>acute care, rehab | Doesn't describe regional rehabilitation centres   | Model of<br>specialist<br>neurological<br>service  |
|--------------------------------------|---|---|--|--|--|--|
| O'Connor<br>and<br>Delargy<br>(2006) | To describe a YDU.  | Original Research Observation and fieldnotes All patients in one YDU Peamount Hosp, Co. Dublin Review of health records, collection of biographical and demographic details.                      | 42 YDU patients Based in 1 centre. TBI (n=13), Subarachnoid haemorrhage and non-h stroke (n=11) Non-T acquired brain inj (n=7), MS (n=2), Central pontine myelinosis (n=2) | YDU  | 24 hour care Accommodation provided in 2 single storey buildings Mix of single, double and 4 bed bedrooms Communal areas for dining and recreation Quiet rooms for relaxation or privacy Input from a consultant and registrar in rehab med. General medical staff of Peamount Hosp provide 24 hr care. Physio and recreational therapy also provided. | Model of specialist neurological service: Description of one YDU and the characteristics of the patients |
| Vaughn<br>and King<br>(2001)         | Lots but they were particularly concerned with origin of funding.   | Qualitative Telephone<br>Survey of US State<br>Head Injury program<br>Administrators  | Contacts for all<br>20 states<br>administering<br>state programs<br>for individuals  | State funded TBI<br>Programs in the<br>US                                  | Examine state funded programs to discover impact on services, and the service delivery system for individuals  | Survey of current services (e.g. across a region)  |

|  |                |   | with TBI |   | with TBI and their families   |   |
|--|----------------|---|----------|---|---|---|
| Multiple<br>Sclerosis<br>Trust<br>(2006) | None specified | A report on the role of<br>therapists in the<br>management of MS,<br>Describes the<br>therapists role,<br>proposals for therapy<br>services | N/A      | Outpatient clinic;<br>Rehabilitation<br>service;<br>Community<br>rehabilitation and<br>support;<br>Vocational rehab;<br>social care<br>services. UK | MS Specialist Team; self-referral; Emergency and acute management; Inpatient rehabilitation; Community based rehabilitation; Vocational rehabilitation; Social services; Palliative care; Families and carers support | Organisation and delivery of service Acceptability of service Effectiveness of service Case Studies |

# Appendix 11 Details of descriptive evaluations, audits and surveys

| Authors                            | Aim   | Methodology<br>Type(s) of data<br>collection used  | Sample                                       | Type of service/setting(s) involved   | Type of intervention provided to participants   | category (s) from<br>SDO brief)                       |
|------------------------------------|---|--|--|---|---|---|
| Sheriff and<br>Chenoweth<br>(2003) | To describe PD research project, difficulties in conducting research, make suggestions for research | Quasi experimental: Pre and post comparison in one group using Questionnaire/survey and "Notes" on Health and functional status, UPDRS* "health questionnaire" , "Carer health questionnaire", "cost- analysis procedures" UPDRS* Unified Parkinson's Disease Rating Scale | 25 mid-stage<br>PD and 25 of<br>their carers | Multidisciplinary o/p<br>therapy and<br>education research<br>programme for<br>Parkinson's in the<br>UK | Individualised programmes with multi disciplinary rehab staff. Counselling support for carers Group targeted education and training to include carers | Acceptability of service,<br>Effectiveness of service |

| Holloway<br>(2006)                    | To develop and implement the tools for a Care Pathway framework for people with Parkinson's disease (PD) in which the patient and/or the carer are the communications centre, resourced and supported by the professionals to achieve their own integrated package of care. To elicit a simplified system of referral and more effective communication. | Mixed methods: Semi-<br>structured interviews,<br>also collected data on<br>patient characteristics,<br>social circumstances,<br>severity of illness, and<br>recent/current use of<br>services. Also<br>neurologist and<br>Parkinson's disease<br>specialist nurse were<br>interviewed. | Convenience sample of 22 people with PD over 12 months aged 50-84 yrs old, average 10 years since onset 3 mild, 11 mild to mod, 7 mod, 1 mod to severe on Hoehn and Yahr 17 male 5 female | Community care pathway for PD in the UK  | Care Pathway approach to management of PD in the community                      | Model of specialist neurological service Organisation and delivery of service Acceptability of service Effectiveness of service |
|---------------------------------------|---|---|---|--|---|---|
| Rossiter<br>and<br>Thompson<br>(1995) | To trial the use of ICPs in a non-acute setting   | Original Research, Documents for 13 integrated care pathways (completed for 13 patients with MS) were inspected.  | Integrated care pathways documents completed for 13 patients with MS.   | UK Inpatient neurorehabilitation setting – The National Hospital for Neurology and Neurosurgery. | MDT<br>Assessment<br>and short-term<br>Rehabilitation<br>(usually 2-6<br>weeks) |   |

| Warner <i>et al.</i> (2005)   | Can you improve<br>the quality of<br>service to people<br>experiencing a<br>relapse of MS?  | Qualitative: Action research, Carried out initial audit of treatment times, type of treatment (day or inpatient) and discharge times. Repeated after intervention. Also interviewed patients for their experience. | People experiencing a relapse of MS. 46 in initial audit but no numbers mentioned for follow up.  | UK District General<br>Hospital  | Relocation to neurology department; develop treatment protocol; specialist nurse telephone helpline and relapse review clinic. More day case management. For original research and reviews but not policy documents | Proposal, model of service/role/intervention Action research   |
|-------------------------------|---|--|---|--|---|--|
| Barnes and<br>Skeil<br>(1996) | "This paper discusses the experience of working within a multidisciplinary neurological clinic in a regional rehabilitation centre." includes number and types of interventions described | Mixed methods: Retrospective survey of aspects of a service and questionnaire to patients on their views and preferences   | Demographic data and diagnostic data describing 77 patients newly referred to Hunters Moore rehabilitation centre disability clinic descriptive data on service – problems recorded, type and number of interventions | Patients referred to<br>Hunters Moore (UK)<br>rehabilitation centre<br>disability clinic April<br>1992- April 1993 | Outpatient<br>specialist<br>disability clinic   | Organisation and delivery of service, Acceptability of service |

|   |   |   | questionnaire<br>data on<br>patients' views<br>and preference<br>for clinic<br>format  |  |                          |  |
|---|---|---|--|--|--------------------------|--|
| Commission<br>for<br>Healthcare<br>(2006) | To find out what patients who have had a stroke thought about the care they received after leaving hospital | Questionnaire/survey  | Follow up<br>survey to 2004<br>survey of 1700<br>patients in 51<br>NHS acute<br>hospital trusts<br>in England.<br>Stroke<br>patients.<br>Current study<br>surveyed<br>participants in<br>2004 study.<br>875 completed<br>questionnaires<br>returned - 75%<br>response rate | NHS acute hospital trusts Community rehab service UK | Stroke<br>rehabilitation | Organisation and delivery of service Acceptability of service  |
| Barker<br>(2006)                          | N/A   | Policy document: Professional/expert opinion, user views Includes experiences of 30 stroke survivors and experiences of callers to helpline | Working age<br>stroke<br>survivors   | UK   | N/A                      | Model of specialist<br>neurological service<br>Organisation and<br>delivery of service<br>Acceptability of service<br>Effectiveness of service<br>Cost effectiveness of<br>service |

| Keaton <i>et al.</i> (2004) |  | Qualitative: Friedemann's framework of systematic organisation Original research E-mail questions from care-givers; Responses from nurse specialist and E-rehabilitation team | 6 male care- givers; 7 women care- givers. Aged 31-77 Care recipients: 6 men 7 women (p6) | Web based resource | Education and advice | Model of specialist<br>neurological service<br>Organisation and<br>delivery of service<br>Effectiveness of service<br>Cost-effectiveness of<br>service<br>Carer support |
|-----------------------------|--|---|---|--------------------|----------------------|---|
|-----------------------------|--|---|---|--------------------|----------------------|---|

# Appendix 12 Details of descriptions of services and service innovations

| Author(s)                            | Aims   | Research design<br>and method of data<br>collection                                   | Sample                          | Type of service/setting(s) involved | Type of intervention provided to participants | Category(s)<br>from SDO brief |
|--------------------------------------|--|---|---------------------------------|-------------------------------------|---|-------------------------------|
| Moskowitz<br>and<br>Marder<br>(2001) | Clinical characteristics are reviewed in this article, followed by a discussion of therapeutic approaches that are effective in the middle and late stages of Huntington's disease (HD). (NB: there are few published studies on long- term care of patients with HD and none on palliative care.) | Unsystematic 'personal' review 39 references. Summary of findings of previous studies | Late stage Huntington's disease | Nursing home care                   | Several interventions discussed               |                               |

| Sheriff and<br>Chenoweth<br>(2003) | Describe PD research project, difficulties in conducting research, make suggestions for research  | Pre and post comparison in one group using Questionnaire/survey and "Notes" on Health and functional status, UPDRS* "health questionnaire", "Carer health questionnaire", "costanalysis procedures" UPDRS* Unified Parkinson's Disease Rating Scale | 25 mid-stage PD and<br>25 of their carers | Multidisciplinary<br>outpatient therapy<br>and education<br>research programme<br>for Parkinson's  | Individualised programmes with md rehab staff. Counselling support for carers Group targeted education and training to include carers   | a. Acceptability<br>of service b.<br>Effectiveness of<br>service  |
|------------------------------------|---|---|---|--|---|---|
| Burke <i>et al.</i> (2000)         | Purpose (p463) To encourage specialist brain injury services to offer extended rehabilitation programmes to patients, even with very severe injuries" p464 to report case study of "a patient who has undergone a long and intensive (and expensive) rehabilitation programme after suffering a severe TBI." to | Descriptive case study, description of clinical case, data collection unclear assume retrospective notes review   | One female with severe brain injury       | Interdisciplinary Team in a specialist private long-term rehabilitation unit in Australia, Private inpatient hospital, paid for from road accident compensation authority in Australia Intensive and specialist services in: Neuro-Surgery Neurology Physiotherapy Music therapy Psychology Orthopaedic surgery (tendon surgery) Recreation therapy Occupational therapy | Details listed include: Baclofen pump Botox Repeated testing of cog, swallowing, eye tracking, communication Tracheostomy Peg Communication board Elongation of Achilles tendon Mobility rehabilitation Self care rehabilitation Part time integration back | g. Model of specialist neurological service h. Organisation and delivery of service i. Acceptability of service j. Effectiveness of service |

| illustrate the outcome | Nursing Outpatient physio, OT and speech therapy Staff to perform video fluoroscopy and similar Surgeon –peg feeding otorhynologist | into school through liaison with school, and presence of an assistant in school Use of computer for communication Speech and breathing exercises Group speech |
|------------------------|---|---|
|                        |   | breathing exercises Group speech therapy for conversation skills Playing musical instruments Song writing Song listening Augmented                            |
|                        |   | communication device Switch device Electric wheelchair Adaptation of home Outpatient therapy programme  |

| Dowswell et al. (2000)       | to capture details about support provided by the specialist nurses, to gain further insight into the process of care and enhance understanding of the principal problems facing stroke patients and their carers in the first year following stroke' (p161) Also to improve understanding of the process of the intervention for future development of the approach for stroke rehabilitation | Diaries (specialist nurses) | Specialist nurses providing support in the year following stroke. Comprehensive written records of involvement with all patients and their carers in randomized controlled trial. 101 complete records | Community - patients' own homes                            | Specialist nurse support - information, advice. Support and monitoring - flexible, individualised approach (p160)             | Organisation and delivery of service Effectiveness of service |
|------------------------------|---|-----------------------------|--|--|---|---|
| Hintgen <i>et al.</i> (2000) |   | Descriptive                 | Community volunteers in a patient focused service delivery system  | Inpatient and outpatient neuroscience and trauma programme | Volunteer training in communication; mentoring of volunteers. Volunteers also draw from survivors of traumatic brain injury - | Innovative use of volunteers in rehabilitation                |

|                    |   |                  |   |   | mentored and<br>trained by<br>experienced<br>staff         |   |
|--------------------|---|------------------|---|---|--|---|
| Holloway<br>(2006) | 'Care pathway framework' detailed on pp65 three elements: An information pack on social care locally, community health and hosp services, local voluntary groups, PD society, welfare rights info A Care Pathway Folder containing problems and needs forms – list sorts of problems and a likert scale for marking degree of problems and needs, also Clinic Summary forms, and service contact sheets one or more members of clinic staff who | Content analysis | Before and after study, on a convenience sample of 22 people with PD over a 12 month period. semistructured interviews, collected data on patient characteristics, social circumstances, severity of illness, and recent/current use of services" pp64 some interviews with partner present, some without partner/carer present | 22 participants convenience sample – letter sent to those on list for a consultant neurologist's outpatient list 21 of these had a partner participants ranged from 50-84 yrs old (pp64) with PD for average 10 years 3 mild, 11 mild to mod, 7 mod, 1 mod to severe on Hoehn and Yahr 17 male 5 female Also neurologist and Parkinson's disease specialist nurse were interviewed. | Care Pathway approach to management of PD in the community | The model includes some innovative ideas particularly regarding the holding of records and the structuring of information provision and communication between patients carers and services. The idea of the patient and carer as communications centre met with apparently mixed success. With problems particularly in getting service providers to fillin the services recording form, and possibly though this is not explicitly |

| use and complete the documentation  Premise of the pathway was the idea that the patient and carer are the communications centre.  Some elements of the especially the Problems and needs form which was taken along to clinics was particularly well received by professionals and patients, and it would have been hard, quantitatively to identify some of the benefits (e.g., making it easier to raise sensitive issues in clinic, giving doctor information that resulted in him asking medical students to leave without the patient having to ask for this.  The model bowever awaits.                                    |                | <br> | <br> |                   |
|---|----------------|------|------|-------------------|
| documentation  Premise of the pathway was the idea that the patient and carer are the communications centre.  Some elements of the intervention especially the Problems and needs form which was taken along to clinics was particularly well received by professionals and patients, and it would have been hard, quantitatively to identify some of the benefits (e.g. making it easier to raise sensitive issues in clinic, giving doctor information that resulted in him asking medical students to leave without the patient having to ask for this.  The model   | use and        |      |      | discussed,        |
| documentation  Premise of the pathway was the idea that the patient and carer are the communications centre.  Some elements of the intervention especially the Problems and needs form which was taken along to clinics was particularly well received by professionals and patients, and it would have been hard, quantitatively to identify some of the benefits (e.g. making it easier to raise sensitive issues in clinic, giving doctor information that resulted in him asking medical students to leave without the patient having to ask for this.  The model   | complete the   |      |      |                   |
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|   |                |      |      | ask for this.     |
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| i i i i i i i i i i i i i i i i i i i   |                |      |      | however awaits    |

|                              |                    |   |  |                             |   | robust evaluation whether quantitative or qualitative.  |
|------------------------------|--------------------|---|--|-----------------------------|---|---|
| Keaton <i>et al.</i> (2004)  |                    | Friedemann's framework of systematic organisation Original research E-mail questions from care-givers; Responses from nurse specialist and E-rehabilitation team  | 6 male care-givers;<br>7 women care-givers.<br>Aged 31-77<br>Care recipients:<br>6 men<br>7 women (p6) | Web based resource          | Education and advice  | Model of specialist neurological service Organisation and delivery of service Effectiveness of service Costeffectiveness of service Carer support |
| Kendall <i>et al.</i> (2003) | Descriptive review | p1464 states they undertook an "extensive literature review" and they conceptualized and implemented a new model of service in the context of Australian SCI rehabilitation 1008 "This paper discusses the factors influencing development of [a transitional | Spinal cord injury<br>Australia  | Transitional rehabilitation | transitional rehabilitation for SCI p1008 "a time-limited, community based service that assists individuals in their home or home-like settings by utilizing a flexible and | a. Model of specialist neurological service   |

| 1                         |  |                   | 1 |
|---------------------------|--|-------------------|---|
| rehabilitation service    |  | client-focussed   |   |
| for SCI] and the          |  | model of service  |   |
| nature of this new        |  | delivery"         |   |
| service delivery          |  | designed to facil |   |
| model."                   |  | early discharge   |   |
| no methodology or v       |  | from hospital.    |   |
| clear report of lit       |  |                   |   |
| review given. Nor         |  | discussions       |   |
| methodologically how      |  | between team      |   |
| the model was set up      |  | and patient prior |   |
| in light of the findings. |  | to hosp           |   |
| rather a general          |  | discharge into    |   |
| discussion of context     |  | the transitional  |   |
| to the model              |  | rehabilitation    |   |
| to the model              |  |                   |   |
|                           |  | programme         |   |
|                           |  | (p1011)           |   |
|                           |  | includes writing  |   |
|                           |  | and signing of a  |   |
|                           |  | written contract  |   |
|                           |  | including .       |   |
|                           |  | programme plan    |   |
|                           |  | and dates for     |   |
|                           |  | commencing        |   |
|                           |  | and achieving.    |   |
|                           |  | (p1012)           |   |
|                           |  | appointment of    |   |
|                           |  | a case            |   |
|                           |  | coordinator       |   |
|                           |  | (p1012)           |   |
|                           |  | team work and     |   |
|                           |  | therapy and       |   |
|                           |  | equipment         |   |
|                           |  | related           |   |
|                           |  | interventions.    |   |
|                           |  |                   |   |

| Steiner<br>and Pierce<br>(2002) | N/A | Descriptive - survey<br>element - online<br>feedback | Care-givers of stroke patients | Web based information and support for caregivers of people with stroke   | 1. Ask a nurse - specialist and rehabilitation team 2. Caretalk - email discussion list 3. Educational information - e.g. nutrition, care-giver stress 4. Links to information about stroke, caring and caregivers (p103) |  |
|---------------------------------|-----|--|--------------------------------|--|---|--|
| La Marche <i>et al.</i> (1995)  | N/A | N/A  | N/A                            | Interactive Community-based Model (ICBM) of vocational rehabilitation A component of the Southeastern Comprehensive Head Injury Centre (SCHIC) The ICBM is a "criterion-based, five-phase vocational rehabilitation program designed to maximise employment, independence, and quality of life | N/A   | Model of specialist neurological service |

|                                       |   |  |   | through community reintegration of adults with TBI and their families." (Page 81) Phase 1 – Home-based evaluation and treatment Phase 2 – Community and work activities Phase 3 – Work-related activities Phase 4 – Work placement Phase 5 – Maximal vocational performance |   |  |
|---------------------------------------|---|--|---|---|---|--|
| Rossiter<br>and<br>Thompson<br>(1995) | To trial the use of ICPs in a non-acute setting | N/A, Original Research, Documents, 13 integrated care pathways (completed for 13 patients with MS) were inspected. The incidence of variance (ie., occasions when actions departed from the pre-mapped ICP) was noted for each pathway and related to one of 40 codes (these were categorised into 4 | The integrated care pathways completed for 13 patients with MS.  Age range 23-50yrs Average age 38yrs All the patients had reached the secondary progressive stage of the disease.  There was a wide range of duration of the disease from 10 months to 23 years. | Inpatient neurorehabilitation setting – The National Hospital for Neurology and Neurosurgery. Unit staffed by: • Neurologist • SHO • Nurse manager • Clinical specialist nurse • Unit sister • Continence adviser • 18 nurses • 4 OTs • 4 PTs                               | MDT<br>Assessment and<br>short-term<br>Rehabilitation<br>(usually 2-6<br>weeks) |  |

|                  | groups. Categories<br>related to<br>patient'/family carers,<br>internal system,<br>clinician and external<br>systems)<br>Number of short term<br>goals set  |   | <ul> <li>1.5 SLTs</li> <li>Neuropsychologist</li> <li>Part-time SW</li> <li>Research SpR</li> <li>Res Therapist</li> </ul>   |  |
|------------------|---|---|--|--|
| Kirshblum (2002) | "Clinical benefits derived MSCIS [Model Spinal Cord Injury System Program] funding have been classified into 5 different areas: shift of spinal cord care from individual centres to care from a 'systems approach'; data collection as a stimulus for improved clinical care; service comprehensiveness to improve clinical care; research as a stimulus for improved clinical care; for improved clinical care; and dissemination of MSCIS research findings for educational purposes and to improve care provided by all SCI | Research and developments at model system centres lead to new standards of care for persons with SCI.  The MSCIS program provides the building blocks of knowledge and experience that every SCI centre needs to improve its program. | Methods of data collection are not explained. It is difficult to judge, therefore, how valid, reliable or transferable the authors' recommendations and comments are to the UK, etc.  A "centres of excellence" model would seem to have particular benefits when developing and evaluating new interventions for conditions/injuries that are both complex and uncommon (eg SCI). |  |

|                                      |  | centres, including those not funded by the MSCIS." (Page 339 – Abstract) Service comprehensive model systems are thought to have many benefits: Emergency care – eg improved survival Acute hospitalisation – eg., decreased secondary medical complications Rehabilitation – eg. Advanced technology capability Outpatient services – eg., improved women health care services Community support groups – eg., improved return to work Lifelong follow-up – eg., decreased rehospitalisations (Page 341 – Table 1) | 42 VDII sakianta  | 'out-reach' satellite centres would seem beneficial .ie., to reach more remote clinical areas and those with a relatively low population density (eg., Wales, Scotland) | 24 have save  |   |
|--------------------------------------|--|---|---|---|---|---|
| O'Connor<br>and<br>Delargy<br>(2003) | The aim of this<br>study was to<br>describe a YDU.<br>(Page –<br>Abstract) | Original Research Observation and fieldnotes All patients in one YDU (of Peamount Hosp, Newcastle, Co. Dublin)  | 42 YDU patients Based in 1 centre. Mean age 42.5 years (Range 22-61) 30 males All major acute | YDU   | 24 hour care Accommodation provided in 2 single storey buildings Mix of single, | Description of<br>one YDU and the<br>characteristics of<br>the patients |

|  |                         |                         | <br>            |  |
|--|-------------------------|-------------------------|-----------------|--|
|  | Review of health        | teachings hospitals     | double and 4    |  |
|  | records                 | (MATHs) in the Eastern  | bed bedrooms    |  |
|  | - biographical details  | Regional Health         | Communal areas  |  |
|  | entered into a          | Authority had referred  | for dining and  |  |
|  | database                | pts to the YDU (do not  | recreation      |  |
|  | Details of past and     | know which % and        | Quiet rooms for |  |
|  | current treatments      | based on what criteria) | relaxation or   |  |
|  | noted                   | Principal diagnosis:    | privacy         |  |
|  | Physical, cognitive and | TBI (n=13)              | Input from a    |  |
|  | behavioural status      | Subarachnoid            | consultant and  |  |
|  | assessed using          | haemorrhage and non-    | registrar in    |  |
|  | standard rating scales. | h stroke (n=11)         | rehab med.      |  |
|  | Rivermead Mobility      | Non-T acquired brain    | General medical |  |
|  | Index (15 pt scale)     | inj (n=7)               | staff of        |  |
|  | (RMI)                   | MS (n=2)                | Peamount Hosp   |  |
|  | Rancho Los Amigos       | Central pontine         | provide 24 hr   |  |
|  | Level of Cognitive      | myelinosis (n=2)        | care.           |  |
|  | Function Scale          |                         | Physio and      |  |
|  | (Rancho)                |                         | recreational    |  |
|  | MMSE                    |                         | therapy also    |  |
|  | Rappaport Disability    |                         | provided.       |  |
|  | Rating Scale (DRS)      |                         |                 |  |
|  | Mobility (RMI)          |                         |                 |  |
|  | Cognitive Ability       |                         |                 |  |
|  | (Rancho, MMSE)          |                         |                 |  |
|  | Overall disability      |                         |                 |  |
|  | (DRS)                   |                         |                 |  |
|  | Time from onset of      |                         |                 |  |
|  | disability to YDU       |                         |                 |  |
|  | Average LOS in the      |                         |                 |  |
|  | YDU at the time of the  |                         |                 |  |
|  | survey                  |                         |                 |  |
|  | Estimation of           |                         |                 |  |
|  | dependency level.       |                         |                 |  |
|  | dependency level.       |                         |                 |  |

| von Koch<br>et al.<br>(2000b) | To describe the content of a programme involving early hospital discharge and continued rehabilitation at home after stroke   | Original Research: Observation and fieldnotes Quantitative and qualitative descriptive study of an intervention within the context of a RCT; Frequency of visits, duration, content.   | 41 patients post stroke   | University Hospital<br>Sweden | Rehabilitation<br>team of six<br>occupational,<br>physical and<br>speech and<br>language<br>therapists | Organisation and delivery of service |
|-------------------------------|---|--|---|-------------------------------|--|--------------------------------------|
| Wahiquist<br>(1984)           | Not clear – description of symptoms  "During the first year, the objective was to define the scope of health problems for a given population."  "In the second year, interventions directed toward a reduction in the principle cause of morbidity were evaluated" (Page 193) | Self-report survey of the clinic population. In addition, Uricult dipslides were distributed to a sample of 9 people to obtain a better understanding of the significance and epidemiology of bacteriuria. i Original Research, survey; 53 people completed survey (full details not supplied – but it included a PULSES profile). Data about hospitalisations gathered, nature of the disability (via Pulses profile), urinary tract infections In addition, a total of 189 Uricult dipslides | Number of participants not clear as reported differently in text/tables  53 people with MS who attended a nurse managed clinic  By the end of the second year, the clinic increased in size to 70 people.  In a table concerning hospitalization.size of clinic reported to be n=49 in year one and n=63 in year two. | Nurse managed MS clinic       | Protocols for the management of urinary symptoms.  | Effectiveness of service             |

|                               |   | were received. The PULSES Profile assesses 6 variables: P – physical condition U – upper extremity function L – lower extremity function S – sensory and communication abilities E – excretory control S – social support |  |   |   |  |
|-------------------------------|---|---|--|---|---|--|
| Barnes<br>and Skeil<br>(1996) | p39 "this paper discusses the experience of working within a multidisciplinary neurological clinic in a regional rehabilitation centre." includes number and types of interventions described |   | Original Research, Questionnaire/survey,, mixed methods survey Please give full details here: demographic data and diagnostic data describing patients referred. descriptive data on a particular service – problems recorded, type and number of interventions questionnaire data on patients' views and preference for clinic format 77 patients newly referred demographic, clinical problem, and | Patients referred to<br>Hunters Moore<br>rehabilitation centre<br>disability clinic April<br>1992- April 1993 | Outpatient specialist disability clinic | Organisation and delivery of service, Acceptability of service |

|  |  |  | intervention data is<br>reported for all these<br>we are told 80%<br>returned the<br>questionnaire                                   |  |   |  |
|--|--|--|--|--|---|--|
| Wood and<br>Langton<br>Hewer<br>(1996) | For original research and reviews but not policy documents Purpose of the paper "To describe the experience of setting up a 16 bed unit for the rehabilitation of non-progressive and progressive neurological disorders".  (Page 533) | Review of medical records. Review of medical records – not explained fully, but probably all the records of 318 patients admitted to the Lime Tree Rehabilitation Unit between 5th October 1992-4th October 1994). | Patients – not research participants 318 patients admitted to the Lime Tree Rehab Unit between 5th October, 1992 – 4th October, 1994 | Stroke and neurological rehabilitation ward (opened in October 1992) – the Lime Tree Rehabilitation Unit (LTRU). "The aim was to move away from a biomedical model of care towards a biopsychosocial model (ref 17) which concentrated on team work and improving patient and family participation in the rehabilitation process." (Page 533). | Patient centred team-work Optimising independence and 'normality': • Leisure activities (group-based activities in the unit and community eg quizzes, bingo, cooking, shopping trips, picnics) • Ward based computer therapy for patients with aphasia • Group exercises and discussions • Involvement of ex-patients | Description of a service (and its development) |

# Appendix 13 Details of quantitative papers reporting models of neurological rehabilitation for people with stroke

| Paper<br>ID<br>number | Author(s)                       | Design                      | Subjects   | Setting                                   | Intervention   | Outcome<br>measures  | Results                                      |
|-----------------------|---------------------------------|-----------------------------|--|---|--|--|--|
| B2                    | Burton and<br>Gibbon<br>(2005)  | RCT-single blind            | 176 stroke<br>discharges                         | Community,<br>Manchester                  | Vague-<br>'specialist<br>nurse' vs<br>special care<br>(SC) | NHP, Carer strain,<br>Barthel, Frenchay<br>Activity, Beck 3,12<br>mnths & carer<br>strain (3 months) | 12mnth, NHP 42.6, p=0.012, CS<br>1.5 p=0.045 |
| B10                   | Grasel and<br>Biehler<br>(2005) | Quasi-<br>randomised<br>RCT | 62 p w stroke<br>& family                        | Bavaria, Germany                          | Intense training<br>for discharge<br>transition vs SC      | Barthel, FIM, Ashworth, Frenchay arm, TUG, Carers-SF36, Giessen depression, Burden scale             | No diff between groups                       |
| B6                    | Dey <i>et al.</i> (2005)        | RCT                         | 308 stroke<br>admissions                         | Manchester, UK                            | inpatient mobile<br>stroke team vs<br>non                  | mortality, Barthel,<br>NEADL, Frenchay<br>Aphasia, Simple<br>Qs, EuroQol,<br>HADS                    | No diff                                      |
| B70                   | Baskett <i>et al.</i> (1999)    | RCT                         | 100 stroke<br>discharges<br>from gen<br>hospital | Community North<br>Health, new<br>Zealand | home-based<br>therapy                                      | motor assessment<br>scale, modified<br>barthel, 10 m<br>walking speed,<br>nine-hole peg test         | no sig diffs except contact time longer      |

|     |                               | т   | ·   | <del></del>   | т               |   |  |
|-----|-------------------------------|-----|-----|---|-----------------|---|--|
|     |                               |     |     |   |                 | grip strength, HAD  |  |
| B71 | Bautz-Holter<br>et al. (2002) | RCT | 82  | community and gen<br>hosp Norway                    | early discharge | GHQ (20 questions), Nottm Ext ADL scale. Montgomery Aasberg Depression rating scale, readmission, place of residence, death   | no sig diff except length of stay  |
| B67 | Andersen et al. (2000)        | RCT | 155 | community,<br>Copenhagen,<br>discharged gen<br>hosp | physician or PT | Scandinavian Stroke Scale, MRC Muscle Strength Assessment, visual fields, Functional Quality of Movement Scale, Mini-Mental State + other cognitive assessments by Waldemar et al. 1994 and Anderson & Tranel 1989, Barthel Index | Re-admission rates within 6 months low in intervention group (Dr or PT) than control; effect of intervention (Dr or PT) strongest for patients with prolonged inpatient length of stay |
| B68 | Anderson et al. (2000a)       | RCT | 86  | gen hosp&<br>community s<br>Australia               | early discharge | SF-36, Nottm<br>Health Profile,<br>MFAD, AAP, GHQ-<br>28, Carer Strain<br>Index, use of   | no diff except poor mental healtl<br>care in intervention  |

|     |                          |     |   |   |   | community services, hospital re-admission, history of falls, place of residence, pt & carer satisfaction with their medical care, rehabilitation and recovery             |  |
|-----|--------------------------|-----|---|---|---|---|--|
| B18 | Ma <i>et al.</i> (2004)  | RCT | 392 acute ischaemic strokes.  | SU vs general ward in China                       | SU: medical care, rehab therapies, SALT, neuropsych, education components | Barthel, NIHSS,<br>OHS  | Greater improvements in BI, NIHSS and OHS were observed. Also fewer complications  |
| B17 | Lincoln et al.<br>(2004) | RCT | Comm rehab<br>team n-189 vs<br>"ordinary<br>care"<br>n=232.stroke   | community   | team,<br>unspecified  | BI, EADL, GHQ,<br>Euroqol-5D,<br>Satisfaction,<br>knowledge, Carer<br>GHQ, CSI<br>satisfaction,<br>knowledge  | No difference except aspect of prospection (emotional support) and improved carer satis and strain   |
| B24 | Ricauda et al. (2004)    | RCT | 120, 60 in home treatment from a geriatric home hospitalisation service (GHHS) or to a general medical ward | S. Giovanni Battista<br>Hospital, Turin,<br>Italy | Home<br>treatment<br>versus hospital<br>treatment                         | cumulative<br>survival at 6<br>months, ADL, 7-<br>item functional<br>impairment<br>measure,<br>Canadian<br>Neurological scale,<br>national institutes<br>of health stroke | Mortality was not significantly different in the two groups but depressive scores and admission rates to nursing homes were better/lower in the home-treated elderly patients. |

|     |                              |  | (GMW)(aged<br>>70)  |                                      |   | scale, Geriatric<br>Depression Scale.   |   |
|-----|------------------------------|--|---|--------------------------------------|---|---|---|
| B29 | Rudd <i>et al.</i><br>(1997) | RCT  | 167 received specialist community rehabilitation and 164 continued with conventional hospital and community care. | Two teaching hospitals, London       | early discharge vs. conventional policy.    | barthel score at 12 months, motoricity index, minimental state examination, Frenchay aphasia screening test, Rivermead ADL scales, HAD scale, 5m walk, NHP, caregiver strain index, patient and carer satisfaction. | Early discharge feasible - no sign<br>differences in clinical outcomes<br>but increase satisfaction with<br>hospital care was found in the<br>community therapy group and th<br>community therapy group also<br>had significantly shorter LOS<br>despite having more impairment |
| B35 | Sulch <i>et al.</i> (2002)   | RCT integrated care pathway vs conventional multidisciplinary care | acute stroke<br>patients<br>undergoing<br>rehabilitation<br>ICP n= 76<br>MDT n=76                                 | stroke<br>rehabilitation unit,<br>UK | integrated care pathway                     | RCP<br>Intercollegiate<br>Stroke Audit Tool   | Higher frequency of stroke speciassessments ICP 84% MDT 60% nutritional assessment (ICP 74% MDT 22%) documentation of provision of information (ICP 89% MDT 45%) and early discharge notification to GP ( ICP 80% MDT 45%)  |
| B39 | von Koch et al. (2000a)      | RCT rehab at<br>home HRG vs<br>routine rehab<br>(RRG)              | stroke patients<br>admitted to<br>SU  | community,<br>Sweden                 | early supported discharge and rehab at home | No. falls, Lindmark<br>Motor Capacity<br>Assessment, timed<br>10m walk, 9 hole<br>peg test, Barthel,<br>Katz ADL,<br>Frenchay AI,<br>Sickness Impact<br>profile, Sense of<br>Coherence,<br>reinvang Aphasia<br>test | No sig differences in outcome,<br>death or dependency higher in<br>RRG (44%) compared to<br>HRG(24%0 Length of stay shorte<br>mean 29 days RRG, 14 days HRC   |

| B44  | Drummond et al. (2005)         | RCT follow-up           | 46 SU patients<br>and 28<br>conventional<br>ward patients        | Stroke Unit vs<br>Conventional ward                         | specialised<br>stroke rehab<br>care                 | Alive, Barthel,<br>Place of residence   | Stroke unit patients tended to have better outcome for death, death or disability, death or institutional care                    |
|------|--------------------------------|-------------------------|--|---|---|---|---|
| B41  | Anderson et al. (2000b)        | RCT                     | 86 patients 42<br>home based<br>care, 44<br>conventional<br>care | Home based care vs conventional care                        | early supported<br>discharge plus<br>community care | overall economic<br>cost to health care<br>system and<br>patients and<br>carers   | Early supported discharge and home based rehab less costly the conventional care. But not statistically significant.              |
| B46  | Evans <i>et al.</i> (2002)     | RCT                     | 267, 164 large<br>vessel, 103<br>small vessel                    | Stroke unit vs<br>stroke team                               | Stroke unit care vs stroke team care                | mortality, institutionalisation, orgozo scale, barthel, Frenchay, mRankin, Euroquol, amount of therapy and time in hospital | Stroke units improve care in patients with large vessel disease Pats with small vessel disease do equally well in either setting. |
| B43  | Donnelly et al. (2004)         | RCT                     | 59 early<br>discharge and<br>CST vs 54<br>usual care.            | usual inpt care and<br>CST vs usual inpat<br>and outpt care | early discharge<br>and CSt vs<br>usual care         | Barthel, NEADL,<br>Short Form 36,<br>QoL, Pt and carer<br>satis. Carer strain<br>and COST                                   | No signif diff between two model Except carers more satisfied and CST option cost less.   |
| B100 | Indredavik<br>et al.<br>(1997) | RCT 5 year<br>follow up | stroke patients<br>admitted to<br>hospital                       | community,<br>Norway  | stroke unit vs<br>general wards                     | Survival, Proprtion at home, Barthel  | Stroke unit improved survival, increased chances of being at home and produced better functional outcome at 5 years               |

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| B101 | Indredavik<br>et al.<br>(1999) | RCT 10 year follow up                        | stroke patients<br>admitted to<br>hospital           | community,<br>Norway | stroke unit vs<br>general wards  | Survival,<br>Proportion at<br>home, Barthel   | Stroke unit produced better survival , proportion at home ar proportion with Barthel > 60 at years  |
| B98  | Indredavik<br>et al.<br>(1998) | RCT 5 year<br>follow up                      | stroke patients<br>admitted to<br>hospital           | community,<br>Norway | stroke unit vs<br>general wards  | Barthel,<br>Nottingham Health<br>Profile, Frenchay<br>Activities Index,<br>VAS for quality of<br>life   | Stroke unit produced better functional outcome (FAI) and quality of life ( total NHP and VAS).  |
| B99  | Indredavik<br>et al.<br>(2000) | RCT  | stroke patients<br>discharged<br>from stroke<br>unit | community,<br>Norway | early supported<br>discharge with<br>mobile team vs<br>standard<br>service | early supported<br>discharge with<br>mobile team vs<br>standard service   | ESUS patient s were more independent in ADL , more were at home at 6 weeks and they spent sig less time in hospital. Note that sig differences in proportion at home at 26 weeks or survival. |
| B95  | Holmqvist et al. (2000)        | RCT rehab at<br>home HRG vs<br>routine rehab | stroke patients<br>admitted to<br>SU                 | community,<br>Sweden | early supported<br>discharge and<br>rehab at home                          | Length of stay,<br>Therapy contacts,<br>Resource use,<br>Patient satisfaction   | 50% reduction in hospitalization HRG  |
| B96  | Holmqvist et al. (1998)        | RCT rehab at<br>home HRG vs<br>routine rehab | stroke patients<br>admitted to<br>SU                 | community,<br>Sweden | early supported<br>discharge and<br>rehab at home                          | Frenchay Activities Index, Extended Katz ADL, Barthel, Lindmark Motor Capacity, Nine- hole peg test, Walking speed, Falls, Sickness Impact Profile, | No significant differences in<br>outcome. 50% reduction in<br>hospital stay, 15 days in HRG vi<br>30 days in RRG  |

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|------|-----------------------------|---|---|---------------------------|---|---|--|
|      |                             |   |   |                           |   | Length of stay  |  |
| B97  | Hui <i>et al.</i><br>(1995) | RCT day<br>hospital versus<br>conventional<br>medical<br>management | elderly stroke<br>patients  | community, Hong<br>Kong   | day hospital<br>versus<br>conventional<br>medical<br>management                     | Length of stay, Hospital services received, Use of community services, Barthel, Self rated well being scale, Geriatric Depression Scale, Satisfaction with services | Significant difference in Barthel a<br>3 m in favour of day hospital<br>group. Fewer outpatient visits at<br>months. No significant difference<br>in costs |
| B103 | Juby <i>et al.</i> (1996)   | RCT stroke unit<br>vs conventional<br>wards                         | stroke patients<br>admitted to<br>hospital                                | hospital, UK              | SU vs<br>conventional<br>wards (general<br>medical and<br>health careof<br>elderly) | Barthel, Rivermead ADL, Nottingham Extended ADL, Rivermead Motor Assessment, General Health Questionnaire 28, Cognitive and Instrumental Readjustment               | SU patients were more independent in ADL and showed better mood and adjustment   |
| B57  | Roderick et al. (2001)      | RCT   | 140 stroke pts<br>55+<br>randomised<br>(66 to dom<br>and 74 day<br>hosp). | community and 5 day hosps | new dom rehab<br>prog v geriatric<br>day hosp.                                      | Primary- Barthel.<br>Secondary- RMI,<br>FAI, SF36,<br>Philadelphia<br>Morale Scale.   | No sig diffs seen btw 2 services.  |

| B58  | Ronning and<br>Guldvog<br>(1998a) | Quasi RCT.<br>Stroke pts<br>randomised<br>according to<br>first two digits<br>of dob | 550 stroke<br>pts60+<br>randomised<br>(271 SU and<br>279 gen med)  | Su v gen med<br>wards Norway                                     | treatment on su<br>v gm within 24<br>hrs of stroke                                   | Death, instit, imp/det/died. Sec BI and SSS  | Trend for su better   |
|------|-----------------------------------|--|--|--|--|--|---|
| B62  | Teng <i>et al.</i> (2003)         | RCT  | 114 stroke pts<br>randomised<br>(58 home<br>intervention<br>and 56 usual<br>care)  | Canada.<br>Community.  | 4 week tailored<br>home care of<br>rehab and<br>nursing care v<br>usual care         | SF36; costs;<br>Burden Index<br>(carer stress);  | Sf36 higher scores in interventio group? Not reported here in detail); Costs higher in usual car (bec of readmissions); better scores for carers in intervention group re stress. |
| B63  | Thorsen <i>et al.</i> (2005)      | 5-year RCT<br>follow-up  | 54 stroke pts<br>(30<br>intervention<br>and 24<br>control)- 5<br>years after<br>stroke   | Sweden.Community follow up.                                      | originally<br>randomised to<br>either home<br>rehab OR<br>routine care               | Many!! Eg MMSE,<br>Lindmark, Barthel,<br>Katz EADL, FAI,<br>Sickness Impact<br>Profile           | 66 alive at 5 yrs (30 intervention<br>and 24 controls actually fu). Mai<br>finding is better EADL results at<br>years in intervention group                                       |
| B117 | Rodgers et al. (1997)             | randomized<br>controlled trial-<br>pilot   | 92 stroke pts<br>admitted to<br>hospital in<br>Newcastle<br>area. Not<br>previously in<br>nh. Medically<br>stable with BI<br>5-19. 46<br>randomized to<br>early<br>discharge; 46 | Newcastle.Hosp v<br>community (early<br>supported<br>discharge). | Early supported discharge home under mdt with rehab 5/7 and home care 7/7 if needed. | WDI, NEADL, oxf<br>handicap, global<br>health status<br>(Dartmouth Co-<br>op). Careres-<br>ghq30 | Pilot study therefore looking at feasibility of scheme/assessments/interventic Judged acceptable to roll out.   |

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|   |      |                                   |   | to control<br>(routine<br>treatment).  |  |  |  |   |
|   | B118 | Rodgers <i>et al.</i> (1999)      | randomized controlled trial   | 204 pts (with carers) randomized. Recruited 5-9 days after stroke in hosp; medically stable. Not previously in nh. 121 pts and 107 carers randomized to education programme; 83 pts and 69 carers to control (routine care). | Newcastle. Intervention in day hosp after discharge. | Educ programme for intervention group after discharge in day hospital v routine (control) who also received information and access to hotline. | sf36-perceived<br>health status,<br>NEADL, HAD, oxf<br>handicap, ghq30 | Education programme improved and carer knowledge but not perceived health status. Some carers in intervention group wors than controls. |
| • | B119 | Ronning and<br>Guldvog<br>(1998b) | quasi<br>randomised<br>controlled<br>study. Fu at 12<br>and 18 months | 802 pts with stroke (first or subsequent) admitted to hospital. All 60 plus. Included if seen within 24 hrs. Complicated allocation (which   | Norway- follow up in community                       | Intervention 12-18 months previously treatment in stroke unit or general medical wards.  | survival at 12 and<br>18 months  | Improved survival in su pts at both 12 months and 18 months   |

|      |                                   |   | changed<br>during study)<br>based on<br>digits of dob.<br>364 allocated<br>to su and 438<br>to medical<br>wards.  |  |  |  |  |
|------|-----------------------------------|---|---|--|--|--|--|
| B120 | Ronning and<br>Guldvog<br>(1998c) | prospected randomized controlled trial (although details of randomization not entirely clear) | Acute stroke pts admitted to hosp from home (not nh or residential) within 24 hrs. 60 or more. Consc on admission. Could tolerate rehab. Scand Stroke Scale (SSS) score of 12-52. 251 pts randomised; 127 to hosp rehab and 124 to community. | Norway. Hosp rehab unit and community rehab. | On discharge from acute stroke unit or gen med ward allocated to either hospital rehabilitation unit or to rehab in community. | Prim outcome at 7 months after stroke- death, place of residence and disability by Barthel. Secondary- SSS, SF36, Barthel for ADL. | Better overall outcome in hosp rehab group for dep or death (p=0.01, OR 0.49 (0.28-0.86) but not sig if separated. Secondary measures equivocal bt groups. |
| B51  | Kalra (1994)                      | Randomised control trial  | 146 stroke patients   | General wards versus stroke unit             | Allocation to<br>GW versus SU  | Barthel  | Functional recovery greater and more rapid in SU   |
| B54  | Mayo <i>et al.</i> (2000)         | Randomised control trial  | 114 stroke patients   | Community<br>(Canada)                        | Home intervention versus usual care  | SF-36 Phscl hlth,<br>up-and-go,<br>Barthel, OARS-<br>IADL, RNL, SF-36<br>MH  | Home intervention was better   |

| B127 | von Koch <i>et</i> al. (2001)  | Randomised<br>control trial | 83 stroke patients                          | Community<br>(Sweden) | Early discharge<br>and home<br>rehab versus<br>usual care      | Mortality, ADL,<br>function, resource<br>use                          | No difference on univariate, except for resource use |
|------|--------------------------------|-----------------------------|---|-----------------------|--|---|--|
| B132 | Walker <i>et al.</i> (1999)    | Randomised control trial    | 185 stroke patients                         | Community             | OT versus TAU  | EADL, Barthel,<br>GHQ, carer strain,<br>London handicap               | OT better  |
| B133 | Wolfe <i>et al.</i> (2000)     | Randomised control trial    | 43 stroke patients                          | Community             | Rehab team at<br>home versus<br>usual care                     | Motricity, MMSE,<br>Albert test, FAST,<br>Barthel, HADS,<br>walk, NHP | No overall differences                               |
| B134 | Young and<br>Forster<br>(1992) | Randomised control trial    | 124 stroke patients                         | Community             | Day hospital versus home treatment                             | Barthel, Motor<br>Club, Frenchay<br>activities, NHP                   | Home slightly more effective                         |
| B135 | Young and<br>Forster<br>(1993) | Randomised control trial    | 124 stroke patients                         | Community             | Day hospital versus home treatment                             | Resource use  | Home more cost-effective                             |
| B78  | Corr and<br>Bayer<br>(1995)    | RCT                         | stroke op's                                 | community             | ОТ   | ADL & mood  | no effect  |
| B85  | Fagerberg et al. (2000)        | RCT                         | stroke<br>patients                          | hospital              | integrated<br>stroke service -<br>stroke unit and<br>community | mortality, ADL,<br>impairment   | no difference  |
| B108 | Lincoln <i>et al.</i> (2000)   | RCT 5 year<br>follow up     | 139 adults<br>from original<br>study of 315 | Stroke Rehab Unit     | Stroke rehab   | death, death or<br>disability, death or<br>institutionalisation       | Mortality rates improved if randomised to rehab unit |

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| B109 | Logan <i>et al.</i> (1997)     | RCT | 111patients,53<br>enhanced ssot<br>vs 58 routine<br>ssot          | community   | enhanced ssot   | EADLI, Barthel,<br>GHQ   | Higher EADL scores if enhanced service, also better mood scores of carers at 6 months   |
| C12  | Dennis <i>et al.</i> (1997)    | RCT | 417, 210<br>stroke family<br>care worker,<br>207 standard<br>care | organised stroke<br>service in Edin<br>teaching hosp  | stroke family<br>care worker  | barthel, FAI, GHQ,<br>HAD, Pat<br>satisfaction also<br>carer satis, GHQ,<br>HAD FAI.   | No sign diff on physical outcome patients tended to be worse in care worker group. Satisfaction high in both pat and carer group for family support worker groups   |
| B104 | Kalra <i>et al.</i> (2000)     | RCT | 457, 152<br>stroke unti,<br>152 stroke<br>team, 153<br>dom care   | stroke unit, gen<br>ward and home                     | organisation of<br>stroke services  | mortality or institutionalisation  | Stroke units are more effective i reducing mortality , institutionalisation and dependence than stroke team or dom care.  |
| B87  | Forster and<br>Young<br>(1996) | RCT | 240 patients<br>aged 60 or<br>over                                | Community setting, in Bradford Metropolitan disrict.  | Community setting, in Bradford Metropolitan disrict.                          | Barthel index,<br>Frenchay activities<br>index, Nottingham<br>health profile, .<br>Carers filled in<br>general health<br>questionnaires. | No significant differences for carers in terms of health, social activities, or stress. A subgroup mildly disabled patients with stroke BI15-19) had improved outcomes at 6 and 12 months according to Frenchay activities index. |
| B89  | Gilbertson et al. (2000)       | RCT | 138 stroke<br>patients with<br>definitive<br>discharge plan       | 2 hospital sites<br>within a UK<br>teaching hospital. | 6 week<br>domiciliary<br>occupational<br>therapy or<br>routine follow-<br>up. | Nottingham extended activities of daily living score.  | At 8 weeks the NEXDL score was 4. points higher in the intervention group (P=0.08). Fewer patients in the intervention group had poor global outcomes than control at 12 weeks. At 6 months the differences remained              |
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|     |                                   |  | 1   |                      |  |  | but were not significant.   |
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| B92 | Gladman<br>and Lincoln<br>(1994)  | 6 month to 1<br>year follow-up<br>of RCT | 327 patients<br>mean age 70,<br>48% women | Nottingham, UK       | Home versus<br>hospital<br>rehabilitation<br>post discharge<br>from hospital | Mortality, % in institution, BI, E-ADL, NHP  | The health care for the elderly ward domiciliary rehab group ha a significant improvement in tota E-ADL whilst the Stroke unit gro saw significant increases for the hospital based rehab group on total and mobility in E-ADL. |
| B93 | Gladman <i>et al.</i> (1993)      | RCT                                      | 327 patients                              | Nottingham, uk       | Home versus<br>hospital<br>rehabilitation<br>post discharge<br>from hospital | E-ADL and NHP  | No differences between groups in E-ADL at 3 or 6 months noe NHF at 6 months.  |
| C8  | von Koch <i>et al.</i> (2000b)    | Description of<br>cohort within<br>RCT   | stroke patients<br>admitted to<br>SU      | community,<br>Sweden | early supported<br>discharge and<br>rehab at home                            | duration programme, no visits, focus of visits, total time consumption, face to face contact time, travel time, admin time | Ave. duration programme 14 weeks, mean no visits 12, total time 23h 20 min, Face to face contact 54%  |
| C10 | Dennis and<br>Langhorne<br>(1994) | Meta-analysis interpretation             | Not stated                                | stroke unit care     | specialised<br>stroke unit care  | Interpretation<br>from meta-<br>analysis data  | Stroke services need: neurovascular clinics, acute strol area, stroke rehab unit, outpatient, day hosp or dom car for those not admitted, continuir care and support, close links wit Primary Care                              |

| C13 | Pound <i>et al.</i> (1999)                             | observational<br>study of 3<br>settings  | stroke patients<br>admitted to<br>hospital                 | 3 settings; stroke unit, elderly care unit, general medical ward. London. | None   | Non- participant<br>observation by 2<br>researchers<br>recorded on<br>observation<br>schedule | Many.Su pts spent more time ou of bed and more opp to be indep than pts in other settings.                          |
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| B8  | Early<br>Supported<br>Discharge<br>Trialists<br>(2005) | Systematic<br>review & meta-<br>analysis | 14 stroke<br>RCTs  | community or<br>hospital  | interventions to<br>accelerate<br>discharge  | LOS, dependency,<br>mortality, dis<br>destination prove<br>outcome                            | reduced LOS, institutionalisation long-term dependency  |
| B16 | Langhorne<br>et al.<br>(2005b)                         | meta analysis                            | stroke patients<br>in hospital                             | hospital  | Early supported discharge service  | death,<br>dependency, LOS,<br>Bad outcome   | ESD reduced death or dependen absolute reduction 6%. 8 days shorter LOS greater satisfaction                        |
| B15 | Langhorne<br>et al. (2000)                             | meta analysis                            | stroke patients  | community   | hospital<br>avoidance<br>service   | 4 trials. ADL death hospital use perceived health   | No difference except trend towards higher (sic) hospital use in intervention. Maybe more expensive.                 |
| B14 | Kramer <i>et al.</i> (2000)                            | cohort study                             | stroke patients<br>in residential<br>services for<br>rehab | US rehab units or nursing homes   | HMOs vs fee for service - the latter more likely to have specialised rehabilitation, whereas the former tended to be in nursing homes with an implication of a less intense or | improvement in ADL, residential status  | ADL similar at 12 months but FF pts more likely to be at home (O 1.8) and HMO pts more likely to be in NHs (OR 2.4) |

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|     |  |                            |   |   | no real<br>rehabilitation    |  |   |
| B12 | Jorgensen et al. (1999)                      | cohort study               | stroke patients   | community<br>Denmark                            | SU vs general<br>ward        | survival at 5 years  | OR 0.6 for death in SU cohort   |
| B11 | Greenberg et al. (2004)                      | retrospective cohort study | stroke<br>patients  | hospital OPD                                    | hospital OPD                 | patient complaints   | a variety of complaints were identified   |
| B21 | Murray <i>et al.</i> (2004)                  | Survey                     | 50 district and community nurses (representing 24 of thee 41 teams in the area) | District nursing<br>teams in 3 Bradford<br>PCTs | N/A                          | N/A  | Uncertainty of post-discharge stroke care. Identifies types of long-term problems people after stroke experience. Highlights a lack of training/awareness. Need stroke care coordinator role developed. |
| B22 | Outpatient<br>Service<br>Trialists<br>(2003) | Literature<br>review       | 14 RCTs including 1617 patients.  | Community                                       | Therapy based rehabilitation | poor outcome, ADL, NEADL,, FAI, IEADL, STAIR, OARS, NLQ, COPM, IST, NHP, EuroQol, MOS-36, GHQ, GDS, CES- D,barthel, Motricity, 6- minute walk, Rivermead Motor, Fugl-Meyer, mortality, patient mood and QOL, | Therapy based rehabilitation services reduced odds of a poor outcome (peto odds ratio 0.72) and increased personal ADL scor (mean difference 0.14, p=0.02)  |

|     |                                       |                             |  |   |                               | carer mood and QOL, carer/patient satisfaction.                                     |   |
|-----|---------------------------------------|-----------------------------|--|---|-------------------------------|---|---|
| B26 | Rodgers et al. (2003)                 | National postal survey      | 91 consultant<br>members of<br>the Bristish<br>Association of<br>Stroke<br>Physicians. | Hospital based<br>specialist stroke<br>services<br>, UK                                 | N/A                           | N/A   | The NSF target for hospital-base stroke service is not currently being met in most units.   |
| B28 | Rudd <i>et al.</i> (2001b)            | Retrospective<br>audit      | 6894 patients<br>from 12 trusts<br>covering 210<br>trust sites.                        | England, Wales and<br>Northern Ireland  | NA                            | NA  | Proportion of stroke patients spending more than 50% of thei time in a stroke unit varied from 10% to 27%. 30-day mortality varied between 21% AND 33%. Institutionalisation rates varied between 6% and 19% similar to discharge disability & LOS variations |
| B30 | Salter <i>et al.</i> (2006)           | Retrospective chart review. | 435 patients   | single specialised<br>inpatient stroke<br>rehabilitation<br>program, Ontario,<br>Canada | N/A                           | N/A   | Those admitted early (within 30 days of admission for first-ever stroke) to stroke rehabilitation had greater functional gains and shorter lengths of stay than thos having delayed admission.  |
| B65 | Diez-Tejedor<br>and Fuentes<br>(2001) | cohort                      | 1491<br>consecutive<br>patients  | neurology ward  | stroke unit vs<br>stroke team | mean length of hosp stay, systematic and neurological complications, destination at | Stroke unit outcomes better.  |

|      |  |  |   |   |  | disch, health costs                            |   |
|------|--|--|---|---|--|--|---|
| B61  | Stroke Unit<br>Trialists'<br>Collaboration<br>(1997) | systematic<br>review   | All rcts cf inpt<br>stroke care<br>with<br>conventional<br>care.<br>Preliminary<br>analysis of 19<br>trials with<br>3249 pts with<br>stroke.  | worldwide data  | organised inpt<br>care v<br>conventional<br>treatment  | death,<br>institutionalisation,<br>dependency. | su care assoc with reduction of death (0.83, 95% CI 0.69-0.98) death or dep (0.69, 0.59-0.82); death or inst (0.75, 0.65-0.87). |
| B121 | Ronning et al. (2001)                                | prospective,<br>controlled trial.<br>Stroke pts<br>randomised<br>according to<br>first two digits<br>of dob to 2<br>groups | 135 pts 60-85 yrs admitted to hosp with acute prim intracranial haem (CT verification) within 24 hrs. 62 to su and 73 to gen med ward (allocation on dob). 14 then excluded (6 su; 8 gmw) as outside time limit for study | Norway. Hospital-<br>Su v gen med<br>ward. Definition of<br>stroke unit very<br>specific. | Specific stroke unit management v gen med ward care based on good medical practice but with no specific stroke m/ment guidelines or mdt. | survival, dest on discharge.                   | in general, better survival at 30 days and one year for su pts.No diffs destination   |

| Repeated within 18 months.   Pas admitted consecutively bit 1 Jan 1998 and 1988 AND 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AND 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AnD 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AnD 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AnD 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AnD 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AnD 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AnD 5375 btw 1 Aug 1999 and 31 Oct 1999.   Pas AnD 5375 btw 1 Jan 1998 and 31 March 1998.   Pas And 5375 btw 1 Jan 1998 and 31 March 1998 and 31 March 1998.   Pas And 5375 btw 1 Jan 1998 and 31 March 1998 and 31 March 1998.   Pas And 5375 btw 1 Jan 1998 and 31 Ma |      |        |                 |   |                    |                  |  |  |
|--|------|--------|-----------------|---|--------------------|------------------|--|--|
| Canal Part   Can | B122 |        | Repeated within | pts admitted<br>consecutively<br>btw 1 Jan<br>1998-31 Mar<br>1998 AND<br>5375 btw 1<br>Aug 1999 and | England, Wales and | None             | by RCP under Intercollegiate Stroke Working Party. Included mortality, los, acc bef and after dis, | planning improved but other standards poor eg as of carers     |
| B50   Jorgensen et al. (1995)   Geographically controlled trial (1995)   Geographically controlled trial (1995)   Stroke patients (1995)   Stroke unit (1995)   Stro | B123 |        | National audit. | pts admitted<br>consecutively<br>btw 1 Jan<br>1998 and 31   | England, Wales and | None             | RCP under Intercollegiate Stroke Working   | physician; only 50% had stroke team. 41% of pts contacted by 0 |
| al. (1995) controlled trial consecutive stroke patients versus stroke unit (Denmark) (geographically) to unit discharge to nursing home, length of stay  B52 Langhorne et al. (2005a) Systematic review Six clinical trials Mobile stroke teams Mortality, discharge home, independence Systematic Systematic Organisation of Organised care Mortality, place Substantial benefit for organised  | B49  | al.    |                 | consecutive   | versus stroke unit | (geographically) | outcome (death or discharge to   | Stroke unit generally favourable                               |
| et al. (2005a) review trials teams discharge home, independence SU  B53 Langhorne Systematic Nine clinical Organisation of Organised care Mortality, place Substantial benefit for organised   | B50  | al.    |                 | consecutive   | versus stroke unit | (geographically) | discharge to nursing home,   | Stroke unit did better   |
|  | B52  | et al. | •               |   |                    |                  | discharge home,  | conventional care, equivalent to                               |
|  | B53  |        |                 |   |                    |                  |  | Substantial benefit for organised care                         |

|      | (2001)   |  |                              | care   | alternative   | dependency, ADL   |   |
|------|--|--|------------------------------|--|---|---|---|
| B124 | Stegmayr et al. (1999)                               | Observational study using routine data | 14308 stroke patients        | General wards<br>versus stroke units<br>(Sweden) | General ward<br>versus stroke<br>unit   | Death, discharge<br>home, Length of<br>stay, ADL  | SU show benefit, but less than in trials  |
| B125 | Stroke Unit<br>Trialists'<br>Collaboration<br>(2007) | Systematic review                      | 23 clinical<br>trials        | Inpatient  | Organised<br>inpatient care<br>versus general<br>care                               | Death, discharge<br>destination,<br>independence  | Organised care is better  |
| B131 | Walker <i>et al.</i> (2004)                          | Systematic review                      | 8 clinical trials            | Community  | Community OT versus TAU   | ADL, leisure<br>scores  | Higher ADL and leisure scores   |
| B79  | Dekker <i>et al.</i> (1998)                          | Systematic review                      | stroke<br>patients           | community  | DH vs various alternatives  | vary according to<br>trial, mainly ADL,<br>mood some cost   | neutral trials  |
| B105 | Kalra <i>et al.</i><br>(1993)                        | Controlled study                       | 245<br>Stroke<br>patients    | stroke rehab ward,<br>general medical<br>wards   | care as given<br>on allocated<br>unit   | mortality, hospital<br>length of stay,<br>therapy time.   | Stroke units improve outcome a reduce hosp stay without increasing therapy time.  |
| B107 | Kwakkel <i>et al.</i> (1997)                         | Meta -analysis                         | 9 studies,<br>1051 patients  | Inpatient and community studies                  | intensity of<br>therapeutic<br>intervention   | ADL   | small but statistically sign intensity effect   |
| B86  | Fjaertoft et al. (2003)                              | long-term<br>follow up of an<br>RCT    | 320 acute<br>stroke patients | one stroke unit,<br>Norway                       | Extended stroke unit service (mobile stroke team providing comprehensive follow-up) | Modifies Rakin<br>Scale, Barthel<br>index, differences<br>in final residence<br>and length of stay. | 56.3% in extended versus 45.0% in ordinary service were independent (RS<=2). No significant difference in BI or finaresidence. Patients with moderate to severe stroke benefited from |

|     |                                     |   |  |  | versus ordinary<br>stroke service<br>unit service                            |  | extended service.   |
|-----|-------------------------------------|---|--|--|--|--|---|
| B88 | Geddes and<br>Chamberlain<br>(2001) | Prospective, descriptive, quantitative study. | 6 community<br>rehabilitation<br>teams and the<br>1076 patients<br>within these<br>services. | Community -<br>Derby, Sheffield,<br>Newcastle,<br>Worthing, Merton,<br>North Down. | N/A  | Annual numbers<br>treated, Barthel<br>index, Mortality,<br>Place of discharge,<br>crude costs. | 48.7% patients male, mean age 71, median time between stroke and int. by community service 6 wks, 80.5% pts had been admit. To hospital. BI 15 at start and 10 at end. Median dur. If int. 12 wk At end of int.,86.5%in comm, 4.9% dead, 0.9% hosp., 7.3%Ltcare |
| B90 | Glader <i>et al.</i> (2001)         | prospective<br>cohort study                   | 8194 patients  | Stroke units and general wards,Sweden.   | N/A  | ADL  | Patients treated in stroke units were less likely to be dependent the Adl functions than those in general wards 2 years after the stroke if they had been independent prior to stroke. If living at home prior to stroke the had a lower case-fatality rate.    |
| B91 | Gladman <i>et al.</i> (1995)        | Analysis of two<br>trials                     | 124 in BCST<br>trial and 327<br>in Domino trial  | UK: Bradford and<br>Nottingham,  | Home versus<br>hospital<br>rehabilitation<br>post discharge<br>from hospital | Barthel index, able<br>to walk outside,<br>Nottingham Health<br>Profile                        | Little difference in efficacy between hospital and home base rehabilitation but disability was marginally found to be reduced the home group. No difference found between those that were frail and those not frail in contradiction to previous results        |

| B76 | Claesson et al. (2000) | Cost study | stroke, from<br>previously<br>reported RCT | integrated service<br>(community and<br>hospital) | integrated<br>service stroke<br>unit and<br>community | service costs | no difference in costs between those in this service and control |
|-----|------------------------|------------|--|---|---|---------------|--|
|-----|------------------------|------------|--|---|---|---------------|--|

# Appendix 14 Details of papers reporting models of neurological rehabilitation for people with traumatic brain injury

| Paper<br>ID<br>number | Author(s)                   | Design  | Subjects   | Setting          | Intervention  | Outcome<br>measures  | Results  | Model<br>identified    |
|-----------------------|-----------------------------|---|--|------------------|---|--|--|------------------------|
| B31                   | Semlyen et al. (1998)       | Cohort co-<br>ordinated<br>multidisciplinary<br>rehab at<br>specialist<br>regional<br>rehabilitation<br>unit (HM) vs<br>single discipline<br>approach at<br>local hospitals<br>(OR) | Severe<br>traumatic<br>head injury<br>HM n=33 or<br>n=18 | Community,<br>UK | Co-ordinated<br>multidisciplinary<br>specialist<br>rehabilitation | Barthel, FIM,<br>Newcastle<br>Independence<br>Assessment<br>Form Research<br>(NIAF-R), Carer<br>GHQ28                    | OR better function: to 12 weeks on FIM motor items (t 2.19- 2.60 p = 0.04- 0.02) Up to 6 months on Barthel (z 2.06- 3.21, P0.04 -    | MDT                    |
| B34                   | Smith <i>et al.</i> (2006)  | community<br>rehab service<br>compared to<br>conventional<br>outpatient<br>service  | carers of<br>people with<br>acquired<br>brain injury     | Community,<br>UK | Community rehab   | Family Assessment Device, Family Needs Questionnaire General Health Questionnaire 28 Acceptance and Action Questionnaire | Significant<br>differences on<br>FAD, FNQ and<br>AAQ effect size<br>FAD 0.3, FNQ<br>0.6, AAQ 0.31.<br>No sig<br>difference on<br>GHQ | Community rehab team   |
| B37                   | Turner-<br>Stokes <i>et</i> | systematic review   | acquired<br>brain injury in                              | N/A              | multi-disciplinary<br>rehabilitation                              | No analysis of outcome   | Mild ABI strong evidence   | Multi-<br>disciplinary |

|      | al.<br>(2006)                     |   | adults of<br>working age  |                                  |   |  | suggested that most patients made a good recovery with provision of appropriate information, without additional specific intervention. moderate to severe ABI there is strong evidence of benefit from formal intervention. | rehabilitation         |
|------|-----------------------------------|---|---|----------------------------------|---|--|---|------------------------|
| B64  | Buffington<br>and Malec<br>(1997) | Cohort over 2<br>years  | 80 adults with traumatic or other acquired brain injury                                 | Regional<br>trauma<br>centre USA | vocational rehab  | Vocational outcome scale, satisfaction survey, independent living status, job type, rate of pay, and no of hours worked. | Service effective   | Vocational<br>rehab    |
| B113 | Ponsford<br>et al.<br>(2006)      | TBI pts with matched comparison group (recruited retrospectively) | 77 TBI pts with moderate to severe TBI matched to 77 controls (retrospective out pt TBI | Australia.<br>Community          | cf TBI group<br>receiving<br>community based<br>programme with<br>pts treated as out<br>pts(retrospective). | Structured Outcome Quest (covers ADL, employment, mobility, leisure, communication, emotional state,                     | No sig. diffs. in ADL performance or employment outcomes. community group had more communication  | Community<br>TBI rehab |

|      |  |  | pts).  |  |      | behaviour, cognitive function). Craig Handicap Assessment. Costs of therapy. FU at 2 yrs post injury.  | problems and more inappropriate behaviour. Costs need teasing out by Tracey- not sure what they are saying here!   |  |
|------|--|--|--|--|------|--|--|--|
| B114 | Ponsford<br>et al.<br>(2003)                     | Cohort of TBI pts and families recruited 2-5 yrs post injury | individuals with TBI recruited at clinic 2-5 yrs after injury by invitation to attend fu interview with their physician. Asked to bring family member. | Australia. Follow up of pts in community | None | Many! FAD (family Assessment Device), Leeds self asessment of anxiety and depression quest on cog, beh/emot changes, Criag Handicap (CHART), SIP (Sickness Impact Profile), Anger control quest. | Cf results with data from healthy controls, other TBI individuals, group with medical and group with psychiatric illness (other study data). Essentially group functioning in basic range (?). Anx and dep noted in relatives. | Outpatient<br>follow up<br>clinic  |
| B116 | Rice-Oxley<br>and<br>Turner-<br>Stokes<br>(1999) | Non-systematic<br>literature<br>review/ expert<br>opinion    | TBI, Stroke  | UK and<br>Overseas                       |      | NR   | NR   | Acute units, acute inpatient rehab, post acute rehab (inpatient, community) Vocational |

| B128 | Wade <i>et al.</i> (1997)  | Randomised control trial | 1156<br>consecutive<br>head injury<br>patients   | Outpatient<br>follow-up,<br>UK                     | Offered appointment or not  | Post concussion<br>symptoms,<br>head injury<br>follow-up quest  | No overall diff,<br>query benefit for<br>moderate or<br>severe   | Specialist<br>early TBI<br>team follow<br>up  |
|------|----------------------------|--------------------------|--|--|---|---|--|---|
| B130 | Wade <i>et al.</i> (1998)  | Randomised control trial | 314 patients<br>with head<br>injury  | Community<br>UK and<br>Overseas                    | Early intervention<br>by a specialist<br>service versus<br>TAU  | Head injury<br>follow-up quest,<br>post concussion<br>symptoms  | Less social<br>disability and<br>less severe<br>symptoms   | Specialist<br>early TBI<br>team<br>intervention   |
| B77  | Cope<br>(1995)             | Non-systematic<br>review | TBI  | Hospital<br>and<br>community<br>UK and<br>Overseas | many trials reviewed, divided into acute hospital, sub acute community and residential, and specialist vocational | vary according to study, including impairment, activity limitation, participation, resource use and costs | generally concludes that the totality of evidence is favourable, I fear that we need to say rather more than that. | Acute units, acute inpatient rehab, post acute rehab (inpatient, community) Vocational. |
| B82  | Eames <i>et al.</i> (1996) | Cohort                   | mixed brain<br>injury  | Rehab unit<br>residential                          | residential rehab   | change in need<br>for professional<br>care  | reduction in<br>need from 87%<br>to 55%, with a<br>mean of 11<br>months LOS  | residential<br>rehab unit<br>for severe<br>brain injury                                 |
| B110 | Mackay et<br>al. (1992)    | Comparison<br>study      | 38 severe<br>head injury,<br>21 no<br>formalised<br>TBI<br>programmes,<br>17 formal TBI<br>programmes. | Formal TBI<br>setting vs.<br>adhoc<br>In US        | care as given on<br>unit  | discharge to<br>home, cognitive<br>levels, length of<br>stay  | formalized programmes had shorter lengths of stay, cognitively higher levels and more discharges to home           | specialised<br>TBI facility   |
| B23  | Powell et al.              | RCT                      | 112 (TBI<br>(sustained   | East<br>London, UK                                 | outreach sessions in community  | Un-modofied<br>Barthel index,   | Outreach patients were   | community<br>based  |

|     | (2002)                        |                                 | between 3<br>months and<br>20 yrs<br>previously)<br>patients aged<br>16-65) - 54<br>randomised<br>to outreach<br>and 56 to<br>information | outreach<br>team<br>service          | settings (mean 2 sessions a week) compared to information on alternative resources. | BICRO-39<br>scales,<br>FIM+FAM,<br>HADS                                 | significantly more likely to show gains on the BI and BICRO-39 otal score and self- organistation and psychological wellbeing subscales. Magnitude of gains unrelated to time since injury. | rehabilitation<br>for severe<br>TBI |
|-----|-------------------------------|---------------------------------|---|--------------------------------------|---|---|---|-------------------------------------|
| B25 | Ricker <i>et al.</i> (2002)   | Anonymous<br>mail survey        | 71 individuals who had experienced acquired brain injury, all members of a brain injury association.                                      | Community,<br>USA                    | N/A   | N/A   | strong interest<br>in the possibility<br>of accessing a<br>tele-<br>rehabilitation<br>service.  | Tele-<br>rehabilitation             |
| A27 | Greenwood<br>et al.<br>(1994) | Geographically controlled trial | Closed head injury patients   | UK<br>Acute care<br>and<br>community | Case management   | Impairment, service use   | No difference   | Acute care and community            |
| B5  | de Guise<br>et al.<br>(2005)  | x-section cohort                | 348<br>consecutive<br>admissions<br>TBI   | Canada                               | N/A   | Galveston Orientation Amnesia Test, Glasgow coma scale, neurobehavioral | majority frontal<br>& temporal<br>lesions, mean<br>age 40   | Inpatient<br>Unit                   |

|     |                       |   |  |    |      | rating scale,<br>FIM, Glasgow m   |  |  |
|-----|-----------------------|---|--|----|------|---|--|--|
| B45 | Edwards et al. (2003) | Cohort study -<br>analysis of<br>database | 290 patients Discharged from hosp over 5 year period with brain injury | UK | None | Analysis of<br>database.<br>Standardised<br>measures<br>included FIM<br>and Barthel<br>plus descriptive<br>data | Stable case mix over 5 years, improvement in disability and dependency in majority of patients. Ethnic diversity didn't affect functional outcome. | inner city<br>rehabilitation<br>unit for<br>younger<br>people<br>following<br>brain injury |

# Appendix 15 Details of papers reporting models of neurological rehabilitation for people with spinal cord injury

| Paper<br>ID<br>number | Author(s)                   | Design                     | Subjects  | Setting  | Intervention  | Outcome<br>measures  | Results  | Model<br>identified  |
|-----------------------|-----------------------------|----------------------------|---|--|---|--|--|--|
| C3                    | Kirshblum<br>(2002)         | Discussion paper           | spinal cord injury  | Many   | None specifically   | None measured  | None but 2<br>papers are<br>cited as<br>providing<br>evidence for<br>benefits of<br>elements of the<br>system                      | Funding to entire network rather than individual elements in isolation             |
| B80                   | DeVivo <i>et al.</i> (1990) | Cohort study               | 800 SCI<br>Patients and<br>99 controls  | specialist<br>hospital unit,<br>USA                              | early vs late<br>referral to unit,<br>thereby looking<br>at effect of the<br>early care in the<br>unit compared to<br>early care<br>elsewhere | mainly length of<br>stay, some<br>"complications"<br>data, some<br>costs | LOS lower in<br>the early<br>referral group,<br>costs about the<br>same (unit cost<br>in early unit<br>higher than<br>alternative) | Early care in<br>spinal cord<br>injury rehab<br>unit VS<br>early care<br>elsewhere |
| B27                   | Ronen <i>et al.</i> (2004)  | Retrospective cohort study | 1411, 1117 with non- traumatic spinal cord lesions (NTSCL) and 250 with traumatic | Loewenstein<br>Rehabilitation<br>Hospital<br>Raanana,<br>Israel. | N/A   | Length of stay   | LOS is within<br>the range of<br>other European<br>countries.<br>Etioloy and<br>severity of SCL<br>were<br>associated with         | N/A  |

|     |                 |                                 | spinal cord<br>lesions (TSCL)   |                  |                      |   | different LOS.  |   |
|-----|-----------------|---------------------------------|---|------------------|----------------------|---|---|---|
| B33 | Smith<br>(2002) | Retrospective cohort comparison | spinal cord<br>injury patients<br>on national<br>database of<br>Spinal Injury<br>Association,<br>UK | community,<br>UK | specialist SCI rehab | Questionnaire<br>on secondary<br>complications<br>Modified FIM<br>CHART<br>Rating of life<br>satisfaction | SIU had lower incidence pressure sores, required less assistance in ADL, better social activities, but no sig difference in life satisfaction | Specialist<br>spinal<br>injuries<br>rehab |

# Appendix 16 Details of papers relating to models of neurological rehabilitation for people with Parkinson's disease

| Paper<br>ID<br>number | Author(s)                   | Design                            | Subjects   | Setting                     | Intervention   | Outcome<br>measures   | Results   | Model<br>identified  |
|-----------------------|-----------------------------|-----------------------------------|--|-----------------------------|--|---|---|--|
| B102                  | Jarman <i>et al.</i> (2002) | RCT                               | 1859 PD<br>patients on<br>GP register                    | community,<br>UK            | Specialist PD<br>Nurse vs routine<br>GP care                         | Survival, stand-<br>up test, dot in<br>square test,<br>bone fracture,<br>global health<br>question,<br>PDQ39,<br>Euroquol,<br>healthcare<br>costs | No significant difference in health outcome. Sig difference in scores on global health question in favour of nurses. No increase in patient healthcare costs. | Specialist PD<br>Nurse care  |
| B129                  | Wade <i>et al.</i> (2003)   | Randomised control trial          | 94 patients<br>with PD                                   | Community,<br>UK            | Programme of<br>multi-<br>disciplinary<br>rehab and group<br>support | PDQ-39, SF-36,<br>Euroqol-5D,<br>walking,<br>9holepeg,<br>HADS, UPDRS<br>items  | May improve<br>mobility, overall<br>decline in both<br>groups   | Multidisciplinary<br>day hospital<br>rehabilitation vs<br>routine care |
| C7                    | Trend <i>et al.</i> (2002)  | Before and<br>after<br>comparison | Parkinson's<br>disease and<br>no cognitive<br>impairment | day care unit<br>in DGH, UK | day hospital 1<br>day a week for 6<br>weeks with<br>carers           | Hoehn and Yahr<br>stage,<br>Barthel,HAD,<br>Euroquol5d,<br>Emerson and<br>Enderby   | Significant improvement in patients over time, no sig improvement in carers   | multidisciplinary<br>rehab in day<br>hospital                          |

|     |                           |                                    |   |  |   | measures of voice and articulation, timed 10m walk.  |   |  |
|-----|---------------------------|------------------------------------|---|--|---|--|---|--|
| B48 | Gage <i>et al.</i> (2006) | Cost -<br>consequences<br>analysis | 118<br>Parkinson's<br>patients<br>attending<br>day hospital | Day hospital<br>for<br>Parkinson's<br>disease<br>patients in<br>UK | Programme of MDT rehab, delivered one day per week for 6 wks. 1:1 interventions and group activities on each occasion | direct and overhead costs of treatment, participant travel. Patient and carer outcomes, social service utilization and satisfaction. | Main costs were day hosp overheads and hosp transport. Improved immediate functional outcome but this was lost over 4 mths, high satisfaction. No carer benefits noted. | Weekly MDT<br>rehab in day<br>hospital |

### Appendix 17 Details of papers relating to models of neurological rehabilitation for people with multiple sclerosis

| Paper<br>ID<br>number | Author(s)                    | Design                   | Subjects   | Setting                         | Intervention  | Outcome<br>measures   | Results   | Model<br>identified  |
|-----------------------|------------------------------|--------------------------|--|---------------------------------|---|---|---|--|
| B115                  | Pozzilli et al. (2002)       | RCT                      | 201 MS pts<br>randomised<br>2:1 to<br>intervention<br>(133) or<br>control (68).<br>MS clinically<br>defined. Lived<br>in area of<br>study. | Italy.                          | Home care v control (hospital care). Home care included visits, telephone contact, dedicated phone number for probs. MDT - medics, physio, nurse, sw, psychologist, co ordinator available. | baseline and 1<br>yr. EDSS,<br>MMSEFIM, mood<br>measure (STAXI,<br>STAI), CDQ- clic<br>dep quest,<br>SF36.Economic<br>evaluation. | Baseline diffs adjusted for in analysis. Essentially no sig diff in outcomes btw groups. Trends to improved qol in home group. Ec evaluation suggested home care made saving. | Home care<br>for MS pts  |
| B55                   | La Rocca<br>et al.<br>(1996) | Randomised control trial | 43 MS<br>patients at<br>risk of losing<br>their jobs   | Community<br>(United<br>States) | Job retention<br>programme<br>versus normal<br>medical care   | Job status  | No difference<br>(more about<br>feasibility than<br>effectiveness)  | Job retention<br>programme<br>versus<br>normal<br>medical care |
| B36                   | Thompson<br>(2000)           | Narrative<br>review      | people with<br>MS  | N/A                             | neurological<br>rehabilitation  | N/A   | N/A   | neurological<br>rehab for MS                                   |
| B38                   | Vickrey et al.               | Cohort<br>study 3        | people with<br>MS having   | Community<br>USA                | managed care<br>plan (IPA) vs fee-  | Symptom<br>management and   | few differences in symptom  | insurance<br>based   |

|  | (2000) | groups | physician<br>visits |  | for-service (FFS)<br>vs health<br>maintenance<br>organisation<br>(HMO) | information<br>needs | management, trend to more referrals and treatment in FFS group. No difference in access to disease modifying agents. General health and symptoms more often assessed in FFS and IPA systems |  |
|--|--------|--------|---------------------|--|--|----------------------|---|--|
|--|--------|--------|---------------------|--|--|----------------------|---|--|

# Appendix 18 Details of papers relating to models of neurological rehabilitation for people with epilepsy

| Paper<br>ID<br>number | Author(s)                            | Design                          | Subjects  | Setting  | Intervention                 | Outcome<br>measures   | Results   | Model<br>identified                          |
|-----------------------|--------------------------------------|---------------------------------|---|--|------------------------------|---|---|--|
| C5                    | Reynders<br>and Baker<br>(2002)      | Service review - Questionnaires | 16 centres  | UK   | N/A                          | N/A   | Progress is being made towards meeting the 1991 ILAE recommendations. Areas for development include nationally recognised training for neuropsychologists, developing centres of excellence, assessment of psychological health and quality of life assessment. | N/A  |
| B74                   | Bradley<br>and<br>Lindsay<br>(2001b) | Systematic review               | 647<br>participants<br>with<br>epilepsy                     | mixed  | specialist<br>epilepsy nurse | seizure freq,<br>medication,<br>social % psych<br>function,<br>knowledge,<br>cost of care | no sig diff   | specialist<br>epilepsy<br>nurse              |
| B47                   | Fraser <i>et al.</i> (1983)          | Cohort study                    | 106 patients<br>attending<br>regional<br>epilepsy<br>centre | epilepsy<br>centre<br>criteria<br>for<br>referral<br>not given | None                         | Descriptive<br>data collected.<br>No<br>standardised<br>outcome<br>measures               | Number of months<br>employed in last 2 years<br>predicts continued<br>employment. Subjects more<br>satisfied with one to one<br>contact than group<br>activities.   | Vocational<br>rehab in<br>Epilepsy<br>centre |

### Appendix 19 Details of papers reporting models of service delivery for more than one neurological condition: mixed

| Paper<br>ID<br>number | Author(s)                            | Design  | Subjects   | Setting           | Intervention                    | Outcome<br>measures  | Results   | Model<br>identified                                  |
|-----------------------|--------------------------------------|---|--|-------------------|---------------------------------|--|---|--|
| B32                   | Slade <i>et al.</i> (2002)           | RCT<br>intensive vs<br>standard<br>rehabilitation | patients<br>admitted to<br>rehab unit E 50<br>stroke,12 TBI,<br>18 other C 50<br>stroke, 14 TBI,<br>17 other   | rehab unit,<br>UK | intensity of<br>OT              | Length of stay,<br>Barthel   | Significant reduction in length of stay (14 days) with more intensive (67% more therapy) rehabilitation (PT and OT)  No significant difference in Barthel score | Intensive rehabilitation                             |
| C4                    | O'Connor<br>and<br>Delargy<br>(2003) | Survey  | 42 inpatients of<br>YDU in 2001:<br>13 had TBI, 11<br>sub arach, 7<br>"non traumatic<br>acquired brain<br>injury", 2 MS,<br>2 central<br>pontine<br>myelonolysis, 7<br>others. | YDU, Ireland      | Not an intervention study: none | Specialist nursing interventions (21 in vegetative state, 10 tracheotomies, 20 percutaneous feeding, 30 catheters, 31 needed hoist transfers. Mean Racho Los Amigos Level of Cognitive | See outcomes. Pts were admitted mean 627 days after onset of disability, and stayed for mean 621 days   | YDU for<br>selected<br>severely<br>affected<br>cases |

|     |                                     |                   |  |   |   | Function scale<br>18.5 (>15=severe<br>cognitive<br>disability) |   |                                    |
|-----|-------------------------------------|-------------------|--|---|---|--|---|------------------------------------|
| C6  | Thorn (2000)                        | Literature review | 13 original papers reviewed (sample sizes of papers ranged from 5 to 80) | neurological<br>rehabilitation<br>nursing in<br>USA, UK and<br>5 other<br>countries<br>unspecified up<br>to 1998. | N/A   | N/A  | Research in this area lacks depth and direction such that a sound evidence base cannot be developed at present. This speciality generates little research and what is produced lacks quality. | N/A                                |
| B19 | McMillan<br>and<br>Ledder<br>(2001) | Survey            | 40 Comm<br>rehab teams   | 25 Health<br>authorities,<br>London and<br>SE   | community<br>neuro-rehab<br>teams - self<br>defined | staff numbers,<br>workload                                     | 40 teams in<br>15.6 million<br>people, 35<br>teams surveyed:<br>incomplete<br>coverage, and<br>low rate per<br>head of brain<br>injury when<br>covered  | community<br>neuro- rehab<br>teams |

| B40 | Wilson <i>et al.</i> (2002) | survey             | 35 vegetative or minimally responsive          | hospitals,<br>Northern<br>Ireland | assessment<br>protocol | GCS, Rancho Los<br>Amigos Scale,<br>Wessex Head<br>Injury matrix   | 35 patients identified, reported unsatisfactory services, 7/12 in one unit changed 5/12 remained unaltered on RLA scale, 7 improved on WHIM 5 little progress | Survey , no comparison group                    |
|-----|-----------------------------|--------------------|--|-----------------------------------|------------------------|--|---|---|
| B42 | Beatty <i>et al.</i> (2003) | National<br>survey | 800 adults with<br>CP, MS, SCI or<br>Arthritis | Community,<br>USA                 | None                   | Access to services<br>from primary care<br>drs, specialist<br>services, rehab<br>services, equip,<br>medication<br>prescriptions | Only half population received the rehab services they needed. Respondents with poorest health and lowest incomes were least likely to receive health services | Access to cares services in chronic conditions. |

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