BSRM Position Paper on role of palliative care interventions for people living with long term neurological conditions

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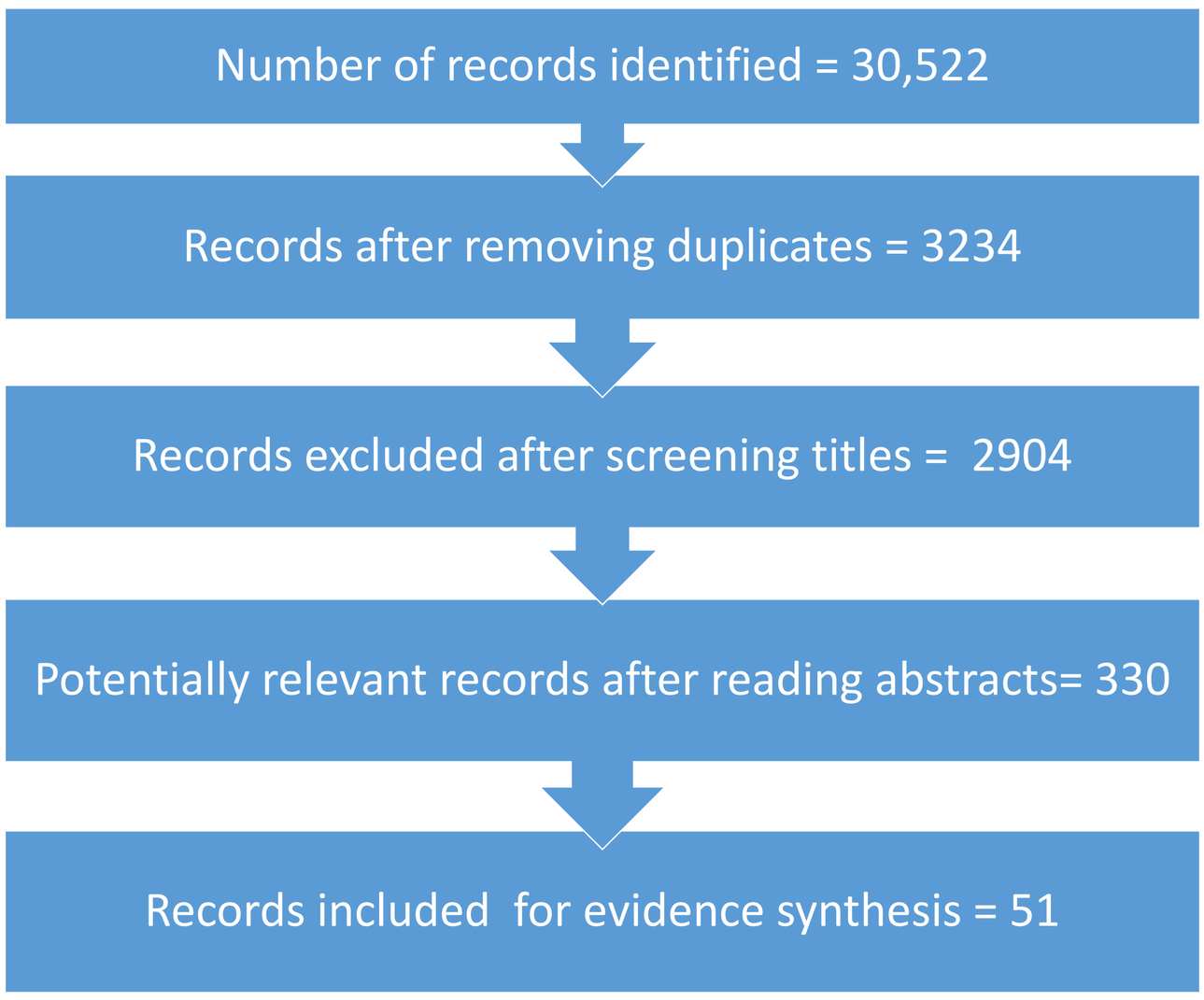
Background

Much of the guidance and protocols of palliative care services have been directed towards the care of patients with cancer. While it may be possible to extrapolate some of these to people with LTNCs, there are obvious differences between the two groups; the clinical course of the illness being the most important.

Aim of this project was review the literature on palliative care interventions for people with long-term neurological conditions and produce evidence based position paper using simplified version of the GRADE method

Methods

- **Data bases searched:** MEDLINE, EMBASE, CINAHL, PsycINFO, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Database of Abstracts of Reviews of Effects, NHS Economic Evaluation Database and Health Technology Assessment Database.
- Evidence to underpin the recommendations in the position statement is assimilated using a simplified version of the GRADE method (Turner-Stokes et al 2016).



Review goals with the patient

Consider revising / removing some goals and establishing new goals.

Make Emergency Care Plans for :

Symptom relief
Avoiding hospital admissions
Reducing unnecessary / inappropriate medication
Avoiding certain medical interventions
Avoiding investigations
Do not attempt cardiopulmonary resuscitation decisions
Ensuring anticipatory medication is available at home or nursing home

Consider obtaining specialist palliative care input for difficult to treat or complex issues, including

Pain
Breathlessness
Nausea and vomiting
Continence
Constipation
Sleep disturbances
Restlessness and agitation.
Psychosocial and spiritual distress

Offer relatives and carers

Opportunity to discuss prognosis and end of life issues
Information about appropriate local services for help with stress and grief
Training and developing skills to use specialist equipment and solve common practical problems

Trainees in Rehabilitation medicine

Gain palliative care skills by attending specialist palliative care clinics and ward rounds and /or working with a rehabilitation consultant with a special interest in neuro-palliative care

Commissioning

The clinical commissioners should commission rehabilitation services including palliative care and end of life care
Time to be allocated in job plans to address palliative care issues and end of life care
Do not discharge persons as they approach end of life
Palliative care / End of life care should be carried out by a team familiar t the patient and family

Key Recommendations for Rehabilitation medicine teams

Be proactive in offering discussion regarding end of life if any of the following occurs

1. Two or more unplanned emergency hospital admissions in 6 months
2. An episode of aspiration pneumonia with general deterioration
3. Cognitive and communication issues likely to interfere with meaningful discussions
4. Swallowing problems with weight loss of 10% or more
5. Dyspnoea and persistent hypoventilation with forced vital capacity of less than 50% in people with neuromuscular respiratory compromise
6. Marked decline in functional status
7. Estimated life expectancy of less than 12 months
8. When considering or starting a new intervention, such as gastrostomy or ventilator support