Quality of life measurement in people with multiple long-term conditions: a co-produced scoping review and visual evidence map

Megan A Kirk, Marta Santillo, Laura J Gray, Thomas Beaney, Forhad Chowdhury, Jonathan A Batty, Vishal R Aggarwal, Lihua Wu, Claire L Brockett, Nathan Davies, Nia W Roberts, Edmund Brooks, Lucina Wilde, Tanatswa Muzembe, William Crabtree, Hannah M L Young

Adults with multiple long-term conditions (MLTC) have complex health challenges that can affect their quality of life (QoL), yet existing QoL measures remain largely generic and might not capture the complexity of MLTC. In this scoping review, we systematically mapped the development and use of QoL measures in adults with MLTC. QoL tools were identified, and measure components were charted using WHO's International Classification of Functioning, Disability and Health (ICF). Patient and public representatives contributed to the methodology, interpretation, and co-production of a visual evidence map to support knowledge translation, including identifying whether current measures capture what matters most to people with MLTC. 77 studies encompassing 754 029 participants were included, mostly conducted in primary care settings (42 [55%]) and defining MLTC as the co-existence of two or more conditions (53 [69%]). Overall, 18 measures derived from eight core QoL scales were identified, with the EuroQol family most frequently used (50 [65%] of 77 studies). Only two measures were developed specifically for populations with MLTC, although neither has subsequently been used to assess QoL in people with MLTC. One measure was validated in populations with MLTC but rarely used (2 [3%] of 77 studies). ICF mapping revealed that components predominantly captured activities and participation (236 [41%] of 574 components) and body functions (188 [33%]), with low coverage of environment (75 [13%]). Our findings highlight that generic QoL measures dominate despite their low capacity to fully capture the complexity of MLTC. QoL measurement requires person-centred and flexible approaches that better reflect the diverse experiences of people with MLTC.

Introduction

Population ageing, health inequalities, changing environmental and behavioural risks, and advances in chronic condition management mean that more people are living with multiple long-term conditions (MLTC; also referred to as multimorbidity) globally.[1] Prevalence estimates are complicated by heterogeneity across studies,[2] although MLTC affect more than half of adults older than 60 years (ie, older adults).[3,4] The high prevalence of MLTC places substantial strain on health-care systems, which are typically organised around the management of single conditions, creating challenges in navigating complex and fragmented care pathways.[5–7] In addition, the evidence for treatments used in people with MLTC often comes from trials of single conditions, leading to uncertainty about their effectiveness in people with MLTC. At present, there is little evidence to support the implementation of MLTC-specific interventions.[8] These interrelated challenges lead to poorer health outcomes,[9] higher health-care utilisation,[10,11] and greater treatment burden,[6] all of which contribute to lower quality of life (QoL) among people with MLTC.[12,13]

QoL, as defined by WHO, refers to an individual's perception of their position in life within their cultural and value context[14] and is a core outcome in MLTC research.[15] A 2019 systematic review reported a consistent association between an increasing number of long-term conditions and lower QoL; however, the measures used were not developed for people with MLTC.[12] Subsequent reviews assessing the use, adequacy, and validity of patient-reported outcome measures in MLTC research have also found no MLTC-specific QoL tools and have highlighted limitations in development methods, content relevance, and performance of generic measures for MLTC.[16,17]

Despite recognition of these limitations, no comprehensive synthesis to date has elucidated which QoL measures have been used in MLTC research, whether they have been developed or validated for MLTC, or which components of QoL they capture. To move beyond simply describing the QoL measures used, we mapped the content of each measure to the WHO International Classification of Functioning, Disability and Health (ICF). The ICF provides a holistic framework for understanding health, encompassing body functions, activities, participation, and environmental influences.[18] Although widely applied to single conditions,[19–21] the ICF has not been systematically applied to QoL measurement in people with MLTC. The use of the ICF facilitates comparison of the concepts captured across different instruments using a common, internationally recognised, aetiologically neutral, and disease-agnostic framework. This approach identifies domains that are well represented, under-represented, or absent from current QoL measurement in MLTC.

In this scoping review, we aimed to identify the QoL measures used in studies involving people with MLTC; evaluate whether these measures were developed or validated for MLTC; and, for each measure, examine the QoL components included using the ICF framework.

Lancet Prim Care 2026

Published Online
https://doi.org/10.1016/j.lanprc.2026.100214

Department of Psychiatry (M A Kirk PhD), **Nuffield Department of Primary Care Health Sciences** (M A Kirk, M Santillo PhD, F Chowdhury MBBS), **NIHR Oxford Health Biomedical Research Centre, Warneford Hospital** (M A Kirk), **Nuffield Department of Medicine** (F Chowdhury), **and Bodleian Health Care Libraries** (N W Roberts MSc), **University of Oxford, Oxford, UK; Department of Population Health Sciences** (Prof L J Gray PhD), **NIHR Applied Research Collaboration East Midlands** (Prof L J Gray), **Leicester British Heart Foundation Centre of Research Excellence** (Prof L J Gray), **NIHR Leicester Biomedical Research Centre** (Prof L J Gray), **and Leicester Diabetes Centre, College of Life Sciences** (L Wilde MPhil, T Muzembe MSc, W Crabtree BSc, H M L Young PhD), **University of Leicester, Leicester, UK; The George Institute for Global Health, Imperial College London, London, UK** (T Beaney PhD); **Hull York Medical School, University of York, York, UK** (J A Batty PhD); **Academic Cardiovascular Unit, James Cook University Hospital, South Tees Hospitals NHS Foundation Trust, Middlesbrough, UK** (J A Batty); **School of Dentistry, Faculty of Medicine and Health, University of Leeds, Leeds, UK** (V R Aggarwal PhD); **School of Nursing, Allied and Public Health, Faculty of Health, Science, Social Care and Education, Kingston University London, London, UK** (L Wu PhD); **School of Mechanical, Aerospace and Civil Engineering, University of Sheffield,**

Sheffield, UK (Prof C L Brockett PhD); **Patient and Public Representative, Wales, UK** (N Davies MPhil); **Patient and Public Representative, McPin Foundation, London, UK** (E Brooks MA); **Therapy Department, University of Hospitals of Leicester NHS Trust, Leicester, UK** (H M L Young); **NIHR Leicester Biomedical Research Centre, University of Leicester and University Hospitals of Leicester NHS Trust, UK** (H M L Young)

Correspondence to: Dr Megan A Kirk, Department of Psychiatry, University of Oxford, Oxford OX3 7JX, UK **megan.kirkchang@psych.ox.ac.uk**

See Online for appendix

Methodology

Protocol and registration

This scoping review was conducted in accordance with the methodological framework for scoping studies[22] and Joanna Briggs Institute Manual for Evidence Synthesis.[23] We followed the PRISMA-ScR checklist (appendix pp 1–2),[24] and our full protocol has been published.[25]

Search strategy and selection criteria

A structured search strategy using Medical Subject Heading terms and free-text keywords was developed and tested in consultation with an experienced librarian (NWR).[25] Search terms were grouped into conceptual domains that corresponded to the Population-Concept-Context (PCC) framework[24] and were combined using Boolean operators (appendix pp 3–4). We searched MEDLINE, Embase, PsycINFO, CINAHL, and the Science Citation Index and Social Science Citation Index for papers published in English from database inception to April 2, 2026. Reference lists of included studies and relevant reviews were also searched. We also conducted a structured Google Scholar search, restricted to the first 10 pages to locate grey literature sources (appendix pp 4).

Inclusion criteria were developed a priori to identify relevant sources of evidence and used the PCC framework.[24] Population: studies that examined adults (aged ≥18 years) living with two or more long-term conditions. The definition of MLTC followed that of the Academy of Medical Sciences[1]—the presence of two or more long-term conditions in a single individual, including any combination of a mental health condition; a physical, non-communicable health condition; and a chronic infectious disease. Studies that required a single index condition or examined co-morbidities in the context of a single index condition were excluded. Concept: studies that investigated the development, conceptualisation, or application of QoL measures for adults with MLTC were included. Guided by the WHO definition of QoL,[14] we recognised the potential for varied interpretations and included studies using any QoL measure or explicitly focusing on QoL. Context: studies across all contexts and geographical locations were included.

Empirical studies were eligible for inclusion. Quantitative studies included those with experimental, observational, measurement validation, and quasi-experimental study designs. Qualitative studies specific to the measurement of QoL were included. Editorials, commentaries, conference abstracts without full texts, and protocols were excluded. Retrieved citations were exported to a reference management software (EndNote 21, Clarivate, London, UK), and duplicates were removed. Pilot testing of screening has been described previously.[25] Screening was undertaken by a team of 10 co-authors (MS, MAK, LJG, HMLY, FC, JAB, TB, LiW, WC, and EB). Each citation was independently screened by two members of this team. Disagreements were discussed at bi-weekly screening meetings and resolved by consensus, with MAK, LJG, JAB, or TB acting as the adjudicating reviewer as appropriate. The adjudicating reviewer was not one of the two reviewers responsible for the initial screening decision. Full-text articles were screened using the same process.

Data extraction and charting

A data-extraction form was co-developed with a patient and public involvement and engagement (PPIE) advisory group of adults with MLTC (appendix pp 5–11).[25] The form was designed to capture study and participant characteristics; definitions of MLTC; and the development, validation, content, and use of QoL measures, with PPIE input informing the outcomes extracted. The form was piloted using 20 randomly selected studies to ensure consistency. Data extraction was undertaken by a team of six co-authors (MS, FC, MAK, HMLY, LuW and TM). Each included study was independently extracted by two members of this team. Discrepancies were discussed and resolved with a third reviewer (MAK, JAB, TB, HMLY, and VRA). The third reviewer was not one of the two reviewers that extracted the citation.

ICF coding

The components of the QoL measures identified were mapped using the ICF framework, facilitated by Microsoft Excel.[18] Further information is given in the protocol paper.[25] ICF mapping was undertaken by a team of four co-authors (MS, LJG, MAK, and HMLY). Two reviewers independently used published linking rules to map QoL measurement outcomes to the ICF.[26–28] Recourse to a third reviewer (HMLY, LJG, and MAK) for discussion and consultation was planned if disagreements between the two reviewers could not be resolved.

In brief, for each QoL measure, all survey questions or items and possible responses were extracted. Reviewers identified each question or item's purpose and perspective, classifying them as appraisal (the individual's evaluation of their functioning), needs (requirement for assistance or services), or dependency (reliance on others to perform an activity). The response format (eg, frequency, intensity, duration, agreement, quality, or dependency) was also recorded to preserve the meaning of each concept and to ensure consistent and transparent coding. Finally, meaningful concepts within each question or item were identified and linked to the most relevant category using the 2017 English ICF browser.[29] Where an item contained more than one meaningful concept, each concept was linked separately.

As the ICF does not distinguish between activity and participation domains, additional conceptual guidance from Badley[30] and Whiteneck and Dijkers[31] was used to operationalise this distinction. In line with this guidance, concepts relating primarily to the execution of tasks or actions by an individual were classified as activity (eg, walking or thinking), whereas concepts reflecting involvement in life situations, social roles, or societal

engagement were classified as participation (eg, employment or relationships). For transparency, we present the combined activity and participation component, consistent with the ICF framework, and both domains separately (appendix p 27). Environmental factors were identified where concepts described the physical, social, or attitudinal environments. Concepts that were not included in the ICF browser were recorded and summarised thematically to capture the full extent of the components measured.[31] Where concepts could not be assigned to a specific ICF category, they were classified according to the ICF linking rules. These rules specify that each meaningful concept identified within an item should be linked to the most precise ICF category possible, and concepts where linkage is not possible are assigned predefined residual classifications according to their content. These included not definable (eg, "How is your health?"), general health (eg, "Would you say that, in general, your health is..."), physical health (eg, "...for how many days during the past 30 days was your physical health not good?"), mental health (eg, "...for how many days during the past 30 days was your mental health not good?"), QoL in general (eg, "In general, would you say your quality of life is..."), health condition (eg, "Have you ever been told by a doctor that you have diabetes?"), personal factors (eg, "How motivated are you to manage your health?"), or not covered by the ICF (eg, "In general, how happy are you with your life?").

Evidence synthesis

We conducted a combination of descriptive numerical analysis and narrative synthesis. Descriptive statistics were used to summarise study characteristics. Findings were organised according to our objectives and research questions. The interpretation of data was refined based on consultation with our PPIE advisory group. The synthesised findings were translated into a co-produced visual evidence map, developed collaboratively with our PPIE group and a creative agency (Nifty Fox Creative, Barnsley, UK), to visually present the QoL concepts represented within existing measures, identify gaps, and support accessible knowledge translation.

PPIE

Our PPIE strategy followed the UK standards for public involvement[32] and GRIPP2[33] reporting, aiming to ensure that our scoping review reflected diverse perspectives of adults with MLTC by capturing relevant and comprehensive QoL concepts in existing measures, strengthening interpretation and supporting accessible dissemination, and to support capacity building and skill development for PPIE members. The group comprised 11 members with lived experience of MLTC, representing 10 geographical regions across the UK (ie, Cheshire, East Midlands, London, Northern Ireland, Oxfordshire, Scotland, South East, South West, Wales, and West Midlands), age range 20–75 years, an equal representation by sex, inclusion from under-represented ethnicities and a wide range of MLTC (appendix p 12). The group contributed to the refinement of the inclusion and exclusion criteria, all stages of screening and data extraction, interpretation and synthesis of the findings, and co-production of the visual evidence map.

Although the ICF provides a framework for classifying the content of existing QoL measures, it cannot establish whether those concepts reflect the priorities of people with MLTC. Therefore, to support the interpretation and synthesis of the findings, complementary PPIE perspectives were incorporated to provide lived-experience views on the relevance and completeness of the QoL research identified through our scoping review. Following completion of the ICF classification coding, our findings were presented to our PPIE group to explore whether the concepts represented within existing QoL measures reflected those they considered important to QoL and to identify any perceived gaps in measurement and wider research in this field. Following completion of the synthesis, PPIE members attended a co-design session with Nifty Fox Creative to present the QoL concepts captured, highlight areas of scarce evidence, and suggest actions for change.

Results

Overall, 89 references reporting on 77 unique studies met the inclusion criteria, collectively examining 754 029 participants (figure; appendix pp 13–22). Studies were conducted across 25 countries, with one multicountry study (table 1). The largest proportion of studies was from the UK (nine [12%] of 77), then Germany (eight [10%]), the USA (eight [10%]), and Canada (six [8%]; table 1; appendix p 23). Only five (6%) of 77 studies were conducted in low-income countries (three [4%]) or lower middle-income countries (two [3%]), with the remaining 72 (94%) studies conducted in upper middle-income countries (five [6%]) or high-income countries (67 [87%]).

Across the 77 included studies, sample sizes ranged from 11 participants to 592 958 participants (table 1). 28 (36%) of 77 studies used cross-sectional designs, followed by randomised controlled trials (24 [31%]), observational cohort studies (10 [13%]), psychometric validations (five [6%]), and qualitative interviews or focus groups (two [3%]). 42 (55%) of 77 studies were conducted in primary care, followed by the general community (11 [14%]), tertiary care (10 [13%]), secondary care (eight [10%]), in the home (two [3%]), and other settings (four [5%]). Involvement of people with lived experience was reported in 11 (14%) of the 77 studies, all from Europe (UK [six], Denmark [three], Germany [one], and Ireland [one]).

Approaches to identifying MLTC varied (table 2). Most studies derived MLTC diagnoses from medical records (47 [61%] of 77); then self-report (17 [22%]); and from a general practitioner, clinician evaluation, or referral (four [5%]). The remaining studies (four [5%]) used mixed data sources. Five (7%) of 77 studies did not specify their data source. MLTC inclusion criteria varied; most required two or more conditions (53 [69%] of 77 studies), although some required three or more conditions (23 [30%]). Ten (13%) of the

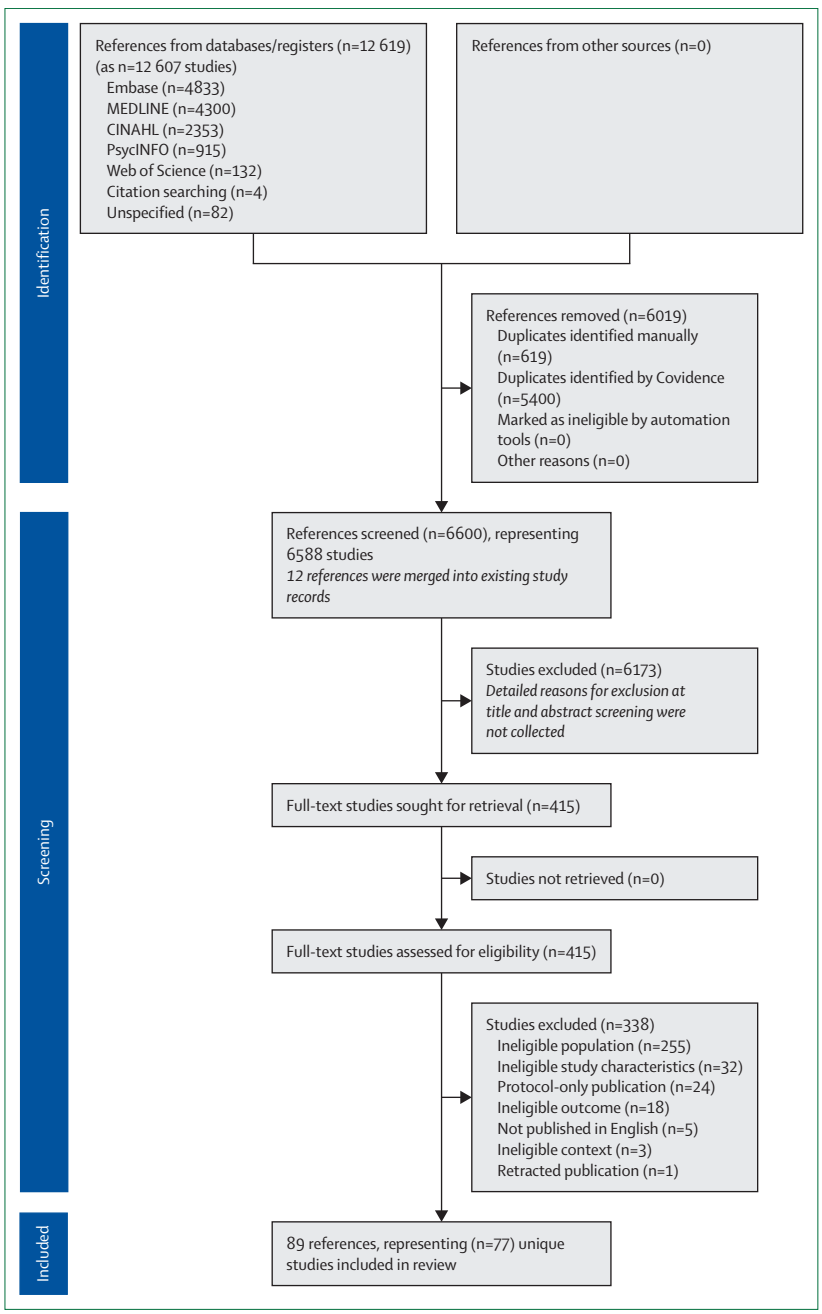


Figure: **Flow diagram**

77 studies incorporated polypharmacy, and one (1%) incorporated polypharmacy and seeing two or more physician specialists as part of their inclusion criteria. Among the 34 (44%) of 77 studies that reported a mean number of long-term conditions, the weighted mean was 5·3 (SD 2·1). In the 15 (19%) of 77 studies that provided a median value, the summary median was 5·0 (IQR 4·0–10·0). Of the 77 included studies, 55 (71%) described whether mental illness was included among the conditions used to define MLTC. Of these 55 studies, 43 (78%) reported data on mental illness and 12 (22%) did not. Twenty-two (40%) studies did not report data on mental illness as an MLTC.

Participant characteristics

Among studies that reported mean age (63 [82%] of 77), the overall weighted mean age was 69·9 years (SD 7·7; IQR 48·9–60·8). The reporting of equity, diversity, and inclusion characteristics highlighted several gaps (table 3). Education level (55 [72%] of 77), socioeconomic status (46 [60%]), and marital status (38 [49%]) were the most consistently reported social factors. 11 (14%) of the 77 studies reported physical or intellectual disability, whereas 66 studies (86%) did not report disability status. Race and ethnicity were under-reported (19 [25%] of 77 studies), and only one study (1%) reported on neurodiversity. No study reported sexual orientation or gender identity.

QoL measures

Of the 18 QoL measures used, two (11%) were specifically developed for people with MLTC (MultiMorbidity Questionnaire 1 [MMQ1] and MultiMorbidity Questionnaire 2 [MMQ2]), and 16 (89%) were generic measures not specific to people with MLTC (table 4). Measures included 5–100 questionnaire items. The Patient-Reported Outcomes Measurement Information System (PROMIS), 29-item profile was the only measure to allow for individualisation.

Derivatives of the EuroQol were most frequently administered, used in 50 (65%) of the 77 studies; specified versions were used in 46 (92%) of these 50 studies, whereas four (8%) did not specify which version of the EuroQol was used. Four measures were derived from the Short Form Health Survey scales and were used in 19 (25%) of 77 studies. Three measures were versions of WHO questionnaires and were used in four (5%) studies (table 4).

Descriptive subgroup analyses showed that the pattern of QoL measures used was broadly similar across studies defining MLTC as two or more conditions versus three or more conditions (appendix p 24). Similar patterns were observed according to whether mental health conditions were included in the definition of MLTC (appendix p 25).

Measurement development and validation

Nine measures were validated in the general population (without requiring specific conditions or MLTC), and nine were validated in populations with a single index condition (appendix p 26). Of the two measures developed for MLTC, four (5%) of the 77 studies reported on either measure development or validation, although no additional studies used the measure to assess QoL in people with MLTC. The 12-item Veterans RAND Health Survey was developed for a general population but validated in people with MLTC and was used in two studies (table 4; appendix p 26). Seven QoL measurement tools (seven [39%] of 18) had been validated in non-English-speaking populations. 18 (23%) of the 77 studies reported using a non-English QoL measure (eg, Korean EQ-5D) tailored to the target sample.

	Summary
Study characteristics (N=77)	
Study design, n (%)	
Cross-sectional	28 (36%)
Randomised controlled trial	24 (31%)
Observational cohort	10 (13%)
Psychometric validation	5 (6%)
Qualitative interview or focus group	2 (3%)
Other*	8 (10%)
Study setting, n (%)	
Primary care	42 (55%)
General community	11 (14%)
Tertiary care	10 (13%)
Secondary care	8 (10%)
Home	2 (3%)
Other†	4 (5%)
Study location, n (%)	
UK	9 (12%)
Germany	8 (10%)
USA	8 (10%)
Canada	6 (8%)
Ireland	5 (6%)
South Korea	5 (6%)
Spain	5 (6%)
Denmark	4 (5%)
Switzerland	3 (4%)
Taiwan	3 (4%)
Australia	2 (3%)
China	2 (3%)
Colombia	2 (3%)
Ethiopia	2 (3%)
Netherlands	2 (3%)
Singapore	2 (3%)
Chile	1 (1%)
Egypt	1 (1%)
Hong Kong	1 (1%)
Iran	1 (1%)
Italy	1 (1%)
Pakistan	1 (1%)
Portugal	1 (1%)
UAE	1 (1%)
Multi-country (ie, Ireland, Netherlands, Belgium, and Switzerland)	1 (1%)
Region n (%)	
Europe and central Asia	38 (49%)
East Asia and the Pacific	15 (19%)
North America	14 (18%)
Latin America and the Caribbean	3 (4%)
Sub-Saharan Africa	3 (4%)
Middle East and north Africa	3 (4%)
South Asia	1 (1%)
Country income status n (%)	
High income	67 (87%)
Upper middle income	5 (6%)
Lower middle income	2 (3%)
Low income	3 (4%)
Participant characteristics	
Total sample size, n=76	754,029 (11–592,456)
Age, years, n=63	69·9 (7·7)
Female participants, %, n=76	54·0 (48·9–60·8)
Male participants, %, n=76	46·5 (39·2–52·1)
White participants, %, n=15	92·4 (86·2–96·8)
Asian participants, %, n=8	6·4 (0·7–98·3)
Black participants, %, n=6	4·8 (1·3–7·6)
Mixed ethnicity, %, n=5	3·3 (1·2–6·7)
Other ethnicity, %, n=11	1·7 (0·4–7·6)

(Table 1 continues in next column)

(Continued from previous column)

Total sample size is given as total N (range). Age is summarised as the mean (SD) across study-level mean ages. Sex and ethnicity percentages are summarised across studies using median (IQR). n denotes the number of studies contributing to each participant characteristic. *Other study design categories (eg, mixed-methods or single-arm interventions) are described in the appendix (pp 13–22). †Other study settings included studies conducted across more than one setting (eg, combined community and primary care); full details are provided in the appendix (pp 13–22).

Table 1: **Characteristics of included studies and participants**

ICF mapping

Overall, 125 ICF codes were linked to questionnaire items within the included measures, with many coded multiple times. In total, 574 component categories were mapped, with 499 (87%) mapped to ICF categories and 75 (13%) uncategorised (appendix p 27-28). Among the ICF domains, activity and participation were most measured (236 [41%] of 574 component categories), followed by body functions (188 [33%]) and environment (75 [13%]). No measures included components relating to ICF categories of body structures. Of the activity and participation components, activity predominated (140 [59%] of 236 components within the activity and participation component category) over participation (95 [40%]). Of the 75 categories not mapped, 43 (57%) were not defined, 14 (19%) were about specific health conditions, eight (11%) were about general health, five (7%) were about general physical health, and five (7%) were about QoL. Components that were not defined included health perceptions and satisfaction, life meaning, attractiveness of surroundings, self-perception, body image, safety, and cancelled appointments.

Linking was conducted at the most appropriate ICF level, with similar items grouped within categories for reporting (appendix p 28). Items relating to body functions most frequently examined mental functions (140 [75%] of 188 components of the body function categories, most commonly emotional regulation, psychological wellbeing, and higher-order cognition). Categories relating to activity and participation most frequently examined mobility (58 [25%] of 236 components of the activity and participation category, most frequently measuring walking). Categories related to environment most frequently examined support

	Summary
MLTC data sources, n (%)	
Medical records	47 (61%)
Self-report	17 (22%)
General practitioner, clinician evaluation, or referral	4 (5%)
Medical records and self-report	3 (4%)
General practitioner evaluation or referral and self-report	1 (1%)
Not reported	5 (6%)
MLTC definition	
≥2 conditions	50 (65%)
≥3 conditions	16 (21%)
≥2 conditions and polypharmacy	3 (4%)
≥3 conditions and polypharmacy	7 (9%)
Other*	1 (1%)
Number of long-term conditions	
Studies reporting a mean number of long-term conditions	34 (44%)
Mean of study-level means	5·3 (2·1)
Studies reporting a median number of long-term conditions	15 (19%)
Median of study-level medians†	5·0 (4·0–10·0)

Studies reporting a mean or median number of long-term conditions are given as n (%) of studies. Mean of study-level means is given as mean (SD); median of study-level medians is given as median (IQR). MLTC=multiple long-term conditions. *Study required at least two treating physicians in addition to MLTC and polypharmacy. †The reported value represents the median (IQR) of study-level medians across studies reporting a median number of long-term conditions; within-study IQRs were not consistently available.

Table 2: **Multiple long-term condition conceptualisation and characteristics**

and relationships (18 [24%] of 75 components of the environment category, most frequently measuring close personal relationships).

MMQ1 predominantly measured activity and participation (23 [35%] of 65 components), with the majority related to activities (13 [56%] of 23). 22 (34%) of 65 components were related to body functions, and 20 (31%) were related to environment. MMQ2 predominantly measured environment (13 [76%] of 17 components), primarily related to respondents' perceptions of stigma and perceptions of the treatment of others towards them; three (18%) related to body functions and one (6%) to activity and participation.

PPIE perspectives, evidence map, and interpretation

For the **evidence map** see https://view.genially.com/6a32759f59225fe95c325298

Through a facilitated co-design workshop with Nifty Fox Creative, we collaboratively co-developed a visual storytelling output to present the findings from our scoping review as an evidence map in a user-friendly format. The impact of PPIE contributions was documented in accordance with GRIPP2 short-form guidance (appendix pp 29–33).[33]

The PPIE group highlighted that QoL is inherently personal, context-dependent, and dynamic. Although mental and emotional wellbeing, financial security, and physical health were important QoL domains to our PPIE group, members emphasised that priorities shift according to condition and life stage, previous experience, and expectations. They also made a key distinction between functioning and enjoyment, with the balance between the two considered a more meaningful marker of QoL than enjoyment alone. Members noted that individual motivation, psychological outlook, lived experience, and the impact of stigma were largely absent from existing QoL measures. The PPIE group expressed a need for representation of younger adults with MLTC, and two members who identified as neurodivergent stressed the importance of including this lived experience perspective in future QoL research. Members also highlighted that key MLTC subgroups were largely missing from existing research, potentially influencing the development of appropriate measures. This under-representation raised questions among the group about the inclusion and exclusion criteria, recruitment and validation methodology adopted by studies, and whether current generic QoL measures can fully capture the lived experience of adults with MLTC.

Discussion

The present review provides the first PPIE-informed evidence mapping of QoL measures in MLTC research including an assessment of their coverage of ICF components. The scoping review identified 77 studies including 754 029 people with MLTC. Most used generic QoL measures, with only two MLTC-developed tools identified. There was substantial variation in how MLTC was defined and how QoL was measured across included studies. Reporting of EDI characteristics was scarce, constraining understanding of QoL in diverse populations. Across measures, ICF components primarily related to activity and participation. Our PPIE group emphasised that QoL is personal, context-dependent, and dynamic across the life course, reflecting not only the absence of difficulties but also the capacity to live well despite them. Our findings suggest that current approaches might not fully capture this complexity.

Core outcome sets for MLTC research have highlighted QoL as an essential outcome, along with mental health outcomes and mortality.[15] However, these outcome sets do not provide explicit recommendations regarding which measures to use, contributing to the variation observed. In this Review, we found that most of the QoL measures used were generic, developed for the general population or adults with single conditions. Although these measures are widely used, allow for comparison across populations and conditions, and support cost-effectiveness analyses, most have not been developed or validated for people with MLTC.[112] However, comparability might be affected by differential item functioning, wherein individual items function differently across patient groups, and could reflect differences in interpretation rather than true differences in QoL, which may be particularly relevant to the heterogeneous population with MLTC. The widespread use of generic measures could also reflect practical advantages, particularly in the absence of well established, MLTC-specific alternatives.

MMQ1 and MMQ2 were the only QoL measures specifically developed for MLTC.[87,88] MMQ1 assesses QoL, whereas MMQ2 focuses on self-perceived inequity and stigma. Both measures were originally developed and validated in Denmark; however, given the country's high

	Number of studies
Sexual orientation	
Yes	0 (0)
No	77 (100%)
Gender identity	
Yes	0 (0)
No	77 (100%)
Race or ethnicity	
Yes	19 (25%)
No	58 (75%)
Marital status	
Yes	38 (49%)
No	39 (51%)
Living situation or social support	
Yes	33 (43%)
No	44 (57%)
Socioeconomic status	
Yes	46 (60%)
No	31 (40%)
Education level	
Yes	55 (71%)
No	22 (29%)
Neurodiversity	
Yes	1 (1%)
No	76 (99%)
Physical or intellectual disability	
Yes, physical only	9 (12%)
Yes, intellectual only	0 (0)
Yes, both	2 (3%)
No, none reported	66 (86%)
Mental illness as an MLTC condition	
Yes	43 (56%)
No	34 (44%)
PPI, lived experience, or patient advisory involvement	
Yes	11 (14%)
No	66 (86%)

Data are n (%). EDI=equity, diversity, and inclusion. MLTC=multiple long-term conditions. PPI=patient and public involvement.

Table 3: **Reporting of equity, diversity, and inclusion characteristics across included studies**

standard of living and low diversity within the development and validation cohorts in terms of ethnicity, their applicability to more diverse, international populations remains uncertain. MMQ1 was translated into English and underwent initial validation in 2025,[89] which likely explains its limited uptake to date. This validation identified redundancy and scale overlap, leading to recommendations that further research is needed to refine the measure. The choice between generic and MLTC-specific measures could depend on the context and intended purpose of measurement, rather than one approach being superior.

Mapping of measures to the ICF framework showed that most instruments (including MMQ1) predominantly capture components of activity and participation, with emphasis on functional activities. Body functions were mainly represented through domains related to emotions, temperament, and fatigue, whereas environmental factors were less frequently assessed in comparison. The low representation of environmental domains is crucial in MLTC, wherein QoL might be influenced not only by function and symptoms but also by the wider context, including financial circumstances, social support, and interactions with health-care services.

The ICF domains captured by existing QoL measures largely align with the perspectives of our PPIE group and findings from qualitative research conducted across both high-income countries and low-income and middle-income countries, including studies involving ethnically diverse and non-English-speaking populations.[113–117] Collectively, these sources suggest that physical functioning and daily activities, emotional and symptom management, and the maintenance of relationships are crucial to how people with MLTC conceptualise QoL.[76,113–116]

The activities most frequently assessed tended to be foundational, such as walking. The emphasis on foundational activities could reflect the older populations in which these measures were predominantly developed or an implicit assumption that such functions are necessary prerequisites for QoL. This assumption might not hold across all perspectives; for example, individuals with mobility impairments, including wheelchair users, might report good QoL despite limitations in these domains.[117] Such differences in perspective highlights the need to critically examine how QoL is conceptualised within existing measures and whether these measures adequately capture diverse lived experiences.

Several important gaps emerge when comparing the results of the ICF mapping with insights from our PPIE group and existing research. These gaps include little representation of perceived future health risks,[115] treatment and self-management burden,[76,113–115] health-care professional relationships and health literacy,[116] spirituality,[113] financial resources,[76,113] coping strategies and sense of control,[76,114,116] and cultural expectations.[114] Notably, stigma was identified by our PPIE group as a key influence on QoL and has also been highlighted in qualitative research.[113] MMQ2 was the only measure to include stigma, focusing on others' perceptions rather than the lived experience of stigma associated with MLTC. Differences between the ICF mapping and PPIE perspectives could reflect both the limited coverage of these concepts in existing measures and challenge of representing complex and subjective aspects of QoL relevant to people with MLTC within a standardised classification.

Our PPIE group emphasised that QoL in people with MLTC is inherently personal and dynamic, a view that is strongly supported by existing qualitative research, which describes QoL as context-dependent and shaped by life stage, condition trajectory, and individual experiences.[76,113–116] These characteristics highlight the importance of

	Studies
Centers for Disease Control and Prevention Healthy Days Measure Health-Related Quality of Life-14	Hochhalter and colleagues (2010)[34]
EuroQol measures	
EQ-5D unspecified	Garvey and colleagues (2015),[35] Lanzeta and colleagues (2016),[36] Muth and colleagues (2016),[37] Schäfer and colleagues (2018),[38] Stewart and colleagues (2021),[39] von Dem Knesebeck and colleagues (2015)[40]
EQ-5D+C	Lutomski and colleagues (2023)[41]
EQ-5D-3L	Ahn and Koh (2021),[42] Brettschneider and colleagues (2013),[43] Cañón-Esquivel and colleagues (2021),[44] Forjaz and colleagues (2015),[45] Lau and colleagues (2021),[46] Lee and colleagues (2021),[47] Lo and colleagues (2026),[48] Müller and colleagues (2020),[49] N'Goran and colleagues (2017),[50] Subramaniam and colleagues (2019),[51] Walsh and colleagues (2020),[52] Yen and colleagues (2021),[53] You and Kim (2025)[54]
EQ-5D-5L	Lutomski and colleagues (2023),[41] Forjaz and colleagues (2015),[45] Evans and colleagues (2025),[55] Falke and colleagues (2024),[56] Ford and colleagues (2019),[57] Fortin and colleagues (2021),[58] Gebresillassie and Kassaw (2023),[59] Gebreyohannes and colleagues (2023),[60] Hardman and colleagues (2026),[61] Hwang and colleagues (2025),[62] Jungo and colleagues (2023),[63] Khunti and colleagues (2021),[64] Kiely and colleagues (2024),[65] Lee and Yun (2020),[66] Lozano-Hernández and colleagues (2020),[67] Mercer and colleagues (2016),[68] Panagioti and colleagues (2018),[69] Peters and colleagues (2018),[70] Rijken and colleagues (2020),[71] Salisbury and colleagues (2018),[72] Samorinha and colleagues (2025),[73] Schäfer and colleagues (2023),[74] Skou and colleagues (2023),[75] Sweeney and colleagues (2025),[76] Tew and colleagues (2024),[77] Xu and colleagues (2024),[78] Yang and colleagues (2022)[79]
EQ-VAS	Garvey and colleagues (2015),[35] Muth and colleagues (2016),[37] Brettschneider and colleagues (2013),[43] Cañón-Esquivel and colleagues (2021),[44] Lau and colleagues (2021),[46] N'Goran and colleagues (2017),[50] Subramaniam and colleagues (2019),[51] Evans and colleagues (2025),[55] Falke and colleagues (2024),[56] Gebresillassie and Kassaw (2023),[59] Gebreyohannes and colleagues (2023),[60] Hardman and colleagues (2026),[61] Hwang and colleagues (2025),[62] Jungo and colleagues (2023),[63] Khunti and colleagues (2021),[64] Kiely and colleagues (2024),[65] Lozano-Hernández and colleagues (2020),[67] Peters and colleagues (2018),[70] Schäfer and colleagues (2023),[74] Skou and colleagues (2023),[75] Yang and colleagues (2022),[79] Martínez-Velilla and colleagues (2022),[80] Petersen and colleagues (2014),[81] Pizarro-Mena and colleagues (2022),[82] Ryan and colleagues (2022),[83] Stuber and colleagues (2025)[84]
Medication-Related Quality of Life Scale	Jennings and colleagues (2022)[85]
MultiMorbidity Questionnaire 1 or MultiMorbidity Questionnaire 2	Bissenbakker and colleagues (2022),[86] Bissenbakker and colleagues (2023a),[87] Bissenbakker and colleagues (2023b),[88] Sweeney and colleagues (2025)[89]
Short Form Health Survey scales	
SF-12	Stewart and colleagues (2021),[39] Jennings and colleagues (2022),[85] Bernabeu-Wittel and colleagues (2010),[90] Cheng and colleagues (2020),[91] De Maria and colleagues (2020),[92] Fisher and colleagues (2020),[93] Prazeres and Santiago (2016),[94] Schuttner and colleagues (2020)[95]
SF-36	Fortin and colleagues (2007),[96] Lear and colleagues (2021),[97] Lee and colleagues (2022),[98] Mesa-Melgarejo and colleagues (2022),[99] Sultana and colleagues (2025),[100] Tyack and colleagues (2018)[101]
VR-12	Fortin and colleagues (2021),[58] Markle-Reid and colleagues (2021)[102]
VR-36	Edelen and colleagues (2018),[103] Rose and colleagues (2018),[104] Rose and colleagues (2019)[105]
Patient-Reported Outcomes Measurement Information System, 29-item profile	Tew and colleagues (2024),[77] Edelen and colleagues (2018),[103] Rose and colleagues (2018),[104] Rose and colleagues (2019),[105] Gallo and colleagues (2023),[106] Gustafson and colleagues (2024),[107] Huang and colleagues (2019)[108]
Vulnerable Elders Survey	Walsh and colleagues (2020)[52]
WHO questionnaires	
WHOQOL-100	Mohamed and colleagues (2024)[109]
WHOQOL-BREF	Panagioti and colleagues (2018),[69] Warner and colleagues (2010)[110]
WHOQOL-OLD	Jafari-Koulaee and colleagues (2026)[111]

Some studies used more than one quality of life measure. EQ-5D is the official name of the EuroQol instrument. EQ-5D+C=EQ-5D with a cognition dimension. EQ-5D-3L=three-level EQ-5D. EQ-5D-5L=five-level EQ-5D. EQ VAS=EQ visual analogue scale. SF-12=12-Item Short Form Health Survey. SF-36=36-Item Short Form Health Survey. VR-12=Veterans RAND 12-Item Health Survey. VR-36=Veterans RAND 36-Item Health Survey. WHOQOL-100=World Health Organization Quality of Life 100-item assessment. WHOQOL-BREF=World Health Organization Quality of Life brief version. WHOQOL-OLD=World Health Organization Quality of Life Older Adults Module.

Table 4: **Quality of life measures used across included studies**

ensuring that measures of QoL reflect individual variation and lived experience. We identified one measure that incorporates some degree of individualisation.[118] The PROMIS captures physical, mental, and social aspects of health, using item banks of validated questions for each domain. This measure can be administered by selecting specific items to suit particular study populations or through computer-adaptive testing, wherein items are selected dynamically on the basis of previous responses to generate a tailored assessment.[118] Although this adaptive approach introduces flexibility, it does not allow individuals to prioritise the domains that matter most to them. This limitation is important given the heterogeneity of people with MLTC, not only in terms of conditions but also across life stage, EDI characteristics, and wider contextual factors. Consequently, it might be difficult for a single standardised MLTC-specific measure to capture this complexity. Rather than requiring a new instrument, future approaches could combine core domains relevant across people with MLTC with adaptive components that reflect individual conditions, circumstances, and priorities.

In this Review, we identified key EDI gaps across studies. Most evidence originated from high-income countries, with minimal representation from low-income and lower

middle-income countries. Representation of socially marginalised groups, such as racially minoritised populations, individuals who are neurodivergent, people with disabilities, and LGBTQ+ communities, was poorly reported or absent. Given that MLTC disproportionately affects disadvantaged populations and is shaped by structural determinants of health,[119] these gaps raise concerns about the generalisability of the evidence generated using existing QoL measures and whether these measures adequately capture QoL across diverse populations and contexts. Limited reported PPIE involvement suggests that many QoL measures used in MLTC research might not reflect the priorities or realities of those most affected. Further qualitative research is needed to understand how different groups conceptualise QoL, providing a foundation for developing measures that are responsive to individual, cultural, life stage, and condition-related differences.

This Review is the first to comprehensively map the literature on QoL measurement in individuals with MLTC. A key strength was the substantial involvement of our PPIE group, all of whom had lived experience of MLTC. Their contributions informed the interpretation and framing of the findings by identifying concepts important to people with MLTC that were not represented in existing measures or captured through the ICF mapping, helping to ensure that the identified evidence gaps reflected issues meaningful to people living with MLTC (appendix pp 29–33). Although diverse, the group might not have captured all perspectives.

A further strength was the systematic mapping of QoL measures to the ICF framework, which allowed us to identify in detail the components captured by existing instruments and highlight gaps. The ICF is an internationally recognised framework that has been widely applied across long-term conditions, facilitating comparison with previous research.[18,19,21] However, personal factors, stigma, and other contextual influences identified as important by our PPIE group and qualitative research, alongside other concepts within the identified QoL measures, could not be classified using the ICF. Thematic content analysis of undefined concepts within the measures helped capture these important components, while the integration of PPIE highlighted additional conceptual gaps, thereby mitigating this potential limitation. Nevertheless, future research could consider combining the ICF with complementary conceptual frameworks, such as the Item Perspective Classification. Combining these frameworks could enable characterisation of constructs that cannot be classified using the ICF alone, providing a more comprehensive representation of the components captured by QoL measures.[120]

Finally, the review was conducted in accordance with international guidance. The protocol was published before commencement, enhancing transparency and methodological rigour. Reporting also adhered to established guidance, supporting the validity and credibility of the findings and their interpretation.

Limitations of this Review include substantial heterogeneity in the per-study definition and operationalisation of MLTC, restricting comparability. Many studies also did not have detailed reporting of demographic or EDI characteristics, restricting our ability to assess representation. During data extraction, we noted that several studies excluded individuals with specific conditions (eg, sight loss and dementia). Although these exclusions were likely implemented for pragmatic reasons (eg, capacity to consent or survey completion), such exclusions could have restricted the representation of the complexity of real-world MLTC populations. Such exclusion could also have influenced our QoL ICF mapping, as individuals with cognitive or visual impairments often have unique functional limitations, treatment burden, and reduced wellbeing. Although seven QoL measures identified in this Review had been validated in non-English-speaking populations, and 18 studies used translated versions of established instruments, our restriction to English-language publications could have excluded measures developed and reported exclusively in other languages. Therefore, culturally specific conceptualisations of QoL might be under-represented in our synthesis and ICF mapping, particularly from low-income and middle-income countries, thereby restricting generalisability of our findings.

Current QoL measurement practices might not sufficiently capture the lived experience, diversity, and complexity of MLTC. Although generic measures offer comparability and feasibility, their dominance risks narrowing understanding to what is easily quantifiable rather than what matters most to people with MLTC. MLTC-specific measures could provide a framework for capturing core domains that are relevant across people with MLTC but, given the inherent heterogeneity of MLTC, greater individualisation or adaptive approaches are required to capture individual priorities. Our findings also suggest that reliance on a single conceptual framework, including the ICF, might not fully represent the multidimensional nature of QoL in MLTC.

Future research should prioritise 1) building on MMQ1 and MMQ2, to ensure that QoL measurement captures the personal and changing needs of people with MLTC, incorporating mental health, participation, environmental context, and personal priorities; 2) improving the reporting of participant demographic and EDI characteristics, including ethnicity, socioeconomic status, disability, and other relevant characteristics, to support assessment of the representativeness and generalisability of QoL measures; 3) ensuring meaningful involvement of people with lived experience and improving inclusion of under-represented populations across the full measurement lifecycle, from conceptualisation to validation; 4) undertaking qualitative research with under-represented populations and in low-income and middle-income countries, to identify culturally relevant QoL concepts that should inform future measure development; 5) validating existing and emerging MLTC-specific QoL measures across diverse populations,

health-care settings, and disease trajectories before widespread implementation; and 6) considering adaptive measurement approaches, such as the PROMIS, wherever appropriate and feasible, to support personalised QoL assessment across life stages and disease trajectories, in alignment with individual goals, while recognising that implementation could be restricted in settings without access to computer adaptive testing infrastructure, especially in LMICs.

From a clinical and policy perspective, more meaningful QoL measurement has the potential to improve person-centred care, support shared decision-making, and inform service design for people with MLTC. More comprehensive measures could also strengthen the evaluation of interventions, health technology assessment, and economic evaluations by capturing outcomes that are meaningful to people with MLTC. Conversely, reliance on measures that incompletely represent lived-experience risks underestimating the burden of MLTC, potentially influencing priorities for research, resource allocation, public health, and health policy. Given the predominance of older adults among people with MLTC, our findings are also relevant to wider healthy ageing, wherein maintaining functional ability, independence, and QoL are key priorities.

QoL measurement in adults with MLTC is dominated by generic instruments that only partly capture the complexity and heterogeneity of lived experience among people with MLTC. Meaningful assessment of QoL in this population requires a shift towards co-produced, inclusive, context-sensitive, and individualised measurement that recognises adaptation, priorities, and the realities of living well with MLTC, with the choice of measure reflecting its intended purpose. Integrating diverse lived-experience perspectives will be essential to advancing equitable and person-centred research and clinical service provision for MLTC.

Contributors

Conceptualisation: MAK, LJG, TB, JAB, VRA, LiW, CLB, ND, and HMLY. Methodology: MAK, LJG, TB, JAB, VRA, LiW, CLB, ND, NWR, and HMLY. Software: MAK, FC, and HMLY. Validation: MAK, MS, LJG, TB, FC, and HMLY. Formal Analysis: MAK, MS, LJG, TB, JAB, FC, and HMLY. Investigation: MAK, MS, LJG, TB, FC, JAB, VRA, LiW, CLB, ND, EB, LuW, TM, and HMLY. Resources: MAK, LJG, TB, and HMLY. Data Curation: MAK, FC, and HMLY. Writing–Original Draft: MAK, LJG, TB, VRA, and HMLY. Visualisation: MAK, TB, FC, JAB, and HMLY. Supervision: MAK and HMLY. Project Administration: MAK, MS, LJG, and HMLY. Funding Acquisition: MAK, LJG, TB, JAB, VRA, LiW, CLB, ND, and HMLY; PPIE: MAK, MS, VRA, CLB, and ND; Writing–Review and Editing: MS, FC, JAB, LiW, CLB, ND, EB, WC, LuW, and TM.

Declaration of interests

We declare no competing interests.

Acknowledgments

This research project was funded by the National Institute for Health and Care Research (NIHR) Team Science Award (NIHR304980). MAK is part-funded by the NIHR Oxford Health Biomedical Research Centre and NIHR Applied Research Collaboration Thames Valley. LJG is funded by the NIHR Applied Research Collaboration East Midlands and NIHR Leicester Biomedical Research Centre (NIHR203327). LJG is an NIHR Senior Investigator and a member of the NIHR Multiple Long-Term Conditions Cross-NIHR Collaboration. LJG is supported by British Heart Foundation Research Excellence Award (RE/24/130031). TB is supported by the NIHR Imperial Biomedical Research Centre and is a member of the NIHR Multiple Long-Term Conditions Cross-NIHR Collaboration. JAB is funded by an NIHR Academic Clinical Lectureship. HMLY is supported by an NIHR Advanced Fellowship (NIHR302926). We thank Marion Walker for providing executive coaching and mentorship to the research team throughout this project. We are grateful to Eden Byrne, Francesca DelGuidice, Naomi Kuryk, Julian Harrison, Kenny Redmond, Sienna-Mae Yates, and all 11 members of our Team Science PPIE group for their time, dedication, and invaluable contributions to this work. We also acknowledge the staff at Nifty Fox Creative for their work in producing the evidence map to support dissemination of our findings.

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