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## Appendix 1

The HighCALS group: Ammar Al-Chalabi, Rachel Archer, Wendy Baird, Daniel Beever, Margaret Boddy, Mike Bradburn, Janet Cade, Mark Clowes, Elizabeth Coates, Cindy Cooper, Munira Essat, Gemma Hackney, Vanessa Halliday, Gillian Marsden, Christopher McDermott, Paul Norman, Ann Quinn, Pamela Shaw, Theocharis Stavroulakis, Martin Turner, David White, Sean White, Isobel Williams, Tracey Young and Nicolò Zarotti.

## Appendix 2 Example Search Strategy (MEDLINE)

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R) <1946 to April 11 2018>

Search Strategy:

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- 1 motor neuron disease/ or amyotrophic lateral sclerosis/ (19758)
  - 2 exp motor neuron disease/ or als.ti,ab. or (pwALS or lateral sclero\* or motor neuron\* disease or MND or progressive muscular atrophy or progressive bulbar palsy or kennedy\* disease or lou gehrig\* disease).mp. (42089)
  - 3 nutritional support/ or enteral nutrition/ or exp parenteral nutrition/ or exp Malnutrition/ (152907)
  - 4 (overfeed\* or overfed\* or PEG or PIG or RIG or gastrostom\* or kalori\* or hypercalori\* or nutrition\* or ONS or vitamin\* or DEANNA or (energy adj2 intake) or (weight adj2 (manag\* or maintain\* or mainten\*))).mp. (820989)
  - 5 (recipe\* or "meals on wheels" or (monitor\* adj2 swallow\*) or (adapt\* adj2 (cutlery or kni\* or fork\* or spoon\*)) or ("food first" or "sip feed\*" or "g tube\*" or "g button\*" or "gastric button" or ((food\* or feed\* or eat\* or meal\* or diet\* or shop\* or financial) adj3 (support\* or assist\* or help\* or advi\* or adapt\* or modif\* or treat\* or intervention\* or fortif\* or enrich\* or enteral or tube))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (118524)

- 6 (dietetic\* or malnutrition or malnourish\* or undernutrition or undernourish\* or under-nutrition or under-nourish\* or underweight or ((under or los\*) adj2 weight)).mp. (159536)
- 7 exp animals/ (21464904)
- 8 exp humans/ (17017485)
- 9 7 not 8 (4447419)
- 10 1 or 2 (42089)
- 11 3 or 4 or 5 or 6 (1032684)
- 12 10 and 11 (1595)
- 13 12 not 9 (1401)
- 14 limit 13 to english language (1203)
- 15 remove duplicates from 14 (1197)

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### Appendix 3

	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Expectation (information need)	Understanding of current nutritional management in health services for pwALS  Evidence must describe the delivery of any form of nutritional care by healthcare professionals to pwALS (including those with a gastrostomy feeding tube). Nutritional care may be delivered face to face or via virtual/remote routes.	Evidence that does not describe the delivery of nutritional care by healthcare professionals to pwALS e.g., experimental studies describing the development or feasibility of an intervention rather than existing delivery of nutritional care
Client group	Adults with ALS >18 years of age (all stages of disease)	Children and adolescents ≤17 years of age
Location	Care setting: All healthcare settings	Evidence originating from countries other than, North America, Australasia

	Geographical: European countries based on membership of ENCALS (including UK), North America and Australasia	and countries that are not members of ENCALS
Impact (outcome)	Mapping of current nutritional management of pwALS to inform design of further research and nutritional interventions.	Non ALS patients and not nutritional management
Professionals	Any healthcare professionals involved in delivering nutritional care to pwALS	Carer's, family members and other non-healthcare professionals
Service	Nutritional management services	Non-nutritional management
Study design	Quantitative, qualitative and mixed methods research studies.  Local and national guidelines and related studies (UK only)	Systematic reviews, reviews, commentaries, editorials and letters
Language	Evidence published in full in English	Evidence not published English language
Dates	Evidence published between January 2008 – April 2018	Evidence published in 2007 and earlier.
ENCALS, European Network to Cure Amyotrophic Lateral Sclerosis; pwALS, people with Amyotrophic Lateral Sclerosis		