

**Patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition: a qualitative systematic review and meta-aggregation.**

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# Review team

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# Why was review needed?

Despite policy and guidelines regarding community service provision, recent evidence indicates that community services are not adequately supporting quality of life for people with long-term neurological conditions (LTNC) or preventing crises and/or acute admissions

Aim: To inform future policy and practice development

## **Review Objectives**

To identify patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition.

To identify service users' perceptions of the impact of community rehabilitation and/or support services on their quality of life.

# Review approach

Joanna Briggs Institute (JBI) approach and tools

<https://joannabriggs.org/assets/docs/sumari/ReviewersManual-2014.pdf>

Qualitative meta-aggregation

Critical appraisal checklist and data extraction forms (JBI Quality Appraisal and Review Instrument - JBI-QARI)

# Inclusion criteria (PICo)

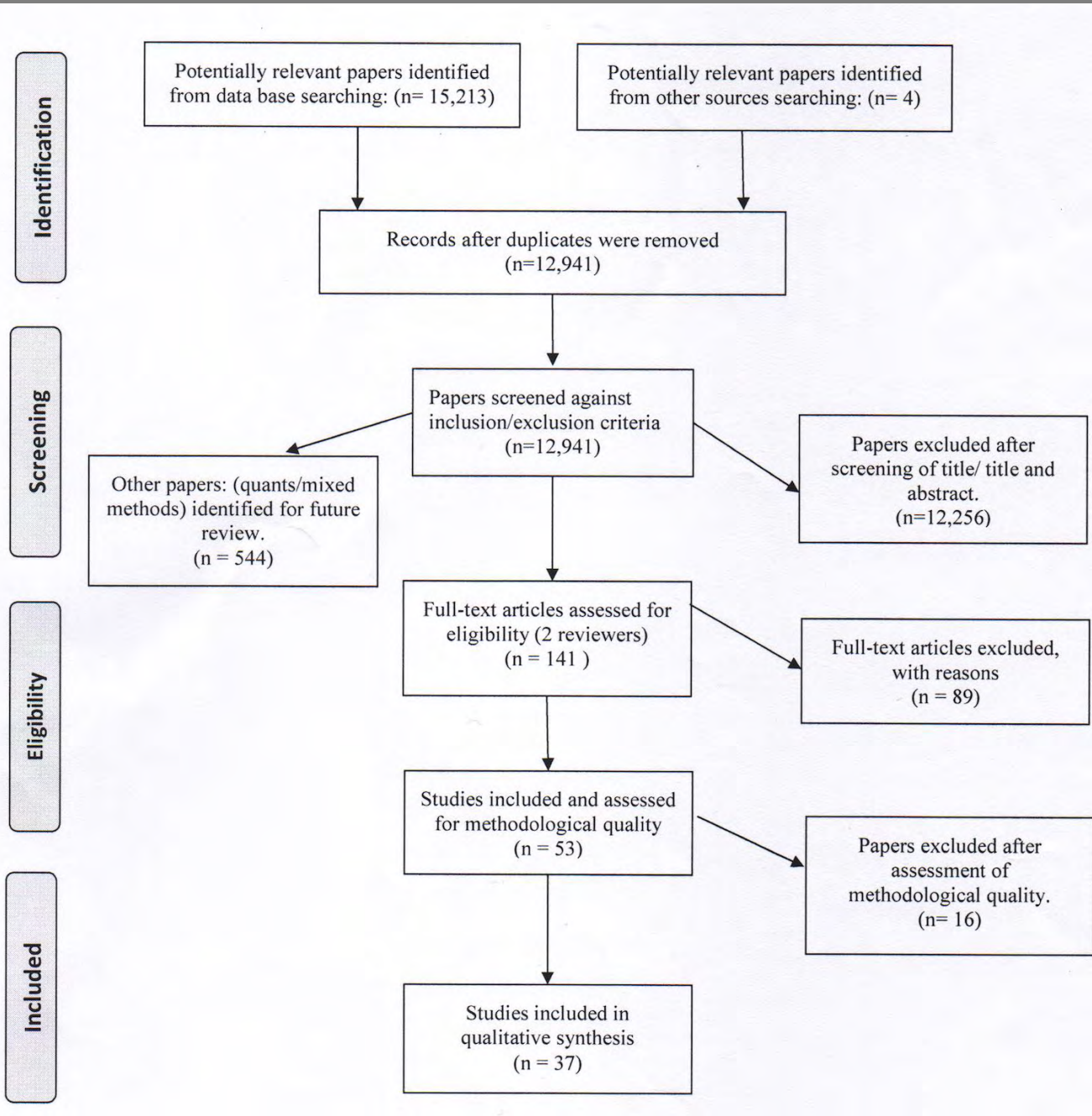
**(P) Population:** Adults, age > 18, living with progressive (MS, PD) and stable (ABI other than stroke, Dystonia) LTNC who are using Community Rehabilitation and Support services.

**(I) Phenomenon of Interest:** Patient reported experiences of community rehabilitation and support services which relate to the activity and participations domain of the ICF

**(Co) Context:** Community rehabilitation and support services which enable and support people with LTNC to lead a full life, provided at home, in the community or in an outpatient setting.

# Types of studies

All qualitative designs, to capture the whole phenomenon of interest including phenomenology, grounded theory, ethnography, action research, descriptive qualitative studies and case studies.





# Characteristics of participants

People with ABI (n=205)

People with MS (n=136)

People with Parkinson's Disease (n=119)

Ages ranged between 18 – 82 years, representing experiences of people with neurological conditions across the lifespan.

Gender - Male (n=253) and female (n=235) participants were represented within the studies. However, the exact number is unknown since four of the studies did not report gender

# Method

Data extraction tool piloted, then used to extract data from included papers, including illustrative quotes

One hundred and one qualitative findings of relevance to the study objectives were extracted from the included studies

Process of meta-aggregation, grouped findings into 17 categories and then 7 synthesised findings

Findings U = unequivocal → C = Credible	Categories →	Synthesised Finding' (SF)
<p><i>Support and opportunities for social interaction with other PwPD. PD [126] U.</i></p> <p><i>'fun factor' associated with socialization and participation MS [93] U</i></p> <p><i>Social value of the programme MS [92] U</i></p> <p><i>Social aspects of group membership valued MS [90] U</i></p> <p><i>Enjoyed social interaction that occurred as part of the exercise group MS [128] U</i></p> <p><i>Outcomes predominantly on social aspects of the programme rather than on the physical ones PD [112] U</i></p>	<p><b>Opportunities for social interaction with peers with similar long term neurological conditions was valued</b></p>	<p><b>SF5. People value opportunities for peer support and social interaction with peers (people with similar long term neurological condition). These experiences may result in friendships, a feeling of collectivism, and encouragement for self-efficacy and self-management.</b></p>
<p><i>Peer support, commonalities and friendship gained MS [95] U</i></p> <p><i>Initial worries and concerns about group setting but over time found it supportive. MS [95] U</i></p> <p><i>Group choral singing influenced physical and mental health PD [97] U</i></p> <p><i>Shared group experience, support and shared voice MS [125] U</i></p> <p><i>Disease-specific exercise programme beneficial for sharing information with others in 'the same boat' PD [112] U</i></p> <p><i>Support and reassurance gained from others in the same situation. BI [78] U</i></p>	<p><b>Sharing of experiences and support with groups of other people with similar long term neurological conditions was important</b></p>	
<p><i>Support from the group was important PD [96] U</i></p> <p><i>Peer support groups with PwMS/ expert patients contributed to self-efficacy/ successful self-management. MS [107] U</i></p> <p><i>Information and advice from peers with MS [88] C</i></p> <p><i>Support and reassurance gained from others in the same situation BI [78] U</i></p> <p><i>Sharing of knowledge and experiences which could potentially assist others MS [128] C</i></p> <p><i>Group sessions provided enjoyment, reassurance and shared experiences MS and ABI [91] U</i></p> <p><i>Motivation and support from group structure of the class PD [97] U</i></p> <p><i>Positive effects of exercising in a group include shared understanding, incentive, competition, and motivation PD [113] U</i></p> <p><i>Empowerment, confidence and sense of achievement gained from group experience MS [90] U</i></p> <p><i>Learning from group rehabilitation helped adapt to change in home role/responsibilities ABI [108] C</i></p> <p><i>Encouragement from peers with MS on programme. MS [92] U</i></p>	<p><b>Peer support resulted in feelings of encouragement, friendship, self-efficacy and successful self-management.</b></p>	

# Key findings

The majority of people with LTNC were **self-managing** most of the time and interactions with professionals were one small aspect of their lives.

Our synthesised findings demonstrated that perceptions of process quality was determined by **interactions** with individual professionals, and these interactions had an impact on **engagement** (active participation), self-efficacy, self-management and motivation.

People with LTNC perceived that **informal support** (physical, emotional, administrative) could be maximised with appropriate assistance from community rehabilitation and support services. These ideas supported the argument that individual environments and social situations should frame rehabilitation and support.

# Experience of interactions with professionals

Interactions with some professionals provided **active participation**, choice, confidence and autonomy in decision-making, **engagement** (active participation) during encounters with professionals was valued.

*However*

Interactions with some professionals were **disempowering** and **depersonalised**, more traditional **didactic** approaches continued to exist, which did not accommodate preferences and individual needs of people with LTNC.

# Strategies for enhancing engagement with community rehabilitation

People with both stable (ABI) and progressive (MS) LTNC believed that **goals** had the potential to enhance motivation, supporting current research for patient centred goal planning.

Growing evidence for **peer support groups** by highlighting their potential impact on motivation, self-efficacy and self-management.

# Importance of supporting PWLTC in their own environment

People with LTNC perceived that **informal support** (physical, emotional, administrative) could be maximised with **appropriate assistance** from community rehabilitation and support services. These ideas support the argument that individual environments and social situations should frame rehabilitation and support

# Experiences of information provision

Our findings demonstrated that **effective communication skills**, **specialist knowledge** and an **individualised approach** to information provision was valued but information needed to be **accurate and timely** if it was to empower people with LTNC.

However, we found that the process of **providing information is not always adequate** within community rehabilitation/ support services for people with LTNC.



# Conclusion

The review produced knowledge which highlighted that process quality [courtesy, respect, choice, autonomy, information provision and communication], and activities associated with patient centred care are important to people with LTNC

Current and future community rehabilitation and support services should consider how patient reported experiences can be used as indicators of process quality during monitoring and evaluation of activities of patient centred care.