## Appendix 1

### Search strategies

#### Search strategy for MEDLINE

(\*motor neuron disease/ or \*amyotrophic lateral sclerosis/ or \*bulbar palsy, progressive/ or \*muscular atrophy, spinal/ or \*bulbo-spinal atrophy, x-linked/) and (exp \*Psychology, Social/ or exp \*Psychotherapy/ or exp \*"Quality of Life"/ or exp \*adaptation, psychological/ or exp \*attitude/ or exp \*emotions/ or exp \*motivation/ or exp \*Decision making/ or exp \*Depression/ or exp \*stress, psychological/ or exp \*Depressive Disorder/ or exp \*Anxiety Disorders/ or exp \*Self care/ or \*"Quality of Health Care"/ or \*"Patient Satisfaction"/ or exp \*Social Environment/ or exp \*Caregivers/ or exp \*health personnel/ or exp \*Professional-Patient Relations/ or exp \*Clinical Competence/)

#### Search strategy for PsychInfo

exp \*amyotrophic lateral sclerosis/ and (\*well being/ or exp \*adjustment/ or \*life satisfaction/ or exp \*mental health/ or \*positive psychology/ or exp \*"quality of life"/ or \*social networks/ or exp \*social groups/ or exp \*social support/ or exp \*support groups/ or \*caregivers/ or \*caregiver burden/ or exp \*family/ or clinicians/ or \*professional personnel/ or \*"quality of care"/)

## Appendix 2

### Scoping categorisation of studies meeting retention criteria

| **SSN role /s\*focus and study type** | **Number of studies** | **Percent of total in this category** | **Percent within category indexed in last year**  |
| --- | --- | --- | --- |
| *Patient wellbeing focus:* |  |  |  |
|  observational quantitative studies | 127 | 41 | 10 |
|  qualitative studies  | 46  | 15 | 9 |
|  intervention studies with any type of evaluation | 23 | 7 | 26 |
|  reviews of any type  | 13 | 4 | 15 |
| *Carer wellbeing focus:* |  |  |  |
|  observational quantitative studies | 60 | 19 | 13 |
|  qualitative studies | 25 | 8 | 20 |
|  intervention studies with any type of evaluation | 6 | 2 | 33 |
|  reviews of any type | 5 | 2 | 20 |
| *Focus on wellbeing of members of the patient’s wider social network – any study type* | 6 | 2 | 17 |
| *Focus on wellbeing of health professionals providing MND care – any study type* | 2 | 1 | 0 |

\* Some publications included more than one SSN role and were therefore counted more than once.

## Appendix 3

### Summary of included reviews

| **Review first author and year** | **SSN group:**  | **Aspects of wellbeing**  | **Types of studies included** | **Lead author discipline\*\*** |
| --- | --- | --- | --- | --- |
|  | **Patient** | **Carer** | **Broader network** | **Health professionals** |  |  |  |
| Bergin 2016 (Bergin and Mockford 2016) |  | √ |  |  | Types of support that may help or hinder carers in providing MND care | Any study design focusing on caring experience | Palliative care |
| Gluyas 2016 (Gluyas, Mathers et al. 2016) |  | √ |  |  | MND caregiver functioning and factors relevant for interventions  | Empirical studies (qualitative and quantitative) and reviews.  | Clinical psychology |
| Oliver 2016 (Oliver, Borasio et al. 2016) | √ | √ |  | √  | Provision of palliative care  | Guidelines, meta-analyses, controlled trials, cohort studies & case series | Palliative medicine |
| Gould 2015 (Gould, Coulson et al. 2015) | √ |  |  |  | Interventions  | Quantitative evaluations | Psychiatry, psychology and neuroscience |
| Murray 2015 (Murray and Butow 2016) | *√* | √ |  |  | Advance care planning | Quantitative and qualitative investigations  | Psychology |
| Aoun 2013 (Aoun, Bentley et al. 2013) |  | √ |  |  | Not limited | All empirical | Palliative care |
| Pagnini 2013 (Pagnini 2013) | √ | √ |  |  | Psychological wellbeing and quality of life | Quantitative\*  | Psychology |
| Foley 2012 (Foley, Timonen et al. 2012) | √ |  |  |  | Perceptions of services, care preferences | All empirical | Occupational therapy |
| Bede 2011 (Bede, Oliver et al. 2011) | √ | √ |  |  | Palliative care aspects | Guidelines | Neurology |
| Mockford 2006 (Mockford, Jenkinson et al. 2006) | Conclusions  | √ |  |  | Not limited | Assessment or interview on carer impact or carer views of services | Health services research |

\* Restriction not stated, but virtually all studies described are quantitative

\*\* Using qualifications or, if these are not provided, employing department

## Appendix 4

### Interventions suggested in review literature for possible development and testing

* Psychotherapies for patients or carers: design and timing of these (eg expressive disclosure, CBT, hypnosis, dignity therapy, counselling, existentially-focused therapies such as life review)
* Psycho-educational interventions for carers including problem-solving, coping skills, self-care, understanding and managing patients’ neurobehavioral changes, maintaining relationship quality (including intimacy), and identifying and valuing beliefs that give meaning to life: design, targeting and timing
* Social support building interventions for patients or carers
* Decision supports for patients: design and timing (to support advance care planning but also other health care decisions)
* Information provision
* Health and social service changes to improve staff skills and service relevance to patient and carer needs, and reduce burden of accessing them: design, timing and implementation