# **Supplement 1. Search terms**

## **Search terms for PubMed**

* 1. **ALS**

(((((((((clinical trial as topic[MeSH Terms]) OR (clinical trial\*[Title/Abstract])) OR (Randomized placebo control[Title/Abstract])) OR (Randomised placebo control[Title/Abstract])) OR (Survey\*[Title/Abstract])) OR (Qualitative research[Title/Abstract])) OR (Interview\* [Title/Abstract])) OR (Questionnaire\* [Title/Abstract])) OR (Focus group\* [Title/Abstract])) OR (Participant-observation\* [Title/Abstract])) AND (((((((((((attitude to health[MeSH Terms]) OR (participate, refusal to[MeSH Terms])) OR (participat\*[Title/Abstract])) OR (patient perspective\*[Title/Abstract])) OR (patient selection\*[Title/Abstract])) OR retention [Title/Abstract])) OR (attitude\*[Title/Abstract]) OR Recruit\* [Title/Abstract] OR Enrol\* [Title/Abstract]) OR Accrual [Title/Abstract]) OR Attrition [Title/Abstract]) AND (((((((Amyotrophic Lateral Sclerosis\*[Title/Abstract]) OR (Gehrig\*[Title/Abstract])) OR (Charcot Disease[Title/Abstract])) OR (Guam disease[Title/Abstract])) OR (motor neuron disease[MeSH Terms])) OR (Amyotrophic lateral sclerosis[MeSH Terms])) OR (ALS[Title/Abstract]))

* 1. **Alzheimer’s disease**

(((((((((clinical trial as topic[MeSH Terms]) OR (clinical trial\*[Title/Abstract])) OR (Randomized placebo control[Title/Abstract])) OR (Randomised placebo control[Title/Abstract])) OR (Survey\*[Title/Abstract])) OR (Qualitative research[Title/Abstract])) OR (Interview\* [Title/Abstract])) OR (Questionnaire\* [Title/Abstract])) OR (Focus group\* [Title/Abstract])) OR (Participant-observation\* [Title/Abstract])) AND (((((((((((attitude to health[MeSH Terms]) OR (participate, refusal to[MeSH Terms])) OR (participat\*[Title/Abstract])) OR (patient perspective\*[Title/Abstract])) OR (patient selection\*[Title/Abstract])) OR retention [Title/Abstract])) OR (attitude\*[Title/Abstract]) OR Recruit\* [Title/Abstract] OR Enrol\* [Title/Abstract]) OR Accrual [Title/Abstract]) OR Attrition [Title/Abstract])AND ((((((((alzheimer disease[MeSH Terms]) OR (Alzheimer\*[Title/Abstract])) OR (senile dementia[Title/Abstract])) OR (Primary Senile Degenerative Dementia[Title/Abstract])) OR (Presenile Dementia[Title/Abstract])) OR (diffuse cortical sclerosis[Title/Abstract]))

* 1. **Huntington’s disease**

(((((((((clinical trial as topic[MeSH Terms]) OR (clinical trial\*[Title/Abstract])) OR (Randomized placebo control[Title/Abstract])) OR (Randomised placebo control[Title/Abstract])) OR (Survey\*[Title/Abstract])) OR (Qualitative research[Title/Abstract])) OR (Interview\* [Title/Abstract])) OR (Questionnaire\* [Title/Abstract])) OR (Focus group\* [Title/Abstract])) OR (Participant-observation\* [Title/Abstract]))AND (((((((((((attitude to health[MeSH Terms]) OR (participate, refusal to[MeSH Terms])) OR (participat\*[Title/Abstract])) OR (patient perspective\*[Title/Abstract])) OR (patient selection\*[Title/Abstract])) OR retention [Title/Abstract])) OR (attitude\*[Title/Abstract]) OR Recruit\* [Title/Abstract] OR Enrol\* [Title/Abstract]) OR Accrual [Title/Abstract]) OR Attrition [Title/Abstract])AND (((((huntington disease[MeSH Terms]) OR (huntington\*[Title/Abstract])) OR (Chorea\*[Title/Abstract])) OR (VEOHD[Title/Abstract])) OR (Woody Guthrie's Disease[Title/Abstract]))

* 1. **Parkinson’s disease**

(((((((((clinical trial as topic[MeSH Terms]) OR (clinical trial\*[Title/Abstract])) OR (Randomized placebo control[Title/Abstract])) OR (Randomised placebo control[Title/Abstract])) OR (Survey\*[Title/Abstract])) OR (Qualitative research[Title/Abstract])) OR (Interview\* [Title/Abstract])) OR (Questionnaire\* [Title/Abstract])) OR (Focus group\* [Title/Abstract])) OR (Participant-observation\* [Title/Abstract])) AND (((((((((((attitude to health[MeSH Terms]) OR (participate, refusal to[MeSH Terms])) OR (participat\*[Title/Abstract])) OR (patient perspective\*[Title/Abstract])) OR (patient selection\*[Title/Abstract])) OR retention [Title/Abstract])) OR (attitude\*[Title/Abstract]) OR Recruit\* [Title/Abstract] OR Enrol\* [Title/Abstract]) OR Accrual [Title/Abstract]) OR Attrition [Title/Abstract])AND ((((((parkinson disease[MeSH Terms]) OR (Parkinson\*[Title/Abstract])) ) OR (hypokinetic rigid syndrome[Title/Abstract])) OR (paralysis agitans[Title/Abstract])) OR (shaking palsy[Title/Abstract]))

## **Search terms for EMBASE**

* 1. **Initial search (up to 2022)**
     1. **ALS**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR   
'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw) AND ('amyotrophic lateral sclerosis':ab,ti,kw OR 'amyotrophic lateral sclerosis'/exp OR 'motor neuron disease'/exp OR 'motor neuron disease':ab,ti,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2000]/sd NOT [20-01-2022]/sd

* + 1. **Alzheimer’s disease**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR 'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw) AND ('alzheimer disease'/exp OR 'Alzheimer\*':ti,ab,kw OR 'senile dementia\*':ab,ti,kw OR 'Presenile Dementia':ab,ti,kw OR 'Primary Senile Degenerative Dementia':ti,ab,kw OR 'diffuse cortical sclerosis':ti,ab,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2000]/sd NOT [20-01-2022]/sd

* + 1. **Huntington’s disease**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR 'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw)AND ('Huntington chorea'/exp OR 'Huntington\*':ti,ab,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2000]/sd NOT [20-01-2022]/sd

* + 1. **Parkinson’s disease**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR   
'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw) AND ('Parkinson disease'/exp OR 'parkinson\*':ti,ab,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2000]/sd NOT [20-01-2022]/sd

* 1. **Updated search (January 2022 – May 2023)**
     1. **ALS**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR   
'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw) AND ('amyotrophic lateral sclerosis':ab,ti,kw OR 'amyotrophic lateral sclerosis'/exp OR 'motor neuron disease'/exp OR 'motor neuron disease':ab,ti,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2022]/sd NOT [15-05-2023]/sd

* + 1. **Alzheimer’s disease**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR 'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw) AND ('alzheimer disease'/exp OR 'Alzheimer\*':ti,ab,kw OR 'senile dementia\*':ab,ti,kw OR 'Presenile Dementia':ab,ti,kw OR 'Primary Senile Degenerative Dementia':ti,ab,kw OR 'diffuse cortical sclerosis':ti,ab,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2022]/sd NOT [15-05-2023]/sd

* + 1. **Huntington’s disease**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR 'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw)AND ('Huntington chorea'/exp OR 'Huntington\*':ti,ab,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2022]/sd NOT [15-05-2023]/sd

* + 1. **Parkinson’s disease**

('clinical trial (topic)'/exp OR 'clinical trial\*':ab,ti,kw OR 'Randomized placebo control':ab,ti,kw OR 'Randomised placebo control':ab,ti,kw OR 'Survey\*':ab,ti,kw OR 'Qualitative research':ab,ti,kw OR 'Interview\*':ab,ti,kw OR 'Questionnaire\*':ab,ti,kw OR   
'Focus group\*':ab,ti,kw OR 'participant observation\*':ab,ti,kw) AND ('attitude to health'/exp OR 'refusal to participate'/exp OR 'participat\*':ab,ti,kw OR 'patient perspective\*':ab,ti,kw OR 'patient selection':ab,ti,kw OR 'retention':ab,ti,kw OR 'attitude\*':ab,ti,kw OR 'recruit\*':ab,ti,kw OR 'Attrition':ab,ti,kw OR 'enrol':ti,ab,kw OR 'Accrual':ti,ab,kw) AND ('Parkinson disease'/exp OR 'parkinson\*':ti,ab,kw) AND ([embase]/lim NOT 'conference abstract'/it) AND [01-01-2022]/sd NOT [15-05-2023]/sd