

ANZSOG

FINAL REPORT

Peer support approaches:

To what extent are they appropriate, acceptable, beneficial? What is needed to implement them well?

A systematic review of systematic reviews of international literature

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June 2019

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Acknowledgements

Financial support for conducting the review was provided by the National Disability Insurance Agency, Geelong, Australia as part of the 'NDIA Peer to Peer Programme' awarded to the Evidence and Evaluation Hub of the Australia and New Zealand School of Government (ANZSOG) through a competitive Request for Quotation (RFQ) process.

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Competing interests

The authors declare that they have no competing interests.

Citation

Peersman G, Fletcher G (2019). Peer support approaches: To what extent are they appropriate, acceptable, beneficial? What is needed to implement them well? A systematic review of systematic reviews of the international literature. Melbourne: The Australia and New Zealand School of Government (ANZSOG), with research input from Alice Macfarlan, Sara Rahman, and Keryn Hassall.

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EXECUTIVE SUMMARY

Rationale for the review

Peer support has been researched around the world for several decades and various forms of peer support applications have been credited with a range of beneficial effects. It has become a significant element in the search for improved outcomes that matter to ‘patients’, or ‘those affected’ more generally, and a move towards solution-based approaches that engage them to meet their needs.

The National Disability Insurance Scheme (NDIS) was introduced in Australia in 2013 and provides individualised funding to eligible people with disability in order to access ‘reasonable and necessary supports’ to live ‘an ordinary life’. Once fully established, it is expected to serve 460,000 people with disability. Peer support is an important component of the NDIS programme. Given the mixed results reported in the literature, “what is it that we know about peer support?”, and, “what are implications for funding, running and participating in peer support?” remain pertinent questions for decision making within the NDIS.

Review questions

1. What types of evidence did we find?
2. What were the benefits of different peer support approaches? Can peer support do harm?
3. What was needed to implement peer support well and do no harm?

Methods

Inclusion criteria

Types of studies – published and unpublished systematic reviews of evaluation and other research from OECD countries.

Types of interventions – any type of peer support intervention.

Types of participants – people with a disability or their carers, other population groups in the context of addressing health issues or other challenges deemed relevant to the NDIS context.

Types of results – any type immediate, intermediate or longer-term result, any unintended consequences, any findings related to implementation of the intervention, perspectives of participants or others involved in implementation, and contextual issues.

Locating, screening and describing relevant reviews

Extensive searches on specialist databases of published and unpublished systematic reviews; assessing reference lists and bibliographies of evidence maps and reviews; iterative web searches and searching specialist websites for grey literature.

Search results were screened using the inclusion criteria and standardised keywords were assigned to describe key characteristics of all reviews meeting the inclusion criteria.

Analysing and synthesising findings

Data analysis was conducted in two consecutive phases:

In the first phase, standardised data extraction was conducted to obtain detailed descriptive information about the intervention, study population, and results and to assess risk of bias in the reviews. Two researchers independently extracted data and any differences were resolved in discussion with the lead researcher. Based on this coding, a sub-set of reviews – those focusing on interventions with a substantial peer-to-peer component – was selected for further in-depth qualitative analysis.

In the second phase, inductive coding was conducted on the sub-set of reviews to identify key themes and to understand similarities and differences between the reviews and their findings. A typology of direct, buffering or mediating effects was applied to analyse the variety of positive effects reported across different reviews.

A descriptive mapping was presented for all included reviews and for the reviews focusing on substantial peer support. Findings from the latter were also synthesised in narrative form to answer the three review questions.

Key findings

1. What types of evidence did we find?

A total of 79 systematic reviews met the inclusion criteria. Of these, 30 reviews focused on substantial peer support and, between them, reviewed more than 700 studies. All but two of the 30 reviews sought to review peer support for a specific group of people or in a specific setting (including people with a specific disease or physiological health condition, people with mental health issues, carers, prison, schools). One review focused on people who are ‘hardly reached’ by health programmes. A small number of reviews focused on specific modes of delivery of peer support for specific groups (such as mutual help groups for people with mental health problems; peer telephone support for people with a wide range of health issues; internet-based peer support for parents).

Twenty-three reviews reported on outcome evaluations; three reviews included findings from process evaluations in addition to reporting outcomes; only two reviews incorporated cost-effectiveness information. Seven reviews focused on qualitative and/or quantitative research about participation in support groups, experiences of participants in relation to different types of peer support, the roles of peers, and/or peer relationships.

Almost half of the effectiveness review restricted study design to randomised controlled trials (RCTs) only, for reasons of their perceived rigour. However, the appropriateness of using an experimental design was questioned as randomisation may change the very nature of what is fundamental to peer support. In addition, the RCTs were not always conducted well. Importantly, obtaining a clear picture of the peer support relationship and peer support implementation requires the use of a variety of methods as was demonstrated by more inclusive reviews.

Poor reporting of crucial information such as how a peer or peer support was defined or the characteristics of the study populations involved and methodological issues such as attrition and selective outcome reporting hindered analysis and learning.

2. What were the benefits of different peer support approaches? Can peer support do harm?

There was a wide variety of peer support interventions – less to highly structured, stand-alone or part of a broader intervention. Different terms and definitions of ‘peer’ and ‘peer support’ were used but only just over half of the reviews had defined these explicitly. While there were many important differences between the reviews in terms of how they were done and what they found, all stressed the importance of reciprocal sharing of experience. How experiential knowledge was used in the implementation of a peer support intervention seemed to be linked to taking an empowerment perspective or a behaviour change perspective.

There was also a wide variety in types of ‘outcomes’ reported and in the instruments used to assess them; not all measures were standardised or validated. Our qualitative analysis reflecting underlying mechanisms for peer support found ‘some level of positive changes’ in the following domains:

Direct effects – reported in two-thirds of the reviews and related to the psycho-social realm (e.g., increased social integration, reduced feeling of isolation, improved quality of life, a mental health or emotional health outcome).

Buffering effects – reported in half the reviews and related to ability to cope (e.g., improved beliefs, attitudes, self-esteem).

Mediating effects – reported in two-thirds of the reviews and most commonly related to changes in behaviour.

Some review authors questioned the significance of positive changes in terms of ‘statistical significance’, ‘clinical significance’, ‘significance in terms of cost savings’. Very little was reported on cost or cost effectiveness of peer support. Last but not least, ‘the significance of a positive result as perceived by the individuals themselves’ and ‘who benefited most’ were not systematically investigated; the few studies that included sub-group analyses made it clear that peer support can have differential effects based on specific characteristics of the participants.

Some reviews also reported on unintended negative consequences including: uneven power relationships between peers, feeling rejected when a peer ‘dropped out’ of the group or one-on-one relationship, becoming over-dependent on a peer, exhibiting negativity or negative social comparison which adversely affected group dynamics, feelings of emotional entanglement, tension or conflict. Issues related to large group sizes and perceived alienation, burden of care, time effort, and misinformation linked to online support were also reported. Given the potential for adverse effects is real, they should be investigated alongside any peer support implementation, whether in research or in practice settings.

The reviews contained scant data on intervention implementation including how peers were recruited, whether or not they were trained for their specific role and in what. The most notable absence from primary studies and reviews was an explicit programme logic underpinning the interventions – the ‘what’, ‘why’ and ‘how’ of peer support that ‘plausibly’ leads to achieving the outcomes intended. Where some level of searching for an underlying theory occurred, ‘social support’ was most commonly mentioned. Augmenting the social relationship, which is at the heart of any form of peer support, influences results positively and minimises harm.

3. What was needed to implement peer support well and do no harm?

Overall, peer support was well-accepted. However, while some studies included populations of diverse cultures, tailoring of the intervention was not mentioned or described, and the findings were analysed by sub-groups. Peer support has been found to provide an important opportunity for engaging individuals who are alienated from or not easily reached by formal services. It was also found that peer support was an acceptable source of help in particular settings such as prison.

There were no discernible patterns about what types of peer support were favoured over others. Several reviews assessed online support using different formats (such as public and open, closed and private; group and one-on-one). These were found to provide some advantages over face-to-face groups such as: providing a degree of anonymity which may be perceived as important when discussing sensitive issues, or being more comfortable when lacking confidence to join a face-to-face group. However, negative issues were also identified such as: lack of continuity, limited ability to establish relationships, occurrence of mis-information.

Each peer support intervention needs to be underpinned by a plausible programme logic to achieve intended outcomes. Two key models, 'the empowerment model' and 'the behaviour change model', can be built on and further expanded with consideration for:

- the needs and circumstances of those engaged/to be engaged
- the diversity of participants (including culture and language)
- different peer support modalities to suit preference and increase accessibility
- the timing and duration of peer support dependent on individuals' readiness, needs, and motivation as well as expectations for immediate, intermediate and/or longer-term results
- appropriate mechanisms for engagement
- adherence to standards and ensuring safeguards
- strengthening competencies and providing supportive supervision

Obtaining the perspectives and experiences of those involved in peer support relationships and gathering information about implementation processes and context are not optional extras; they should be included in any investigation or M&E approach. Start with questions about what it is you need to know about the peer support intervention and why you need to know this (i.e., how the information will be used). Then, choose the most appropriate methods to address these and use the findings to continuously improve peer support relationships. When reporting on a peer support studies, ensure all essential information is provided so others can learn from it and the findings can contribute to the growing evidence base on peer support.

Conclusion

Social relationships and reciprocal sharing of experiences are at the heart of peer support. Augmenting this peer relationship can influence results positively and minimise harm.

It is worth investing in peer support but what is being done needs to be underpinned by an explicit programme logic. Its implementation needs to be supported by competency building, supportive supervision and appropriate reflective practice.

Abbreviations and Acronyms

ANZSOG	the Australia and New Zealand School of Government
CALD	populations of culturally and linguistically diverse backgrounds
IAC	Independent Advisory Council of the NDIS
ILC	Information, Linkages and Capacity Building
IPS	Intentional Peer Support
M&E	monitoring and evaluation
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
OECD	Organisation for Economic Co-operation and Development
RCT	Randomised controlled trial

BACKGROUND

Why is there interest in peer support?

Peer support is, essentially, about giving and receiving help in dealing with different types of social circumstances, emotional challenges or health issues (Penney, 2018). It has a long history of use as a deliberate strategy, most notably within the mental health domain, and can be seen as an extension of the natural human tendency to respond compassionately to shared difficulty (Penney, 2018) with a philosophical basis in the potential for mutual growth and healing (Mead and MacNeil, 2005). Solomon (2004) traced the oldest –and most pervasive– form of peer support back to self-help groups in the 1970s.

Peer support has been formally researched around the world for several decades, especially within the context of health care systems that are struggling with rising costs and, often, unsatisfactory and uneven quality of care (Pomery et al. 2016). Various forms of peer support applications have been credited with a range of beneficial effects (see, for example, The Evidence Centre, n.d.). It has become a significant element in the search for improved outcomes that matter to ‘patients’, or ‘those affected’ more generally, and a move towards solution-based approaches that engage them to meet their needs (Hislop et al., 2016).

How does peer support feature within the NDIS in Australia?

The National Disability Insurance Scheme (NDIS) was introduced in Australia in 2013 and represents a fundamental change to how support for people with disability is funded and delivered across Australia (DSS 2016). A key principle of the NDIS is that people with disability have the same fundamental rights as all members of Australian society to participate in the social and economic life of the community and to make their own choices and decisions to realise their full potential (NDIS n.d.). Rather than providing ‘block-funding’ to service providers for particular types of support, the NDIS provides individualised funding to eligible people with disability in order to access ‘reasonable and necessary supports’ to live ‘an ordinary life’³. The NDIS is administered by the National Disability Insurance Agency (NDIA) and, once fully established, is expected to serve 460,000 people with disability (DSS 2016).

Community-based support can be accessed through the information, linkages and capacity building (ILC) functions of the NDIS and is open to people with disability whether receiving individual funding or not. ILC supports provision of targeted information, coordinated referrals to and from mainstream services, and, capacity building to influence attitudes and practices across communities, organisations and mainstream service delivery aiming for greater inclusion and engagement of people with disability, their families and carers.

The Independent Advisory Council (IAC)⁴ of the NDIS produces discussion papers, reports and submissions which culminate in formal advice to the NDIA Board on matters related to the delivery of

³ Reasonable and necessary support refers to the nature and quantum of support to enable a participant to pursue goals and aspirations to live an ‘ordinary life’. In other words, people with disability share the ordinary aspirations of their peers without disability but need reasonable and necessary NDIS support to achieve them. (IAC advice on reasonable and necessary support across the lifespan: *An ordinary life for people with disability*. The Independent Advisory Council, 84 pages. <https://www.ndis-iac.com.au/what-is-an-ordinary-life>. Accessed February 2018.)

⁴ <https://www.ndis-iac.com.au/resources>

the Scheme and how it meets its objectives. In a report to the IAC on *Capacity building for people with disability, their families and carers*, the authors stated:

“The IAC argues that capacity building within the context of the NDIS is essential to assisting people with disability move from being dependent clients to active citizens...Capacity building not only has great outcomes for individuals and their communities, it is critical to delivering the insurance principles of the Scheme...Capacity building is, however, a term and practice that covers a range of activities, many of which have been evaluated to offer little or no value, either for money or for achieving the goal of sustainably building capacity... [This] paper discusses different approaches to capacity building and their relative merits including mentoring, role models, learning by doing, one off information sessions and **becoming a member of an ongoing group where capacity is built by learning from people in a similar position**” (Report to the IAC, 2015:3; emphasis added).

They defined these ‘ongoing groups’ or ‘peer support groups’ as:

“run by a trained novice facilitator who has experiential knowledge of the problem and is involved in an organisation or agency providing education, counselling, advocacy, mediation and mutual support.” (Report to the IAC, 2015:54)

and provided a specific recommendation stating:

“Peer support groups demonstrate:

- A focus on the unique ethos, values and practice principles that distinguish peer support from other groups and contribute to positive outcomes for participants.
- Accessible online peer support groups/s.” (Report to the IAC, 2015:6).

They provided these recommendations based on “an extensive review of evidence” (p.3) and referenced 16 published studies, four of which were about on-line support. They noted a range of results about peer support in different settings including: “high level of satisfaction with peer support programs”, “change in both positive and negative outcomes”, “not helpful in all situations”, “evidence of psychosocial benefit was mixed”, “patients with better mental functioning could be at risk of deterioration in support groups”, “evidence of efficacy is mixed, partly because of the lack of rigour in studies investigating impact”, “found no robust evidence”(Report to the IAC, 2015:54-55).

Peer support is now an important component of the NDIS programme. Given the mixed results reported in the literature, “what is it that we know about peer support?”, and, “what are implications for funding, running and participating in peer support?” remain pertinent questions for decision making within the NDIS. Using an evidence-based approach to running the peer support component of the NDIS programme can help to safeguard quality (i.e., achieve benefits while avoiding or minimising unintended negative consequences) and obtain reasonable efficiencies (i.e., results are deemed commensurate with money, time and other resources invested).

Why a ‘systematic review’ of ‘systematic reviews’ of the international evidence?

A recent evidence map⁵ confirmed that there is a large body of evidence about different types of peer support (The Evidence Centre, n.d.). The authors used systematic processes for identifying relevant research and screened more than 20,000 studies. They found 1,023 studies that met their

⁵ “Evidence maps pull together and categorize systematic reviews, impact evaluations and other primary-research studies in a particular area and visually distil the scope and effects of interventions that have been implemented. [They] can show at a glance which areas or relationships have been studied most. They can also highlight key gaps in the evidence base, and so guide the prioritization of research.” McKinnon et al., 2015: 185.

inclusion criteria⁶; of these, 524 studies examined outcomes of peer support including 147 randomized controlled trials (RCTs) and 27 reviews synthesising findings from multiple studies (The Evidence Centre, n.d.). While useful to obtain a sense of the extent to which peer support has been researched and of general trends in findings, the authors emphasized that their work was “not exhaustive” and aimed to “spark discussion rather than providing definitive answers about the most effective peer support or specific findings from each study” (The Evidence Centre, n.d.:4).

Again, the evidence map reported mixed results for peer support, so it was important to try and tease out any learnings from research about ‘what works/does not work’ and ‘why’, but also ‘what is considered appropriate’, ‘what do people want’, and ‘what might be needed to implement peer support efforts well’. The best possible way to do this is through a broad-focused systematic review of the international evidence.

With ‘systematic review’ we mean:

A review of empirical research that aims to be principled, methodical and explicit. A systematic review addresses a clearly defined research question and uses explicit and standardized methods to identify and review the literature in order to be transparent, accountable, and, in theory, replicable. A systematic review aims to report details about the search strategy used, criteria for inclusion/exclusion of research studies, and data abstraction and analysis including how the methodological quality of included studies was assessed and, where appropriate, how sensitivity analyses were conducted (Gough et al., 2017). These details are not trivial, as it has long been established that the way a review is done, affects its findings (see, *for example*, Harden et al., 1999; Oliver et al., 1999; Peersman et al., 1999).

Systematic review methodology aims to minimize biases such as ‘publication bias’ –a systematic bias in favour of positive results leading to over-estimating the benefits of an intervention⁷– and ‘selection bias’.

In line with a basic principle in systematically reviewing the literature, it is important to check if the required evidence to answer the review question(s) of interest is not already presented by an existing systematic review. Based on the evidence map, referred to above, and our exploratory searches, it became clear that there were several existing systematic reviews. Hence, we opted for conducting a ‘systematic review of systematic reviews’ reported in peer-reviewed journals as well as the grey literature.

⁶ Research of any type focused on any type of peer support conducted during 2000-2015 in OECD countries and published in English.

⁷ Statistically significant ‘positive’ results are more likely to be: published (publication bias), published rapidly (time lag bias), published in English (language bias), published more than once (multiple publication bias), cited by others (citation bias). Publication bias is not restricted to effectiveness research but also an important consideration for qualitative research, as this may be less frequently conducted and submitted to, or published in frequently accessed and easily accessible journals (Gough et al., 2017).

OBJECTIVES OF THE REVIEW: What did we want to know? Who wanted to know this?

As this systematic review was commissioned within the context of the NDIS, a written consultation was conducted with representatives from the NDIA and Disability Support Organisations (DSOs) – organisations providing help in establishing and maintaining peer support groups within the NDIS. The purpose and focus of the review were explained and details about the review process provided. Feedback was invited on:

- the definition of peer support – to make sure we sought relevant studies
- priority questions for the review – to make sure we focused on analysing the right information
- important considerations for inclusion and analysis – to make sure we did not exclude anything of importance to peer support policy and practice within the NDIS

Based on this feedback, the review aimed to address the following key questions:

1. What types of evidence did we find?
2. What were the benefits of different peer support approaches? Can peer support do harm?
 - 2.1 What approaches to peer support have been tested? How?
 - 2.2 What types of benefits were achieved by different peer support approaches? What conditions were associated with achieving benefits or not?
 - 2.3 To what extent were unintended results reported? How did they occur?
 - 2.4 What don't we know?
3. What was needed to implement peer support well and do no harm?
 - 3.1 When and for whom were peer support approaches appropriate?
 - 3.2 Which peer support approaches were favoured by participants? Why?
 - 3.3 What was needed to do peer support well?

REVIEW METHODS: How did we go about finding relevant evidence and analysing it?

Criteria for inclusion and exclusion of reviews

Types of studies: We included published and unpublished systematic literature reviews because, when done well, they minimise important known biases (such as publication bias, selection bias). We included systematic reviews of evaluation studies (outcome, process, economic) and other types of research (qualitative, quantitative) conducted in [OECD countries](#)⁸ within the period 2000–2018. We excluded primary studies and literature reviews that were not intended to be systematic.

Types of interventions: We included systematic reviews of any type of peer support using the following broad definition: Peer support involves “people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help to each other, often in a way that is mutually beneficial.”(The Evidence Centre, no date, p.3). This includes self-advocacy groups – people who work together to have their voices heard to have the same rights, choices, and opportunities as anyone else (adapted from SARU 2018). We excluded reviews that were exclusively focused on peer education as information provision or on clinical support only.

Types of participants involved: We included peer support approaches in which people with any type of disability and/or their carers were engaged. We also included peer support approaches with other

⁸ Australia and 34 other countries; deemed comparable in terms of political and socio-economic contexts.

population groups in the context of addressing health or other issues (such as chronic diseases, health promotion) deemed to have direct transferability to the NDIS context. We excluded reviews that *exclusively* targeted employees, health care professionals, groups with particular experiences not deemed directly relevant to the NDIS context (such as veterans, sex workers).

Types of results: We included reviews of studies that reported on any type of immediate, intermediary or longer-term result and/or unintended positive or negative results. We included reviews of other types of qualitative and quantitative research related to levels of participation, satisfaction, perceptions of peers, peer leaders and other relevant individuals as well as any implementation-related information including, but not limited to, facilitators and barriers for implementation, costs, expertise, training and support needs, context. We excluded reviews that were *exclusively* focused on adherence to medication or other clinical treatment, clinical outcomes, or parenting outcomes.

Locating, screening and describing relevant reviews

We conducted extensive searches on specialist databases of published and unpublished systematic reviews using a wide range of alternative terms for peer support (see **Annex 3**). We also systematically checked the reference lists and bibliographies of identified evidence maps and reviews for other relevant reviews. We conducted broad, iterative Google searches for gray literature including unpublished systematic reviews and documents providing information on implementing peer support (such as standards, 'how to' guides, training materials) and for conducting monitoring and evaluation (M&E) of peer support. We also searched specialist websites (e.g., [Intentional Peer Support](#), [Centre of Excellence in Peer Support](#)) for relevant information.

The search results were screened based on the inclusion and exclusion criteria. This was done on the basis of titles and abstracts and, subsequently, on the full-text papers. The screening was done by the researchers individually and any queries resolved with the lead researcher. The lead researcher also conducted a 10% random sample spot-check on the screening results.

We developed and systematically applied a keywording strategy to describe key characteristics of the identified reviews (such as topical area, type of report, study population, etc.) to allow for a descriptive mapping of the reviews.

Analysing and synthesising findings

Data analysis was conducted in two consecutive phases:

Phase 1: standardised data extraction and quality assessment of the reviews

We developed a standardised data extraction tool to obtain detailed data from each of the systematic reviews in terms of: the type of review, the review methodology, the type of peer support researched, the study populations involved, the outcomes targeted, key findings and conclusions. This also included an assessment of the quality of the systematic review to determine the risk of bias in the review findings. Data extraction was conducted, using EPPI Reviewer⁹, by two researchers

⁹ [EPPI-Reviewer](#) is a web-based software programme for managing and analysing data in literature reviews. It has been developed for all types of systematic reviews and manages references, stores PDF files and facilitates qualitative and quantitative analyses such as meta-analysis and thematic synthesis. It was developed by the EPPI-Centre and is regularly updated with new features –based on methods research for systematically reviewing evidence, including text mining

independently; the results were compared and any differences resolved by discussion with the lead researcher.

Based on this coding, we selected those systematic reviews that focused on interventions that were exclusively peer-led or had a substantial peer-to-peer component. This sub-set included 24 effectiveness reviews (i.e., reviews summarising the findings from outcome evaluations of peer support approaches) and 10 reviews of other types of quantitative research and/or qualitative research about peer support.

Phase 2: Inductive coding and narrative synthesis of the results

This phase included an in-depth qualitative analysis of the sub-set of 34 systematic reviews. It began with a further assessment of the relevance of these reviews. Four reviews were excluded from the analysis for the following reasons: (a) they either made no or passing reference to either 'peer' or 'peer support'; and, (b) the primary studies they reviewed could not be understood as referring to peers or peer support by other terms. We refer to the final sub-set of 30 systematic reviews as 'reviews focusing on substantial peer support'.

Using EPPI-Reviewer, an initial 'big picture' grouping of data from the remaining 30 reviews was carried out, using the following broad categories: terms used and definitions; peer support what and how; and changes noted. These categories were chosen as an initial organising framework against which an overall picture of peer support, as reported on in the systematic reviews, could be developed. Reviews were then assessed again, using NVivo software¹⁰, for key themes arising under each of these broad categories, as well as for other emerging themes. Two further stages of review and refinement were undertaken. Throughout all stages, similarities and differences between the reviews and their respective findings were explored. To make sense of the effects reported across different reviews, we adapted and applied the typology of effect models developed by Dennis (2003) and used word clouds¹¹ to visualize the outcomes reported within each effect model.

A descriptive mapping, based on frequencies of key characteristics of the reviews, was presented for all included reviews as well as for the reviews focusing on substantial peer support. Findings from reviews were synthesised in narrative form and presented in answer to the three review questions and their specific sub-questions.

See **Annex 2** for further details on the review methodology and **Annex 3** for search and screening results.

technology. See [Evidence for Policy and Practice Information and Co-ordinating Centre](#) (EPPI-Centre), Social Science Research Unit, Institute of Education, University of London.

¹⁰ [NVivo](#) is a software tool for qualitative (and mixed methods) data analysis.

¹¹ [Word clouds](#) are graphical representations of word frequency that give greater prominence to words that appear more frequently in a source text; they can be used for communicating the most salient points or themes.

REVIEW FINDINGS: What did we find in terms of evidence and what can we learn from it?

1. WHAT TYPES OF EVIDENCE DID WE FIND?

1.1 A descriptive mapping of systematic reviews focusing on substantial peer support

The searches and screening found 79 relevant systematic reviews. A descriptive mapping of these reviews is provided in **Annex 4**. As noted above, 30 of those were systematic reviews focusing on substantial peer support.

The topical focus of the 30 reviews is provided in **Table 1** and the focus on people with a disability and/or their carers is provided in **Table 2**. Most of the reviews were focused on disability and chronic diseases; the majority of reviews related to people with disabilities were about mental health.

Table 1. Topical focus of systematic reviews with a focus on substantial peer support

Topical focus	Nr (%) of reviews [N=30]
Aged care	1 (3%)
Chronic disease	13 (43%)
Disability	15 (50%)
Other topical focus (e.g., health promotion, general education)	12 (40%)

[Note: percentages do not necessarily add up to 100% as some reviews have multiple foci]

Table 2. Disability focus of systematic reviews with a focus on substantial peer support

Disability focus	Nr (%) of reviews [N=15]
People with a disability	14 reviews
Intellectual, cognitive or learning disability	0 (0%)
Physical disability	2 (14%)
Psychological disability or mental health	12 (86%)
Sight, hearing or speech	0 (0%)
Disability not specified	1 (7%)
Carers of people with a disability	4 reviews
Relative	3 (75%)
Non-relative	1 (25%)
Carer not specified	2 (50%)

[Note: the percentages do not necessarily add up to 100% as some reviews have multiple foci which could include a focus on different disabilities, on people with a disability exclusively or also on (different types) of their carers]

Table 3 provides an overview of the types of primary studies that were included in the 23 effectiveness reviews. All of these reviews included a synthesis of outcome evaluations; three reviews also included findings from process evaluations; and, only two reviews incorporated findings from cost-effectiveness assessments of peer support.

Seven reviews focused on other types of qualitative or quantitative research and included data on: levels of participation in support groups; experiences of participants in relation to different types of peer support; roles of peers; and, peer relationship issues.

Most reviews synthesised the findings related to specific outcomes. Randomised controlled trials (RCTs) were favoured for inclusion in almost half of the effectiveness reviews (i.e., the authors restricted the inclusion of studies to RCTs only) due to their ‘perceived’ rigor. However, many of these authors then went on to record bias/quality issues with the included RCTs. We discuss the appropriateness of evaluation approaches and other methodological issues in Section 1.2 below.

Table 3. Types of primary studies included in systematic reviews with a focus on substantial peer support

Types of primary studies synthesised	Nr (%) of reviews [N=30]
Reviews of intervention studies	23 (77%)
Outcome evaluations	23 (100%)
Experimental design	20 (87%)
Quasi-experimental design	8 (35%)
Other designs	10 (43%)
Process evaluations	3 (13%)
Economic evaluations	2 (9%)
Reviews of non-intervention studies	7 (23%)
Qualitative research	7 (x%)
Quantitative research	2 (x%)

[Note: percentages do not necessarily add up to 100% as some reviews included different types of studies]

All but two¹² of the 30 reviews sought to review peer support for a specific group of people. These groups included:

- People with a specific disease or physiological health condition (e.g., prostate cancer, people with acquired brain injury, people with burns injury). In one case, this was further categorised by age (i.e., adolescents with asthma)

¹² The two exceptions to the above were Pomery et al. (2016): ‘Skills, knowledge and attributes of support group leaders: A systematic review’; and Watson (2017): ‘The mechanisms underpinning peer support: a literature review’.

- People caring for others with a specific disease or chronic physiological health condition (e.g., parents of children with chronic disabling conditions, carers of people with dementia)
- People with mental health issues (e.g., schizophrenia, ‘mental health problems’) *and*
- Groups defined by a specific setting (e.g., people in prison, school pupils).¹³

For Sokol and Fisher (2016), the group of interest was defined as people who are ‘hardly reached’¹⁴ by health programmes due to the following (often intersecting) circumstances:

- individual (e.g., psychological–cognitive factors, occupation, sexual orientation, transiency, substance use, history of incarceration, disability)
- demographic (e.g., age, gender, socioeconomic status), and
- cultural–environmental (e.g., social network, ethnicity, geography, discrimination).

A small number of reviews focused on the effectiveness of specific modes of delivery of peer support for specific groups (e.g., mutual help groups for people with mental health problems; peer telephone support for people with a wide range of health issues; internet-based peer support for parents).

1.2 Methodological issues in reviews and included studies

Overall, the evidence base for peer support was substantial. Of the 30 systematic reviews referred to above, 28 explored studies of specific peer support interventions¹⁵. Between them, these 28 reviews explored 780 studies, each of which assessed a number of interventions. In addition, we located another 47 reviews summarising peer support studies. This vast evidence base was, however, not without problems. We will discuss some important methodological and reporting issues, focusing on those that have a direct implication for how peer support is evaluated in the future and evidence is accumulated and synthesised.

1.2.1 *Relying on published studies only*

We noted the importance of including unpublished studies to minimise publication bias (see Background Section). Eysenbach et al. (2004: 1169) provided an excellent example of this:

“Another concern is publication bias, which we attempted to minimise by including five dissertations. Their inclusion in this systematic review proved to be crucial. Interestingly, the four dissertations with “negative” (non-significant) findings remained unpublished whereas the one dissertation with positive results was published as a journal article.”

1.2.2 *Focusing on RCTs as ‘the gold standard’*

As noted in the descriptive mapping above, authors restricted the inclusion of study designs to *RCTs only* in almost half of the effectiveness reviews for reasons of their ‘perceived’ rigour. While the review by Niela-Vilen et al. (2014: 1534), *for example*, also included other study designs, they clearly favoured RCTs as they noted:

“The evidence of effectiveness of [internet-based] peer support remained inconclusive due to the limited number of experimental designs.”

¹³ Some of the interventions explored in studies focused on groups further categorised by sex, but none of the reviews of those studies did so.

¹⁴ The authors intentionally used the term ‘hardly reached populations’ rather than ‘hard to reach’ because “the latter suggests that fundamental qualities of the group and its members, rather than the intervention trying to reach them, are responsible for members not being reached by health services.” (Sokol and Fisher, 2016:e2).

¹⁵ Pomery et al. (2016) and Watson (2017) were exceptions; they examined, respectively, ‘skills, knowledge and attributes of support group leaders’ and ‘the mechanisms underpinning peer support’.

However, it has been well-documented that randomisation is not a sufficient safeguard against bias in intervention allocation and that it not necessarily results in equivalent groups (Parry et al. 2010). In addition, not all RCTs are designed and implemented well. Hence, quality assessment of RCTs – as well as any other study design – is an important element of critically appraising the evidence. *For example*, Raphael et al. (2013) assessed seven items known to be associated with potential risk of bias in RCTs (such as whether or not there was random sequence generation, blinding in outcome assessment, completeness of outcome data). However, they discussed findings from studies that were rated as ‘low’ risk together with those who had ‘unclear’ risk (meaning we don’t know) which seems to defeat the purpose of doing the quality assessment in the first place.

Several review authors questioned the appropriateness of using a RCT design to test peer support. *For example*, Repper and Carter (2011: 393) quoted a study by Resnick and Rosenheck (2008):

“For peer services built on the principle of inclusion and the development of a supportive, empowering culture, randomised manipulation may change the peer service being researched... The understanding provided by narrative, personal and qualitative accounts is as valuable as more outcome focused comparative and quantitative studies.”

They identified seven RCTs which tested peer support workers in mental health services and found them to present inconsistent findings and varied outcomes measures. Therefore,

“...for the purpose of this review, a wider evidence base was used, including follow-up studies and naturalistic comparison studies. The aggregated results paint a more complete picture of the impact of the employment of PSWs.” (Repper and Carter, 2011: 395).

Pistrang et al. (2008: 119) noted:

“We have tried in this review to take a middle line between two different methodological positions. On the one hand, traditional evidence-based medicine regards the randomised controlled trial (RCT) as the gold standard in research design. On the other hand, RCTs can be a poor methodological choice for evaluating mutual help groups if researchers operate the groups themselves and take control of participation, in effect changing it from a peer-led to a professionally-controlled intervention... our review included some good examples of RCTs in which the autonomy of group members seemed to have been preserved... also included examples of carefully conducted quasi-experimental and longitudinal designs.”

And, they provided the following advice:

“More studies should use longitudinal designs with comparison groups in order to provide more clearly interpretable data about the effectiveness of mutual help groups. Whether such studies are randomized should depend not on a priori judgment but on the purpose of the study and whether randomization will or will not conflict with the peer control inherent in mutual help groups.” (Pistrang et al., 2008: 120).

At times, investigators have also taken a reductionist approach to fit the intervention to the method of experimental or quasi-experimental designs or to specific systematic review approaches (such as meta-analysis). This means that the design and/or implementation of some interventions have been simplified or standardized to an extent that no longer reflects how they have been conceived to work or are far removed from what is being implemented in practice (and has to be evaluated). While there is a place for experimental designs as part of an array of methods and processes in our research and evaluation toolbox, it is not good practice to adapt an intervention to be able to use a favoured method.

1.2.3 Not enough mixed methods

There is a need for combining process evaluation with outcome evaluation and for using both qualitative and quantitative data collection approaches.

It is crucial to understand what is being/has been implemented to be able to interpret outcome data. This needs to be assessed as it cannot be assumed that an intervention is implemented according to plan (i.e., with fidelity) without any changes or challenges, not even under experimental conditions. Knowing how and to what extent the intervention was implemented can help with understanding whether observed ineffectiveness may be due to inadequate implementation rather than the intervention design. *For example*, a RCT on peer mentoring included in the review by Petosa and Smith (2014: 353) found “...only 55% of assigned youth attended mentoring sessions...”. Eysenbach et al. (2004) reported that one of the RCTs had less than 10% participation in the peer-to-peer intervention and more than half of the participants did not respond to a follow up survey. Similarly, in the review by Pistrang et al., (2008) noted that in a study on self-help groups for adults hospitalised for unipolar or bipolar depression it could not be determined “whether the negative results for the experimental condition reflected lack of an effect of self-help group participation per se or the fact that many individuals who were assigned a sponsor never attended any meetings.” (Pistrang et al., 2008:117).

Pistrang et al. (2008) also noted:

“the value of in-depth qualitative studies investigating group members’ experiences of participation and change. This does not only provide important insights into understanding the process of peer support but can also help to identify outcomes (such as mediating effect) that are important to assess in quantitative studies of effectiveness.” (Pistrang et al., 2010: 120).

Likewise, Smith and Greenwood (2014: 16) stated that:

“although dissatisfaction with the peer support was not cited as a reason [for dropping out of the study]... improved understanding of the processes of mentoring from the carers’ and volunteers’ perspectives may help to identify difficulties they may experience during mentoring, which may at least be partially responsible for some of the withdrawals.”

It was hard to understand why some review authors did not include implementation studies or qualitative evidence. *For example*, Cooper et al. (2014) conducted a systematic review investigating the effectiveness of peer support interventions on a range of outcomes related to self-management of chronic (non-cancer-related) pain. As they stated, the nature of chronic pain is multidimensional and can affect several aspects of an individual’s health and quality of life. Thus, by ‘its very nature’, it requires self-management but several barriers to continued self-management have been reported in the research. The review authors excluded qualitative studies “as this was a quantitative review investigating effectiveness of interventions; the meanings or experiences of peer support were therefore outside the scope of this review” (Cooper et al., 2014: 348). Their broad search strategy located a total of 4,078 references which were all assessed for applicability; 12 studies underwent critical appraisal and, ultimately, five quantitative studies were included. After this intensive and time-consuming work, they concluded:

“There is some evidence that peer support interventions may be more effective than usual care for some groups of patients with chronic non-cancer pain. However, it is not possible to make specific recommendations for practice until further high-quality research is conducted.” (Cooper et al., 2014: 319)

“One study does provide some useful information regarding the practical aspects of designing and delivering a peer support intervention, but its pilot nature must be acknowledged.”
(Cooper et al., 2014: 348)

It was puzzling to understand, why – when assessing more than 4,000 references – other potentially relevant evidence was ignored. It may have provided a better insight into the problem at hand. As Niela-Vilen et al. (2014: 1535) stated: “Both quantitative and qualitative methods are essential for evidence-based [nursing]” and “A qualitative approach might provide a fresh insight into peer support from the users’ perspective.”

Shilling et al. (2013: 602) in a mixed method review went as far as saying:

“Qualitative studies strongly suggest that parents perceive benefit from peer support programmes, an effect seen across different types of support and conditions. However, quantitative studies provide inconsistent evidence of positive effects. Further research should explore whether this dissonance is substantive or an artefact of how outcomes have been measured.”

Glenton et al. (2011) found that there is still too little qualitative research to shed light on results from reviews of effectiveness trials. By looking at processes, contextual factors, or intervention characteristics that may have influenced outcomes, qualitative research can help explain heterogeneous results across different studies. The methodology for combining the findings from both qualitative and quantitative research in systematic reviews has been well-established (see, *for example*, Thomas and Harden, 2008; Gough et al., 2017). However, the absence of qualitative research linked to outcome assessments is not just an issue for reviews but, in the first instance, for primary studies. Glenton et al. (2011) found that in more than half (63%) of the 82 trials about effectiveness of lay health workers no qualitative research had been conducted alongside the trials and, thus, they yielded limited insights into intervention mechanisms (Glenton et al., 2011). They suggested factors influencing whether qualitative studies are done alongside trials may include the attitudes of funding bodies and the attitudes and skills of the research community.

1.2.4 Poor quality reporting

Poor quality reporting was an issue in some of the reviews as well as in the primary studies they included, particularly with regards to key elements of the intervention design or implementation, the study design and/or analysis. This made it difficult to understand what is being evaluated and what can be learnt from it.

- Poor reporting of the nature of the intervention posed significant challenges in the analysis and interpretation of the studies. Just over half of the 30 reviews defined ‘peer’ (in 17 reviews) or ‘peer support’ (in 18 reviews). This is discussed in detail in Section 2.1.5 below.
- Incomplete reporting on characteristics of the study populations, the implications for intervention design and for analysing differential effects. While age and sex were reported for the vast majority of studies, ethnicity was not. *For example*, Cabassa et al. 2017 noted that only 67% of the studies they included in their review reported on ethnicity. They stated: “Where studies involved people of mixed ethnicity, cultural or linguistic adaptations of the interventions were not mentioned in any of the studies reviewed... [this] complete inattention to cultural and linguistic issues is very concerning since these factors influence critical intervention elements.” Cabassa et al. (2017: 88).

Few reviews conducted a subgroup analysis. Review authors frequently reported that this was not possible because of constraints in the primary studies. *For example*, Zhong and Melendez-Torres (2017) stated that there were insufficient data available. Some review authors attempted to obtain additional or raw data, but some of the studies were conducted too long ago to be able to still contact the investigators. Where reviews or primary studies did include subgroup analysis, it was clear that – not surprisingly – there were differential effects for different population groups involved. *For example*, a study by Wegener et al. (2009) reviewed in Cooper et al. (2014: 329) found that a group intervention delivered by trained peer leaders for pain self-management “had greater benefit for people less than three years post amputation, people with a secondary condition at baseline, and people under 65 years of age.”

- Incomplete reporting on the number and/or characteristics of individuals dropping out of a study or on how attrition was dealt with in the analysis. This is problematic because participants who are lost may be different from those who remain in the study and, thus, may have very different outcomes from those available for assessment. Hence, results could potentially be under- or over-estimated (i.e., being more or less positive than claimed). Attrition may also be related to dissatisfaction with the peer support intervention (Parry et al., 2010). *For example*, Pistrang et al. (2008) noted that several of the studies they included, found a correlation between higher levels of participation and involvement (regardless how this was operationalised) and positive outcomes. Rather than a dose-response relationship, they cautioned that this could also be explained by differential attrition (i.e., the more severely troubled participants dropped out) leading to overstatement of the effects. Similarly, Smith and Greenwood (2014:6) stated that “attrition bias could have led to only the healthiest [of carers] or those coping best completing the study”.
- Incomplete reporting on the reliability and validity of the outcome indicators used, though many primary studies indicated the use of validated measurement tools (e.g., CES-D/the Centre for Epidemiological Studies Depression Scale; HADS/Hospital and Anxiety Depression Scale; MSPPS/Multidimensional Scale of Perceived Social Support; RSES/Rosenberg Self-Esteem Scale). As part of assessing risk of bias in studies, the review by Sokol and Fischer (2016) coded studies according to their use of ‘objective’, ‘standardised’ or ‘non-standardised’ measures.
- Selective outcome reporting raises the possibility of biased findings. This is not only a problem for primary studies included in a review but also for how the authors of a synthesis of multiple studies present their findings. *For example*, Raphael et al. (2013: 412, emphasis added) stated: “Given the heterogeneity of outcomes assessed and analyses performed, standardized measures of intervention effect could not be reported across the different studies. We present **the most informative** measures of effect and statistical confidence available from the published studies.”

When reporting on studies – regardless of the design –, it is essential to adhere to recommended reporting guidelines (several have been agreed and published in the research and evaluation community) to ensure that all crucial information is included for others to understand what was done, how it was done, and what can be learnt from it.

2. WHAT WERE THE BENEFITS OF DIFFERENT PEER SUPPORT APPROACHES? CAN PEER SUPPORT DO HARM?

2.1 What approaches to peer support have been tested? How?

Overall, there were more differences than similarities between the systematic reviews (aside from the type of review – e.g., meta-analysis, qualitative synthesis analysis, thematic synthesis).

Important differences were: (1) inclusion and exclusion criteria; (2) the nature of the interventions explored; (3) the number of studies included; (4) outcomes considered; and, (5) terms and definitions related to peer support.

We will describe each of these in detail in the following sections as they have important implications for synthesising the findings from the reviews.

2.1.1 Criteria for including and excluding studies

Some reviews only included RCTs, others included experimental as well as quasi-experimental designs. Some reviewed qualitative and quantitative data, others reviewed only qualitative data. Some reviews applied specified criteria related to the nature of an intervention, but these criteria, in themselves, were divergent, *for example*:

To be considered for our review, studies had to include ... assistance in applying behaviour change plans, and at least 1 of the 2 following components: social and emotional support or encouragement of recommended care... (Sokol, 2016:e3)

or

Studies were included if the group being evaluated met all of the following criteria: (1) it aimed to provide support by and for people with a common problem; (2) it was primarily run by its members or facilitated by someone with the same problem (i.e., at most, outside professionals provided occasional consultation); (3) the content of the sessions was determined by members (e.g., the group was not built around a structured self-help intervention such as a series of prescribed cognitive-behavioral techniques; and, (4) members met either face-to-face or via the internet. (Pistrang et al., 2008:112)

Others sought to ensure peer support intervention ‘purity’ as a stand-alone intervention (e.g., Wobma et al. 2016: ‘Studies were excluded if they reported organized or unorganized contact with other acute survivors of ABI [Acquired Brain Injury] in the hospital or rehabilitation centre’). Other required that the peer support activity be undertaken. In one third of the reviews, one of the inclusion criteria was that the studies reviewed had to have been RCTs. This was despite acknowledgement in Repper and Carter (2011) of ‘the restrictions imposed by the process of random assignment in controlled trials’. They added:

For peer services built on the principle of inclusion and the development of a supportive, empowering culture, randomised manipulation may change the peer service being researched (Resnick and Rosenheck, 2008:393).

2.1.2 Nature of the interventions explored

Of the 30 systematic reviews assessed, 28 explored studies of specific types of peer support interventions¹⁶; Pomery et al, 2016 and Watson, 2017 were the exceptions; they examined, respectively, 'skills, knowledge and attributes of support group leaders' and 'the mechanisms underpinning peer support'. Between them, these 28 reviews explored 780 studies, each of which assessed a number of interventions.

While, overall, there was limited detail provided with regards to interventions studied, it was clear that one key difference could be conceptualised as whether they were what we term 'highly structured' or 'less structured' interventions.

Highly structured interventions

By highly structured, we refer to interventions that:

- a) Always have a peer support worker role (albeit often described using a variety of terms);
- b) Use 'peer-dom' primarily as the basis on which relationships with 'participants' are established;
- c) Peer support workers deliver pre-determined content, covering a pre-determined set of topics (e.g., clinically-based lessons on managing asthma);
- d) Training for peer support workers focuses on delivery of pre-determined content (with varying degrees of attention paid to 'being a peer').

These highly structured interventions exist either as stand-alone interventions, or as part of broader interventions including clinical or institutional service provision.

Less structured interventions

By less structured, we refer to interventions that:

- a) May or may not have a defined peer support worker role;
- b) Use 'peer-dom' proactively and reciprocally; if there is a designated peer support worker role (as opposed to a naturally occurring one), he/she is focused primarily on facilitating participation;
- c) Shared experience/experiential knowledge of everyone involved is used to generate 'new ways of thinking and behaving' (Repper and Carter, 2011).

Neila-Vilen et al.'s (2014) work on internet-based peer support for parents had as an inclusion criteria that 'the main focus of the community in the studies included needed to be participant-directed discussion without a predetermined goal' (in other words, a less structured intervention).

When Zhong and Melendez-Torres (2017) reviewed the effect of peer-led self-management education programmes for adolescents with asthma, their inclusion criteria were: 'interventions that are tested in RCTs, involve participants aged 10–19 years old with asthma, use a peer-led educational intervention that addressed self-management of asthma, and report a measure of health status or behaviour as an outcome'. (A highly structured intervention.) Just four studies met the criteria, and three of these four studies implemented the same programme, the Adolescent Asthma Action (Triple

¹⁶ 'Intervention' is used as an umbrella term that refers to all modes and structures of peer support covered by the studies. These include online, non-facilitated support groups for parents; a mailing list facilitated by three professionals for parents of children who had completed cancer treatment, including 'semi-structured peer discussions led by an experienced facilitator'; peer support telephone calls for breastfeeding mothers; face-to-face peer support provided in prison, by prisoners; the work of consumer-providers and more.

A) Program. The fourth studied implementation of the Open Airways (OA) curriculum in addition to Triple A.

At the other extreme, Ramchand et al. (2017) reviewed ‘RCTs of US-based programmes utilizing a peer as either intervention or control and aimed at promoting health and/or wellness among adults and adolescents (mean age of 13 years or greater)’. Their review included 116 RCTs that, variously, had explored interventions with diverse characteristics:

- Group, one-to-one and group plus one-to-one interventions;
- Interactions as one-off, ongoing, or a fixed number;
- Peers functioning either as part of a larger clinical team or not;
- Peer training provided or not provided;
- Interventions aimed at groups of people defined as ‘adolescents (including college students), adults, aged/elderly, women only, pregnant or new mothers, men only, members of a minority/racial ethnic group, veterans, [and] caregivers.’ Further, these interventions covered primary health related domains of ‘substance abuse, chronic conditions, severe mental illness/mental disorder, exercise/diet, breastfeeding, sexual behaviour [sic], social/well-being, cancer, prenatal or postpartum health, homelessness, [and] general health and wellness promotion’.

The review by Ramchand et al. (2017) did not place any parameters on the meaning of the word ‘peer’ (see 2.1.5 below), but used a key word search that included: ““peer support” OR “peer-support” OR “peer based” OR “peer- based” OR “peer led” OR “peer recovery support” OR peer provider* OR “service user run” OR “service user led” OR “service user involv*” OR “consumer case management” OR “assertive community treatment*” OR “buddy” OR “buddies” OR “consumer-provider*”.

2.1.3 Number of studies included

This ranged from just two (Wobma et al., 2016) to 116 primary studies (Ramchand et al., 2017).

2.1.4 Outcome data considered

The data presented in the reviews were compiled from data that had previously been presented in a range of different primary studies, each with their own decision-making processes regarding what data to collect. In addition, the studies had to meet specific review inclusion criteria which included, in some cases, specified types of outcome data.

Some reviews only included quantitative data, others only included qualitative data, and some included both quantitative and qualitative data.

Attempts were made by review authors to achieve some level of comparability across studies reviewed – *for example*, by only including studies that had collected data on specific outcomes—but even so, comparability was limited. *For example*, in Eysenbach et al.’s (2018: 1167) systematic review of the effects of online peer to peer interactions, one of the inclusion criteria was that ‘the outcomes measured were knowledge, health, psychological or social outcomes, or use of health services’. A total of 45 publications were included, reporting on 38 studies; depression and social support outcomes were assessed within 12 of the 45 publications but these outcomes were assessed using three and 12 different instruments, respectively.

2.1.5 Terms and definitions related to peer support

'Peer support'

Of the 30 systematic reviews focusing on substantial peer support, just over half (18) defined peer support. There was no one definitive explanation of the term used across these reviews, nor within the studies explored by the review authors. This was remarked upon by some; Wobma et al. (2016) noted: 'In literature, different definitions are given for "peer support", suggesting that this concept may reflect different constructs'. Dale et al. (2008) also noted that within studies reviewed, 'Broad interpretations of the term 'peer support' are used'. Pomery et al. (2016) stated: 'as yet there is not a specific or all-encompassing model developed for peer support'.

Dennis' (2003) work was cited in six of the 18 reviews that defined peer support.¹⁷ Her definition is firmly grounded in a health care context (the article was published in the *International Journal of Nursing Studies*) and specifically related to 'interventions designed to alter the social environment and the individual's transactions within it' (Dennis, 2003: 321). All six of the reviews that cited Dennis reviewed studies of interventions that sought changes in health status: self-management of chronic pain (Cooper et al., 2014); improved physical, psychological and behavioural health outcomes (Dale et al, 2008); chronic disease management (Embuldeniya et al., 2013); adjustment to heart disease (Parry and Watt-Watson, 2010); improved offender health within prison settings (South et al., 2014); and, rehabilitation after acquired brain injury (Wobma et al., 2016).

Dennis reviewed health-related literature available at that time and concluded:

... peer support, within the health care context, is the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person. (Dennis, 2003: 329)

She argued that 'program-specific training [was] essential', and should be 'structured to orient the peer to program objectives and the promotion of skills that enable the use of experiential knowledge and peer's unique understanding of the target population'. However, this training should be minimised so as not to threaten 'peer-ness', she added.

Dennis' definition is of particular relevance to peer support as implemented by highly structured interventions, where there is a 'created social network member' who receives health-related training in order to provide pre-determined support to member(s) of a 'target population'.

A contrast to this definition can be found in the work of Mead and colleagues, cited in five of the reviews.¹⁸ Mead has firsthand experience of the mental health system and is the founder of the

¹⁷ Dennis CL. (2003). Peer support within a health care context: a concept analysis. In the *International Journal of Nursing Studies*; 40: pp321–332.

¹⁸ Mead, S. and Copeland, M.E. (2000). What recovery means to us: consumers' perspectives. *Community Mental Health Journal*; 36(3): 315-28. Mead, S., Hilton, D., Curtis, L. (2001) Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, 25, 134-141. Mead, S. (2003) Defining peer support. Available from <https://www.intentionalpeersupport.org/articles/> Mead, S., MacNeil, C. (2006). Peer support: what makes it unique? *International Journal of Psychosocial Rehabilitation* 10 (2), 29–37. Mead, S., Filson, B. (2017). Mutuality and shared power as an alternative to coercion and force. *Journal of Mental Health and Social Inclusion*, 21, 144–52.

Intentional Peer Support (IPS) movement (www.intentionalpeersupport.org), described on the IPS webpage as ‘a tool for community development’.¹⁹

The reviews that cited Mead explored: support by and for people with mental health difficulties (Miyamoto and Sono, 2012); internet support for parents where ‘the main focus of the community in the studies included needed to be participant-directed discussion without a predetermined goal’ (Niela-Vilen et al., 2014); peer support in statutory mental health services (Repper and Carter, 2011); mentoring for carers of people with dementia (Smith and Greenwood 2014); and, the mechanisms underpinning peer support (Watson, 2017).

In their review on peer support in mental health services, Repper and Carter (2011) refer to Mead’s ‘short and all-encompassing definition of peer support as, “a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful”’ (Mead, 2003). Further, in a section in their review titled ‘Power’, Repper and Carter (2011:398) stated:

Mead et al. (2001) pointed out that formalising peer support by offering payment, training and titles will inevitably lead to power differences—even if these are minimised. Furthermore, if these power differences go unrecognised or are not worked through then it could lead to peers being less than honest and saying or not saying things through fear of retribution.

Watson (2017) cites Mead and Silson’s (2017) work on peer support as requiring ‘a shift in focus from helping to learning together’. Niela-Vilen et al. (2014), in their review of internet support for parents, defined peer support as social emotional support (citing Solomon, 2004) that is:

voluntary, informal, flexible, non-hierarchical and non-medical (Mead and MacNeil, 2006). Peer support is giving and receiving help and understanding another’s situation through shared experience (Mead et al., 2001).

While Miyamoto and Sono (2012) did not define peer support—noting, instead, that ‘the concept of peer support is broad, and the definitions, effects, outcomes and benefits of peer support are varied’—they chose a quote from Mead and Copeland (2000: 320-321) to begin their review of literature on lessons from peer support among individuals with mental health difficulties:

Health care professionals need to relate to us that they have their own struggles and own that change is hard for all. They need to look at our willingness to “recover” and not perpetuate the myth that there is a big difference between themselves and people they work with. Support then becomes truly a mutual phenomenon where the relationship itself becomes a framework in which both people feel supported in challenging themselves. The desire to change is nurtured through the relationship, not dictated by one person’s plan for another. The outcome is that people don’t continue to feel separate, different, and alone.

‘Peer-ness’

Just over half of reviews (17 out of 30) provided some level of definition of ‘peer’ (albeit often subsumed within a definition of peer support). South et al. (2014) noted that, of the 58 studies included in their review of peer-based interventions to maintain and improve offender health in prison settings, ‘only two defined what was meant by “peer”’.

¹⁹ Accessed May 22, 2019.

Among the reviews that did define 'peer', the differences between definitions mirror the differences between Dennis' (2003) and Mead's/Mead et al.'s (2000, 2001, 2006, 2017) definitions of peer support (discussed above). In Dennis' definition, someone who fulfils a peer support worker role needs both experiential knowledge *and* 'similar characteristics', because together these facilitate the building of a relationship between peer support worker and others. In the work of Mead and colleagues, shared experience is paramount because it is the process of sharing and learning from each other that helps generate change.

In line with the work of Dennis (2003), Tolley and Foroushani (2014) described 'the concept of pairing peer-support recipients with a peer who is closely aligned to them in terms of particular characteristics or attributes, and may include factors such as sex, anatomical site, etiology of injury, cultural factors, or life stage'. In their review of the effect of peer-led self-management education programmes for adolescents with asthma, Zhong and Melendez-Torres (2017) included studies of interventions where 'peer educators had to undergo training, but did not necessarily have to have asthma, as long as the participant could relate to the educator, which could be through age (Bandura, 1986)'. In Petosa and Smith (2014), where the focus was on 'peer mentoring' in schools for health behaviour change, 'peer-ness' was based on an assumption that older school children would know the challenges faced by younger school children and could, therefore, serve as 'role models and health coaches'.

In line with the work of Mead, when Shilling et al. (2013) reviewed peer support for parents of children with chronic disabling conditions, they found:

The need for a close match in parents' experiences was variably reported ... Not all studies ... reported that close matching by diagnosis was necessary. Many issues are common to all families of disabled children, and for some parents in group settings this was enough to form the identity.

Similarly, in Embuldeniya et al.'s (2013) qualitative synthesis of the experience and impact of peer support interventions related to chronic disease, 'Peer mentors were required to have experiential knowledge of chronic disease, but not necessarily the same chronic disease as their mentee'.

In their review on the impact of volunteer mentoring schemes on carers of people with dementia and volunteer mentors, Smith and Greenwood (2014) emphasised the importance of 'experiential similarity' in terms of being (or having been) a carer for a person with dementia, and concluded that provided this existed, then 'extensive matching criteria are not needed'.

This issue of how one's definition of 'peer-ness' and peer support relates to intervention design and implementation will be explored further below.

2.2 What types of benefits were achieved by different peer support approaches? What conditions were associated with achieving benefits or not?

The following sections report on key findings across the 30 reviews.

2.2.1 Where outcomes were reported, they were mostly positive

As described above, one of the key differences between reviews was the outcome measures assessed and the instruments used to assess them. Further, some reviews (e.g., Eysenbach et al., 2018) reported conflicting findings with some of the primary studies reporting positive changes of a specific indicator (e.g., smoking cessation) and others reporting either no or negative changes on the (reportedly) same indicator. This posed a major challenge in terms of being able to draw useful conclusions about the effectiveness or otherwise of peer support. However, the majority of reviews that concluded changes had occurred as a result of peer support reported that these changes were positive.

When looking for a useful way in which to categorise these outcomes given the complexities of a range of outcomes assessed and a range of instruments used even where the same outcome was being assessed, we returned to Dennis' (2003) concept analysis.

Dennis developed a typology of effect models as a means of categorising different theoretical perspectives on the mechanisms underlying peer support. She defined these effect models as: direct effect; mediating effect; and buffering effect. We adapted this typology to create broad domains of the positive effects reported in the reviews as follows:

Direct effects – engagement in the intervention brings its own psycho-social benefits.

Increased social integration; reduced feelings of isolation; reduced depression; improved Quality of Life; and expanded access to multiple sources of information.²⁰

Buffering effects – engagement in the intervention leads to increased ability to cope.

Individuals are more protected from potentially harmful influences of stressful events through improved coping mechanisms and reduction in self-blame.

Mediating effects – engagement in the intervention encourages changes in behaviour, usually related to physical health or use of services.

Increased self-efficacy through positive encouragement and the provision role models (positive changes in the use of health services was considered a proxy for increased self-efficacy); positive changes in health-related behaviour or in physical health state (e.g., weight loss, smoking cessation); positive changes in experience of pain.²¹

²⁰ Dennis did not specifically include changes in Quality of Life under direct, buffering or mediating; however we have included it here because of the well-recognised connections between social integration, reduced depression, reduced feelings of isolation—all of which she referred to under the direct effect model—and overall quality of life.

²¹ Dennis ascribed adoption of healthier behaviours to the 'direct effect' model of peer support. Yet her description of the 'mediating effect' model built firmly upon Social Cognitive Theory and 'self-efficacy' (Bandura 1977, 1986). These concepts have been widely used in public health work on behaviour change; hence we categorised such reported changes under 'mediating effect' because it is reasonable to assume that such changes resulted from the participant 'doing something different' thanks to the mediating influence of peer support. For the same reason we also categorised reports of positive

These domains are not mutually exclusive. For example, it is possible that someone who feels better able to cope will, in turn, feel greater self-efficacy, and similarly that someone who has increased self-efficacy will feel less depressed. Further, the outcomes reported in the reviews are by no means the only outcomes of the studies; they are simply the outcomes that could be somehow aggregated across studies, based on the parameters of the studies included and of the reviews themselves.

Table 4 provides an overview of the types of outcomes reported in the 23 effectiveness reviews. As can be seen, most outcomes were in the domains of the direct and mediating effects.

Table 4. Types of outcomes reported in effectiveness reviews with a focus on substantial peer support

Outcomes reported in the review [*NDIA/ILC outcomes]	Effectiveness reviews [N=23]
Direct effect outcomes	
Mental or emotional health outcome	18
Quality of life	14
Participation in community life*	1
Relationship building*	6
Social change	4
Social support	11
Buffering effect outcome	
Attitude	10
Belief	5
Coping	5
Empowerment*	3
Motivation*	1
Self-awareness	1
Self-esteem	4
Trust	2
Mediating effect outcome	
Adherence to treatment	5
Behaviour	13
Capacity*	2
Intention	4
Knowledge*	4
Physical health outcome	11
Self-confidence*	7
Self-efficacy	10
Self-management	5
Service utilisation	10

changes in use of health services (e.g. reduction in visits to emergency by asthma sufferers) and reported changes in level of pain as a 'mediating effect'.

Using the typology of direct, buffering and mediating effects, we were interested in investigating whether there were any discernible patterns of positive results across the variety of primary and secondary studies? In other words, what outcomes are still visible after several layers of aggregation of *difference* (in terms of: design, implementation, specific population group or other focus and expected outcomes of the initial interventions, the studies of these interventions, and, the reviews of studies)?

In the direct effects domain, some level of positive outcomes was reported in 22 out of 30 reviews. As can be seen in the associated word map, key changes reported were in the psycho-social realm:



For example, the review by Pistrang et al., (2008) examined peer support groups within the context of chronic mental illness, depression and anxiety, and bereavement. They found that seven out of the 12 studies that met their inclusion criteria reported some positive mental health changes for group members. These outcomes were assessed with standardised tools and included both self-reported outcomes as well as ratings by independent clinicians. As another example, the review by Cooper et al. (2014) found several well-conducted studies reporting improvements in quality of life measures including for specific sub-groups (e.g., people with chronic pain and burnout, women with disabilities).

Where reviews explored interventions with specified peer support worker roles, some (but not all) looked for outcomes among peer support workers. Where this occurred, repeated references were made to the reciprocal, relational nature of peer support and the benefits this brought to the peer support workers, for example:

Mentoring decreased mentors' own sense of isolation by allowing them to forge meaningful human connections and cultivate hope (Embudeniya et al., 2013).

However, such benefits were counterbalanced by what South et al. (2104) defined as 'the emotional burden' of being a peer support worker. This was also explored in Dale et al. (2008), which included data from qualitative studies on peer support workers' experience of providing support. The review noted:

Three key themes emerged: 1. peer supporters needed to feel that they were of help to the recipient, 2. peer supporters valued the sharing of experience, and 3. peer supporters sometimes felt confronted by their own anxieties and vulnerability ... peer advisors identified helping as the most significant aspect of their role ... When the helping role was absent, the peer experience became more difficult and less satisfying.

... [there were also] difficulties associated with peers becoming aware of their own hidden feelings and sensitivities [and] problems associated with the intimacy and dynamics of mutual sharing. This not only included difficulties in severing relationships, but also how peers felt when discussions resulted in the recollection of difficult and distressing aspects of their own experiences (Dale et al., 2008).

In the buffering effect domain, there were fewer reported positive outcomes (in 15 out of 30 reviews). These can be summarised in the following word cloud:



There were reports of practical support that, in turn, assisted people in coping (e.g., support in terms of accessing benefits, understanding medication, going shopping) but predominantly, the positive outcomes in this category were both affective and relational. *For example*, positive outcomes included:

... parents of children with chronic disabling conditions becoming more accepting of themselves as a result of engaging in discussions with other parents in a similar situation. This in turn had a positive impact on their relationship with their child' (Shilling et al., 2013)

King et al. (2015) wrote of men with prostate cancer being able to 'confront and accept disease progression' through engagement in peer support; 'patients dealing with uncertainty about a prostate cancer prognosis determine[d] a positive reconstruction of the situation, thus giving mental shape to an uncertain future' as a result of engaging with others whose disease had progressed (King et al., 2015).

As with direct effects, there were some reviews that explored buffering outcomes for peer support workers. In their review, 'Lessons from peer support among individuals with mental health difficulties' Miyamoto and Sono (2012) stated:

Peer-support providers noted that the benefits of peer support are personal growth (specifically, increased knowledge about oneself), initiative and perseverance. Growth came about from sensitivity to the emotional states of clients, fulfilling commitments and acknowledging and learning from mistakes. They also described the development of specific skills and talents, improved communication abilities and increased confidence.

Again, concerns were raised about the vulnerability of positive buffering effects to changes in context or in relationships. *For example*, in Repper and Carter's (2011) review on peer support in mental health services, they reported:

... many [peer support workers] may have to work with professionals who have treated them in the past (Fisk, Rowe, Brooks, & Gildersleeve, 2000). This could challenge the possibility of respectful equal relationships within the team as staff may fail to treat them as professional equals (Mowbray et al., 1998) or continue to view them as 'patients' (Davidson et al., 1999) ... Yuen and Fossey (2003) found that [peer support workers] emphasise that they need to monitor their own workloads and demands that are placed on them, they also need to feel able to take time out when required. McLean, Biggs, Whitehead, Pratt, and Maxwell (2009) also reported that several of the 11 PSWs in [a] Scottish pilot study had experienced readmissions to hospitals since starting in the role. These admissions were not in the same service that the [peer support worker] was working in and that was believed to be a key factor in preserving relationships with colleagues and peers. Furthermore, the [workers] used the experience to enhance the ways in which they could apply their experience to their role. [Peer support workers] reflecting on the benefits and limitations of their employment (Mowbray et al., 1998) stated that some of the people who they were assigned to work with, created stress because they directly affected [their] ability to do their job. For example, peers who were 'uncooperative', 'unmotivated', did not turn up for appointments, peers who were very troubled or in major debt, created feelings of frustration, disappointment, failure, fear and guilt.

In the mediating effects domain, positive outcomes were reported in 22 of the 30 reviews. The most commonly sought changes related to changes in behaviour (e.g., smoking cessation, weight loss). These were mostly reported as quantitative data (hence, we are not presenting a word cloud here). The results for behaviour change were largely mixed, but 'statistically significant' changes were reported in some reviews such as: increases in breastfeeding, condom use, healthy eating, mammography take-up and maintenance, physical activity for women (but not for men), weight loss; and, decreases in: injecting drug use, smoking rates.

There are also questions as to definitions of 'significance' of changes related to 'statistical significance', 'clinical significance', 'significance in term of cost savings' and 'significance as perceived by the individual'.

For example, Raphael et al. (2013) reviewed the effectiveness of lay health care workers in improving health care utilization, symptom management, and family psychological outcomes for children with chronic conditions and reported:

“Although statistically significant positive outcomes of lay health worker interventions have been demonstrated, the clinical benefits are relatively small in scale. Though any improvement is noteworthy, a critical question for policy makers will be whether this scale of improvement will make any appreciable impact on costs associated with management of pediatric chronic disease, particularly when there is increasing emphasis on identifying interventions to produce cost savings.” (Raphael et al., 2013:418)

For example, in Stubbs et al.’s (2016) systematic review of ‘peer support interventions seeking to improve physical health and lifestyle behaviours among people with serious mental illness’, they reported on a study by Aschbrenner et al. (2016), that ‘utilized a pre-test and post-test pilot study among community mental health service users (n = 13) who were obese (BMI: 41.5) and on stable antipsychotic medication’. Stubbs et al. (2016) reported:

The authors found that there were no significant improvements in weight, although 45% of the sample lost weight compared to their baseline weight ... The authors found no significant improvement in fitness (determined by the 6-min walk test), although participants did increase their baseline result distance by 45% ... no significant difference was observed in weight after the intervention, although the mean weight loss across the group was 2.7 kg ... Schneider et al. (2011) ... found that the 11 participants lost on average 1.14 kg, but this was not significant.

There are likely to be major differences between what a health care professional might consider to be a significant change, and what an individual (or peers with similar experiences of a particular set of challenges) might consider significant. Losing 2.7kg (or even 1.14kg) could certainly be considered significant for a person with serious mental illness who, previously, has never achieved any success in weight loss.

Mediating effect outcomes related to ‘self-efficacy’ and self-management’ were less commonly sought than the behaviour change outcomes noted above. Where these were sought, the findings were predominantly positive; some reviews reported mixed results from different studies.

For example, Rains and Young (2009) reported that participation in computer-mediated support groups ‘led to significant increases in self-efficacy to manage ... a variety of different health conditions ranging from breast cancer and Parkinson’s disease to depression and disordered eating’. Miyamoto and Sono (2012), who reviewed literature related to peer support among individuals with mental health difficulties, cited one study that found ‘Consumer-providers empowered patients to be more outspoken about pursuing their own goals’. When Parry and Watt-Watson (2010) reviewed peer support intervention trials for individuals with heart disease, they found one study that noted ‘participants who received the peer-led programme demonstrated statistically improved health status, health behaviours and self-efficacy, with fewer emergency room visits’.

Reviews that reported on the mediating effect of ‘utilisation of health services’ found diverse findings including ‘statistically significant improvements in communications with doctors’ in two studies, as well as ‘statistically significant changes in the use of services either by reducing the use of emergency room services or hospitalizations or increasing the use of primary care services’ in four out of eight studies that explored these outcomes (Cabassa, 2017). Results in Parry and Watt-Watson (2010) ‘indicate[d] that participants tended to seek care for [heart disease] symptoms earlier than they might have had they not had peer support. However, there is not enough evidence to indicate whether this early access was appropriate or not’. In Repper and Carter (2011)’s review of peer support in mental health services reported that: ‘The majority of the wider evidence on admission rates report positive results, suggesting that people engaging in peer support tend to show reduced

admission rates and longer community tenure'. Only one review, Cooper et al. (2014) stated explicitly that 'no evidence was found on the effect of peer support on health service utilization' among community-dwelling adults with chronic non-cancer pain.

In conclusion, the reviews reported pre-dominantly on positive outcomes in the direct and mediating effects domains; only half of the reviews reported on outcomes in the buffering effects domain. However, when we analysed the pattern of outcomes targeted, we found that mediating effects were looked for most (71 outcomes, or 45% of all outcomes sought). Just over a third of all outcomes sought related to direct effects (54, or 35%). One in five outcomes sought were buffering effects (31, or 20%). This may indicate that the reviews, and presumably therefore the studies of interventions, drew most strongly on a conceptualisation of peer support as primarily achieving mediating effects which we summarise as changes in behaviour, usually related to physical health and use of services).

Another important question is '*who benefits most?*'. This was not systematically investigated throughout the reviews, but there were several indications that peer support can be particularly effective for those who are more marginalised; in Sokol's (2016) review of peer support for the 'hardly reached', she stated:

Not only does peer support appear to be effective among those hardly reached, but evidence indicates that it may be more effective among these groups ... In 5 of the 6 studies examining moderators of the effects of peer support, peer support benefits were greater among individuals characterized by disadvantage (e.g., low health literacy).

Pistrang et al. (2008) noted that in one of the studies she reviewed of mutual help groups for people with mental health problems, 'there was some indication that, for members with lower interpersonal and coping skills, greater meeting attendance was associated with reduced depression and grief.' And Zhong and Melendez-Torres (2017) warned of the need to be aware of unintentional exclusion from interventions if there is a cost involved; their work included a review of an 'asthma camp' intervention, which was mainly accessed by people from 'families with 'higher ... income'. But they added: 'Among the attendees, however, low SES participants particularly benefited from the intervention'.

[2.2.2 The importance of shared experience](#)

While there were many important differences between the reviews (see Section 2.1), all reviews stressed the importance of reciprocal sharing of experience. *For example*: 'Peer support draws on direct and shared experience as a resource for mutual benefit' (Walker and Bryant, 2013); 'Interacting with others who are suffering, or have suffered, from a specific health condition offers a multitude of potential opportunities to give and receive information, emotional, and esteem support' (Rains, 2009) and, from South et al.'s (2014) review of peer-based interventions to improve offender health in prison settings:

Many peers had experienced first-hand many of the problems faced by prisoners and could relate to the challenges that they faced. The value of 'lived experience', therefore, was a crucial attribute that peers held over staff.

In Tolley and Foroushani's (2014) review of one-to-one peer support for adults with a burns injury, they stated: '... coupling of burn survivors is based on the fundamental principle of sharing experiences related to surviving a significant trauma, and this should not be underestimated'.

In their review of the literature on peer support in mental health services, Repper and Carter (2011) argued that ‘whatever be the setting’, reciprocity—and, specifically, the sharing of experiences—is integral to peer support.

Watson’s (2017) literature review on the mechanisms underpinning peer support in mental health found that:

The ... use of their lived experience emerged as the strongest mechanism by which [peer support] acts, being identified in all 13 studies as an important component of peer support relationships ... That this mechanism is so powerful might partly be due to the traditional cultures of non-disclosure within mental health services. These cultures increase the saliency of PSWs sharing, and their deliberately mutual approach creates a contrast to the overt hierarchies and clinical understandings which often define mental health services.

Such sharing did not appear to be dependent on a high level of peer matching; in their qualitative synthesis of peer support interventions for people with chronic disease, Embuldeniya et al. (2013) reported:

Sharing by mentees referred to the exchange of experiences relating to living with disease, associated emotions, and coping strategies. While sharing was facilitated by a common disease, mentees found that sharing the consequences of disease was also possible across heterogeneous medical conditions. Sharing normalized participants’ conditions, engendered feelings of peer belonging and acceptance, reduced isolation, and built community.

In reviews that included studies of interventions with designated peer support workers, this sharing was identified as a source of *mutual* benefit for both peer support workers and for those with whom they worked. Stubbs et al.’s (2016) review of peer support interventions seeking to improve physical health and lifestyle behaviours among people with serious mental illness noted: ‘There is some evidence from the included studies that peer support workers are reluctant to be seen as experts or coaches and prefer a co-learning model’.

The review by Dale et al. (2008), which explored peer support telephone calls for improving health, cited three studies that provided qualitative data on ‘the peers’ experience of providing support’. Three key themes emerged from these studies:

1. peer supporters needed to feel that they were of help to the recipient,
2. peer supporters valued the sharing of experience, and
3. peer supporters sometimes felt confronted by their own anxieties and vulnerability.

The latter part of this quote reinforces concerns about the ‘emotional burden’ that peer support workers can carry, also described by South et al. (2014). Lack of reciprocity was found to add significantly to this burden.

Some reviews made the point that within peer support provided to enable improvement in health status, the peer employed in the support role is generally considered to be further along their road to recovery’, which creates ‘a shift in emphasis from reciprocal relationship to a less symmetrical relationship of “giver” and “receiver” of care’ (Repper and Carter, 2011). Repper and Carter (2011) concluded:

It appears therefore that the degree of reciprocity expected from peer support workers varies depending on the approach being adopted [reciprocal or ‘giver’ and ‘receiver’].

Nevertheless, it appears that whatever be the setting, reciprocity is integral to the process of 'peer-to-peer support' as distinct from 'expert worker support'.

However, the reviews contained very little evidence of the specific ways in which interventions that had been studied put shared experience to use. This is discussed in Section 2.4.3 below.

2.3 To what extent were unintended results reported? How did they occur?

The potential for peer support to do harm was not systematically investigated, but, as several review authors noted, the fact that negative effects are not reported, does not mean that harm does not exist (Eysenbach et al., 2018; Zhong and Melendez-Torres, 2017). Indeed, we did find reviews (and some reports from our google searches) that reported unintended negative consequences, including:

- Studies pointed to a need to consider experiences and effects related to both 'giving' and 'receiving' peer support. Negative effects were related to uneven power relationships between peers – although they may even out over time (Embuldeniya et al., 2013; Mead et al., 2001; Repper and Carter, 2011) (see also Section 2.1.5 above).
- Misunderstanding occurred when one peer believed the relationship to be reciprocal while the other does not. The peer 'providing' support can feel rejected when the peer 'receiving' support drops out, does not turn up for scheduled appointments or does not return phone calls. Establishing a peer support relationship can also create an overdependence on a peer. Individual negativity can adversely impact group dynamics, and, there is potential for negative social comparison, as well as a competitive culture of whose condition is worse (Embuldeniya et al., 2013).
- Peer support can be challenging and onerous, especially when there are many individuals involved. Negative effects were related burden of care, particularly in roles involving emotional support (South et al. 2014).
- When a helping role (defined here as: giving advice and assisting with problem solving, being an advocate, alleviating fear) was absent, the peer experience became more difficult and less satisfying. Peer advisors tended to limit their emotional involvement when they did not feel they were making a difference or what they had to offer was not really what was needed. Peers also noted difficulties when becoming aware of their own hidden feelings and sensitivities through the intimacy and dynamics of mutual sharing (Dale et al., 2010). Embuldeniya et al. (2013) also noted that intimacy of personal sharing can lead to feelings of emotional entanglement, tension and conflict.
- Adverse effects were reported in the two RCTs reviewed by Wobma et al. (2016) that tested peer support for individuals with traumatic brain injury (TBI). One trial found significant improvements in perceived social support, social integration, social network size, participation in highly valued activities, but also a significant increase in depressive symptoms in the peer-supported group. The other trial found significant positive changes (i.e., more behavioural control, less chaos in the home environment, less emotion-focused and avoidance-oriented coping, good quality of life) compared with those not supported by a peer. However, the sub-group of carers included in this study showed less community integration and greater family dysfunction and anxiety. Both studies hypothesised that this might be due to increased awareness of problems after TBI and the review authors called for getting a better understanding of what lies behind the unfavourable outcomes (Wobma et al., 2016).
- The review by Rains and Young (2009) found that, contrary to expectations, group size was negatively associated with perceptions of social support. They hypothesised that in groups that

are too large, individuals may feel a sense of alienation – as if they are lost in a crowd – and have difficulty making connections.

- Niela-Vilen et al. (2014) in their review of internet-based peer support, reported on negative elements identified in three of the studies they reviewed. Most were related to time taken through a large volume of emails to deal with, and web postings that are ‘off topic’ or repetitive. Perhaps more importantly, studies also pointed to the need for a process to deal with ‘misinformation’ posted online. Participants in these online support groups also noted the lack of replies from the group and negatively experiencing the lack of face-to-face contact.
- In settings employing ‘peer staff’, some research has shown that peer staff felt ostracised, were poorly treated by non-peer staff, and had been ‘co-opted’ into a deficit-focused culture which goes against the essence of what peer support is about (Solomon, 2004).

Given the potential for adverse effects is real, this is clearly an area that needs to be more systematically researched and should be investigated through regular monitoring and evaluation approaches when implementing peer support.

2.4 What don’t we know (much about)?

2.4.1 Most reviews provided scant data on intervention implementation

The 28 reviews that focused on peer support ‘interventions’ had explored a total of 780 studies (each of which had, in turn, studied a number of interventions.) These interventions were hugely diverse. Perhaps as a result of this, the reviews contained limited data related to intervention implementation. Several reviewers commented on this.

In their review on peer support telephone calls for improving health, Dale et al. (2008) commented:
Given the heterogeneity of studies included in the review, it was not possible to undertake sensitivity analyses to explore the impact of the approach taken towards peer recruitment, and the quantity and quality of training offered to peers, on the effectiveness of peer support telephone calls. These aspects are likely to be important, especially for interventions that include appraisal support and emotional support, but none of the studies appeared to have tested different approaches to training and recruitment during either the intervention design or trial phases.

For instance, in reviews that included data on interventions with some form of ‘peer worker’, the majority provided either limited or no data with regards to: peer worker selection; training; supervision; and responsibilities. Yet in order to assess effectiveness, it is important to be able to ascertain, for example, whether or not training was provided, and whether or not the content of that training was consistent with the intervention’s logic: if, indeed, it was possible to identify the logic at all.

2.4.2 Where is the logic?

The qualitative analysis, importantly, served to identify what was *missing* from the reviews: there was a lack of sense-making in terms of the ‘what, why and how’ of peer support. In other words, there was little to be found in terms of the *logic* underpinning the interventions examined in 700-plus studies, and further explored within the 30 systematic reviews.

Such logic is often referred to as programme logic (alternative terms include: logic model, impact pathway, theory of change and theory of action) and can be understood as the description/representation of causal processes that occur between an input and desired outcomes (Funnell and Rogers, 2011). In simple language, this logic equates to a coherent explanation of: what we want to change, and why; what we know about the thing we want to change (including identification of theories considered relevant); our assumptions; how we will act to generate this change; and, why we will act in this way (again, with reference to relevant theories).

Hereafter, we will refer to peer support logic, for the simple reason that this is a review about peer support per se and not about specific peer support interventions or programmes. Further, the lack of information available across reviews means that we cannot provide an over-arching diagram of peer support logic (which is expected when one refers to either logic model or theory of change and theory/theories of action).

Understanding the peer support logic underpinning an intervention is central to thinking through the plausibility of being able to achieve stated outcomes and being able to assess peer support with appropriate methods. It relies heavily on starting from a clear definition of what peer support is understood to be, within this intervention. As noted in Section 2.1.5., only just over half of reviews provided some level of definition or description of peer support.

The definition of peer support adopted by an intervention will be influenced by the theory or theories put forward to explain why peer support has been chosen as an intervention approach, and how it is expected to work. As noted in Neila-Vilen et al. (2014), the theories selected will in part be guided by the field in which an intervention is developed:

... the systematic development of an intervention based on nursing theory might emphasise a nursing perspective (e.g. Davidson et al., 2010), to incorporate the holistic approach to individuals found in nursing theory (Marriner, Tomey and Alligood, 2006).

Sansom-Daly et al. (2102) made explicit reference to the need for theoretical clarity after finding that just 36% of the 25 experimental and quasi-experimental studies included in their systematic review of psychological interventions with young adults living with chronic illness 'reported using a theoretical framework to guide their research'. They noted that using a theoretical framework 'does not guarantee the delivery of positive outcomes', but concluded:

... the presence of an overarching theory in guiding intervention design should entail a thorough consideration of what key elements are expected to affect change, how these may best be modified, and how process factors may be measured in assessment.

Some of the reviews sought to identify the theories underlying interventions that had been studied; some looked for the theoretical underpinning of the studies themselves, rather than the theoretical underpinning of the interventions studied; some did neither.

Where some level of search for underlying theory occurred (either at intervention or study level) the most commonly cited theory was that of social support. No one definition of social support was cited (in some instances, there were no citations provided). Parry and Watt-Watson (2010) referred to social support as 'any process through which social relationships might promote health and wellbeing'. Rains (2009) defined social support as 'an umbrella term that describes the association between participation in social relationships and one's well-being'. Wherever social support was referred to, the emphasis was on relationships. The importance of this is reinforced in Watson's

(2017) review of the mechanisms underpinning peer support; she concluded: 'The review demonstrated that the profoundly connected nature of peer support acted as a mechanism for its success'.

With this in mind, it is worth reviewing the word clouds provided for positive direct and buffering effect outcomes in Section 2.2.1. The words "social support" are central to the direct effects word cloud, while the buffering effects word cloud demonstrates clearly that positive outcomes in this category were both affective and relational.

Returning to the work of Mead and Dennis, both highlight the importance of social relationships; however, Dennis (2003) does so from a health and wellbeing perspective while Mead (2000, 2001, 2003, 2006, 2017) does so from, what can be termed, an empowerment perspective:

The importance of social relationships in the treatment of disease and the maintenance of health and well-being has drawn the attention of scientists and practitioners across a large number of behavioural science and health disciplines (Dennis, 2003: 321)

... peer support in mental health grew out of a civil/human rights movement in which people affiliated around the experience of negative mental health treatment (e.g. coercion, over-medication, rights violations, as well as an over-medicalized version of their "story"). In other words, the shared experience has had more to do with responses to treatment than the shared experience of mental illness (Mead and MacNeil, 2006)

Mead and MacNeil's work on peer support relationships was quoted in Miyamoto and Sono (2012):

MacNeil and Mead identified seven standards that reflect and characterize the ideal peer-support relationship. They conducted interviews on the topic "what makes for good peer support" with peer-support receivers and providers at a peer-support center within a traditional mental health system. They identified the following standards for the helping process: 'Critical learning and the renaming of experiences are promoted,' 'Sense of community,' 'Great flexibility in the kinds of support provided,' 'Activities, meetings, and conversations are instructive,' 'Mutual responsibility across relationships,' 'Clarity about setting limits' and 'Sophisticated levels of safety.'

A core difference between these two perspectives is well captured by the following example cited in Allen et al.²²'s meta-synthesis of long-term self-management support in peer-led online communities. The review, which focused on 'understanding the exchange of experiential information on health' (Allen et al., 2016: 2), stated:

it is perhaps unlikely that the traditional patient education perspective model of information would be able to disseminate highly experiential information, such as how someone with diabetes can count carbohydrates to enable drinking sessions without risking ketoacidosis ... but such facets of information are clearly useful to someone with diabetes wanting to self-manage their condition.

The importance of relationships at all levels of peer interventions was acknowledged in South et al. (2014), who developed the following diagram:

²² This review was excluded from the sub-set of 30 reviews focused on substantial peer support on the basis of overall relevance (see p.13) but it offers pertinent information here.



FIGURE 16 The importance of relationships for the sustainability and success of peer interventions in prison.

South et al., 2014: 86.

2.4.3 [How is experiential knowledge used in practice?](#)

While experience and/or experiential knowledge was broadly acknowledged as a component of peer support across all reviews, the role this was expected to play in the *implementation* of interventions was most often either unclear or unspecified by the authors. Where evidence did exist, the use of experiential knowledge seemed connected to whether the intervention could be understood from an empowerment/transformational social change perspective or a health and wellbeing one.

1. Empowerment perspective

- The experiential knowledge of all participants is valued equally, and facilitation is used to draw this experiential knowledge out;
- The reciprocal exchange of experiential knowledge is central to the intervention;
- This reciprocity is understood to lead to 'new ways of thinking and behaving' that are not defined in advance (Repper and Carter, 2011)

2. Behaviour change perspective

- Shared experience is used primarily to build relationships between peer support workers and participants;
- These relationships then act as conduits through which the peer support worker supports another/others in achieving specific pre-determined outcomes through following pre-determined procedures (e.g., participation in a fixed number of group sessions, the content of which is guided by a manual).

2.4.4 How much does peer support cost?

Very few reviews mentioned ‘anything’ related to the cost, let alone, cost-effectiveness of peer support interventions due to a lack of such data in the primary studies.

The review by South et al. (2014) focused on peer-based interventions in prison settings and found only one primary study that reported on costs (but not health outcomes); this particular study concluded that (relatively small) savings can be made in management costs in prisons through using a therapeutic community programme.

The review by Pennington et al. (2013)²³ set out to determine in which areas peer or lay health-related lifestyle advisors were cost-effective. While they delivered a range of health-related benefits, these were not necessarily cost-effective; most notably, peer-delivered smoking cessation interventions were deemed highly cost-effective when compared to no intervention because of the large potential health gain from the behaviour promoted.

In their systematic review of ‘lay health workers in pediatric chronic disease management’, Raphael et al. (2013) noted that children with chronic diseases represent a high-cost and resource-intensive population of children. They noted that the clinical benefits of having lay health workers were relatively small in scale and not expected to make appreciable impact on costs, particularly when there is increasing emphasis on identifying interventions to produce cost savings within the health care system. However, they also noted that “even if lay health worker interventions do result in cost savings, the returns might not go to those who fund the programs but might be realized by other parties. Therefore, cost savings must be considered from the perspective of all stakeholders, both within and outside the health care system.” (Raphael et al., 2013:418)

The review by Pistrang et al. (2008) noted that for one of the studies they included and found to be the robust in study design, peer-led groups were ‘as effective’ as professional therapists in terms of changing a range of depression-related outcomes (including both self-reported and ratings by an independent clinician). While the study did not include a formal cost-effectiveness analysis, the authors stated: “it goes without saying that the training and employment of professionals is substantially more costly than “helping” provided by peer volunteers. In other words, this finding of equal effectiveness demonstrates superior cost-effectiveness for the peer-led groups.” (Pistrang et al., 2018: 117).

²³ This review was part of the 79 systematic reviews that met the inclusion criteria but not of the sub-set of 30 reviews that focused on substantial peer support.

3. WHAT WAS NEEDED TO IMPLEMENT PEER SUPPORT WELL AND DO NO HARM?

3.1 When and for whom were peer support approaches appropriate?

Overall, peer support is well-accepted and builds on experiential similarities. Embuldeniya et al. (2013) found that facing similar challenges and disease experiences, personal and social characteristics, lifestyles and life experiences, cultural value systems, a shared commitment to the programme, and reciprocal support, all helped to forge a sense of connection. Conversely, a perceived lack of similarity with peers hindered rapport.

Solomon (2004) emphasised freedom of choice as a critical ‘ingredient’ of peer support regardless of how it is defined or what form it takes. Not everyone is ready for peer support or is motivated to join a group. The question “is peer support for me?” is, therefore, an important one. Challis (2016) pointed out that this needs to be addressed in terms of what type of support is most helpful for a particular individual at a certain time and for his/her particular circumstances and needs. Challis (2006:11) proposed a set of questions for individuals to consider before trying peer support to help manage their mental health-related issues:

- Am I comfortable talking about my experiences to new people?
- Do I want to focus on talking about my experiences, or take part in an activity?
- Am I comfortable hearing about others’ experiences?
- Do I need more personal support?
- Am I well enough?
- Is the right time?

Changing needs and circumstances over time may also lead to people ‘dipping in and out’ of peer support.

In terms of evidence about peer support for people from culturally and linguistically diverse (CALD) backgrounds, some reviews included studies involving diverse populations but the findings were not analysed according to specific population groups. Cabassa et al. (2017: 88) also noted that only 67% of the studies they included in their review reported on the ethnic characteristics of the study population and warned that:

“...a complete inattention to cultural and linguistic issues...is very concerning since these factors influence critical intervention elements...”

There were no systematic reviews specifically focused on Indigenous communities in Australia or elsewhere but our grey literature search identified peer support materials from Aotearoa New Zealand. These used a variety of practice models, some of which were locally developed or adapted and some of which were imported directly from peer support developed in the US (such as the [Intentional Peer Support \(IPS\)](#) movement that places “mutual empowerment” central). A prominent peer support model within the Maori context used a strengths-based approach emphasising empowered choice and the importance of the peer relationship. Kaupapa Maori peer providers worked with Maori concepts such as the ‘building of family-like connections and relationships’. The authors noted a good fit between peer support approaches and Indigenous peoples’ more holistic ways of providing services. An important condition for success was the provision of ‘training and support’ for competencies around ‘mutuality’ –taking responsibility for oneself, but not for the other (Scott, 2011).

Peer support may provide the only opportunity for positively engaging individuals, especially those who are alienated from or not easily reached by formal services. The review by Sokol and Fisher

(2016) focused on what they called ‘hardly reached populations’ –a term they preferred over ‘hard to reach’ because

“the latter suggests that fundamental qualities of the group and its members, rather than the intervention trying to reach them, are responsible for members not being reached by health services.” (p.e2).

This review identified distinct operational strategies to engage the hardly reached including: frequent contact with group participants, assertive contact, monitored contacts, providing support to peer ‘supporters’ (often including debriefing sessions and opportunities to discuss challenges), tailoring content to needs, ‘just being there’ (e.g., meeting for coffee to talk), ready availability (contact when needed).

The review by South et al. (2014) focused on peer education and peer support in prisons. They found that peer support services were an acceptable source of help. They particularly noted the benefits of being a ‘peer worker’.

3.2 Which peer support approaches were favoured by participants? Why?

There were no discernible patterns about what types of peer support were favoured over others. However, several systematic reviews assessed the use of online support and noted reasons why individuals might favour this format. Online support included groups that were: public and open (i.e., anyone can join) or closed and private (i.e., requires application to the owner of the group); and, had a distinct group aspect or employed one-on-one support. It was noted that online support offers a high degree of anonymity and that one can confide in others without any social repercussions. Online support may be useful for people who do not feel comfortable going to a group in person for the first time. *For example*, in the context of self-management for long-term conditions, Allen et al. (2016) found that social ties forged online can address areas that are particularly difficult to navigate offline (such as issues related to sex, incontinence) and, because online communication lacks nonverbal cues, people don’t have to worry about how they look or sound. However, online groups may also lack continuity, limiting the ability to establish a relationship. Other negative issues were also reported on (see Section 2.3).

Campbell et al. (2004) noted that peers are not necessarily the best channel for providing timely and accurate information. The kind of knowledge peers bring into the support relationship can best be characterised as practical knowledge or lived knowledge. Up-to-date, factual information is best provided by a knowledgeable and credible individual/source. Due to lack of knowledge about most-up-to-date information and lack of confidence in getting it right, peers may actually feel uncomfortable providing factual information (Campbell et al., 2004). Engaging expert speakers in support groups can be a good approach to dealing with this issue (Thaxton et al., 2005).

A study conducted in the context of the introduction and roll-out of the NDIS in Australia found that people need accessible, accurate and timely information as a pre-requisite to making informed choices in individual funding programmes. The researchers identified a set of key principles for information provision: (1) accessible and diverse in format, mode, source and location; (2) personalised and targeted; (3) accurate, consistent and timely; (4) from a trusted source; (5) independent; (6) culturally appropriate; (7) actively promoted to ‘hard to reach’ groups; and (8) gender appropriate (Laragy et al., 2016).

3.3 What was needed to do peer support well?

A key learning from this review is that augmenting the social relationship, which is at the heart of any form of peer support, can influence results positively and minimise harm.

As explained in Section 2.4.2, understanding and making explicit a theory of change or plausible ‘if-then’ logic, informed by best available evidence, is central to being able to achieve intended outcomes and to minimise the potential for doing harm. We discussed two major models – the empowerment or transformative social change model and the behaviour change or public health model. We have summed up these models in **Figure 1** below with key questions and considerations for implementation and appropriate M&E. These models are an important starting point for a programme logic and need to be further expanded taking the following into consideration:

Needs and circumstances: What are the specific needs and circumstances of those (to be) engaged? Is peer support right for each of them at this time? Do they need something else instead or in addition?

Diversity: Different types of peer support that appropriately address different needs and cultural diversity; and, are geographically dispersed and supplemented by on-line activities, where relevant and acceptable, to allow easy access.

Timing and duration: Individuals may ‘dip in and out’ of peer support depending on readiness, needs and motivation. Transformative change takes longer to achieve than short-term outcomes, so realistic timeframes for sustaining peer support and for assessing longer term outcomes are needed.

Standards and safeguards: Several organisations/networks have a code of conduct, ethical guidelines or a set of ground rules for the operation of ‘meetings’ or other interactions (see, *for example*, WHO 2017). Mead et al. (n.d) points out that a relationship of giving and receiving help needs to be based on explicit values, principles and standards including ‘mutual agreement of what is helpful’, ‘process standards’ (beliefs, styles, values)²⁴, and, ‘structural standards’ (basic rules and how a group is constructed)²⁵.

Those engaged: The majority of the reviews did not provide details on recruitment of peers. We referred earlier to the importance of ‘experiential similarity’ as a mechanism for peer support to act on, more so than a close match by diagnosis (Embaldeniya et al., 2013; Shilling et al., 2013; Smith and Greenwood, 2014). The kind of knowledge peers bring into the support relationship can best be characterised as practical knowledge, or a lived knowledge from which learning and understanding are embedded in contextualised lived experiences (Mead et al., n.d.). This knowledge is not easily made explicit and thus, needs particular guided processes to bring to the surface, going beyond merely soliciting information from peers. Mead et al. (n.d.) developed core competencies with reference to criteria (or standards), principles, practice tips and a scoring scale as part of their [Intentional Peer Support](#) trainings and practice.

These include, *for example*:

²⁴ *For example* : Process standards: peer principle –finding affiliation with someone with similar life experience and having an equal relationship; helper principle –notion that being helpful to someone else is also self-healing; empowerment, advocacy, choice and decision making opportunities, skill development, reciprocity etc

²⁵ *For example* : Structural standards: free from coercion (e.g., voluntary), consumer run and directed (both in governance and operation), informal setting with flexibility, non-hierarchical, and non-medical approach (e.g., not diagnosing)

1. Engages in co-learning rather than helping
 2. Focuses on the relationship and relational care
 3. Focuses on hope and possibility
 4. Nurtures and cultivates connections with others
 5. Awareness of the power of language to create reality
 6. Listens to open up and explore worldview
 7. Aspires to mutually responsible relationships that work for everyone
 8. Shares the risk of negotiating challenges and discomfort relationally
 9. Directs energy and attention toward what is wanted and how it can be created
 10. Cultivates self-awareness in service of relational needs
 11. Gives difficult messages with dual awareness of other worldviews and one's own
 12. Receives difficult messages with dual awareness of other worldviews and one's own
 13. Participates regularly and meaningfully in co-reflection
 14. Demonstrates IPS in all relationships and contexts, leading to personal and social change
- (Intentional Peer Support Core Competencies – Full Version, p32)

The review by Pomery et al. (2016) focused on what it takes to be a good support group 'leader'. This question was seen as particularly relevant to cancer support groups in Australia where funding, resources and support staff have been made available to group leaders as a way of strengthening the delivery of support provided by such groups (Pomery et al., 2016). It is equally relevant to peer support groups within the NDIS which operate under similar conditions. The quest for a good leader is not a trivial matter as "group leaders are typically self-selected, and motivated by the desire to help others, while at the same time placing themselves into a role they may know very little about"; it is known that "alongside the many benefits, leaders have reported a range of difficulties ... such as struggle to deal with issues like difficult and demanding personalities, maintaining adequate group numbers, disease progression, and death (Pomery et al., 2016:673). Hence, the review authors aimed to deduce the requisite knowledge, skills and attributes of support group leaders by drawing on a range of qualitative, quantitative and mixed methods studies related to cancer and other life challenges (e.g. bereavement, suicide survivors, carers of people with dementia). They identified seven main qualities: group management –tasks to ensure the continuity of the group; group process –group facilitation involving confidentiality, cohesion, safe environment; role modelling – demonstrate desirable qualities such as acceptance of difference, positive reinforcement; awareness –about needs of individuals and the group, groups dynamics; willingness –giving and receiving support, follow up outside the group; agreeableness –likeability and engagement (supportive, warm, empathetic; openness –mentally open with a positive or solution-based approach. (Pomery et al., 2016). The authors noted:

"...qualities could be readily sub-divided into those more relevant to selection (i.e., awareness, willingness, agreeableness and openness) and those more relevant to knowledge and skills development (i.e., group management, group process and role modelling)...Within a community-based setting where most group leaders are volunteers, it is not practical or reasonable to expect potential group leaders to have all the requisite knowledge and skills prior to undertaking the role...On the other hand, it is recognised that certain qualities may not be able to be taught. In practice this means that some people may be unsuited to the role regardless of their intention, background or access to training and support." (p.685-684).

Figure 1. Key peer support models, questions and considerations for thinking through how intended outcomes might be achieved and evaluated

Underlying issue	The people with whom we work face challenges in their lives. How do we support them to overcome those challenges?	
Preferred model of peer support:	<p style="text-align: center;">Empowerment/social change model</p> <p style="text-align: center;">Those with whom we work are often excluded and marginalised; providing space for these people to share their experiential knowledge together, as equals, will support them in making their own decisions for the future.</p>	<p style="text-align: center;">Behaviour change/public health model</p> <p style="text-align: center;">There are specific changes that we know will make people's lives better; these changes can be best supported by others who are 'like them' but who have already made these changes and have been trained to support others in making the same changes.</p>
Resulting in:	<ul style="list-style-type: none"> - Less structured intervention - Non-hierarchical model, no fixed roles - Focus on process of sharing of experience 	<ul style="list-style-type: none"> - More/highly structured intervention - Inevitable element of hierarchy - Focus on achieving pre-specified changes
Potential for positive direct, buffering and mediating effect outcomes		
Key considerations	<ul style="list-style-type: none"> - How will you support those involved in building and managing relationships of trust? - How will you ensure effective supervision that pays attention to the constantly shifting 'emotional burden' of peer support, and seeks to ensure that the intervention maximises reciprocity between those participating? - How will you ensure that the intervention proactively includes those with the greatest challenges? 	
How will you assess effectiveness?	<ul style="list-style-type: none"> - Who needs what type of information? How will it be used? - What data/evidence is already available? What data needs to be collected and what mixed methods are appropriate? - How will data be analysed? What types of reporting are appropriate and can support use of the findings? 	<ul style="list-style-type: none"> - Broad outcome domains can be defined at the start of the intervention, but there will be limited fixed indicators - Indicators based on the specific changes targeted can be defined at the start of the intervention drawing on existing standardised tools.

Training and supervision: Reviews did not systematically address or provide details on whether and how peers were trained. *For example*, the review by Ramchand et al. (2017) noted that 87% of the 116 RCTs they included ‘described a formal peer training component’ but they did not clarify nor discuss anything about such training. Some reviews referred to intensive training for peers delivering an intervention, such as the review by Burton et al. (2017) which focused on promotion of physical activity in older people. The peers underwent a 30-week preparation programme to improve their own physical fitness as well as gain mentorship skills. The review by Dale et al. (2008) noted that peers were trained by means of providing fact sheets, resource guides or handbooks, but were also receiving follow up support in monthly meetings or supervision. They specifically noted a study that found “supervision was perceived positively by many peer volunteers either ... ‘to ensure that program expectations were being met’ or ... ‘to see how one is doing’” (Dale et al., 2008:15). Another study found that “... a few peer volunteers felt that more guidance and feedback would have been helpful, particularly in the early stages of the intervention” and the need for proactive and ongoing support as well as reinforcement of key elements was emphasised (Dale et al., 2008:15).

Some reviews focused on peer employees or peer specialists reported that they received formal training, sometimes even accredited courses (see, *for example*, Cabassa et al. 2017). Where lay health advisers were used, training was deemed essential (see, *for example*, Fleury et al., 2009). In other cases, peers received ‘delivery guides’ to help with implementation (see, *for example*, Kew et al. 2017). As a cautionary note, Ginis (2013) indicated that peers who receive specialized training to provide peer support may be perceived as paraprofessionals diminishing their mutual identification with those receiving peer support and potentially reducing the effectiveness of the interaction. Indeed, several authors cautioned against undue professionalization of peer support and creating a professional version of peer support to fit with professional expectations, behaviours, rules and regulations (see, for example, Mead et al., n.d.). However, peer support training can help with managing group dynamics (such as the ability to ‘sit with discomfort while exploring the dynamics of relationships), problem solving skills, coordination skills, etc). As was noted above, some qualities cannot necessarily be taught (Pomery et al., 2016).

Monitoring and evaluation (M&E) and building cumulative knowledge: The fact that few interventions were underpinned by a clear theory of change is not only problematic for the design and implementation of peer support but also hinders the development of an appropriate M&E approach in terms of determining:

- (a) key questions / data needs about programme implementation and results;
- (b) what designs and methods are most appropriate for collecting and analysing required data – including what to monitor regularly and what merits more in-depth evaluation based whether or not there is already good existing evidence for the various links in the causal chain; and,
- (c) where indicators are appropriate to use, and, how to ensure sufficient indicators are selected along the causal chain and, where available, to use validated measurement tools and standardised indicators.

In Section 1.2, we discussed that an experimental approach is not necessarily an appropriate design for evaluating peer support – due to the very nature of peer support – and demonstrated the need for combining process and outcome evaluation and using both qualitative and quantitative approaches. When deciding on an M&E approach for peer support – a complex intervention –, it is important to start with questions about what it is we need to know, who needs to know it and why (focus on data use), and then choose the most appropriate methods to address these questions (see **Figure 1** above). Obtaining the perspectives and experiences of those involved in peer support, and

gathering information about implementation processes and context, should be included in any investigation. Data should be used for continuously improving peer support practice, including refining the initial programme logic to understand better how peer support works, who benefits and why.

When reporting on peer support studies, it is essential to adhere to recommended reporting guidelines (several have been agreed and published in the research and evaluation community) to ensure that all relevant information is included. This is crucial for others to understand what was done, how it was done, and what can be learnt from it. It is clear from the evidence we presented in this review that this is still not common practice.

CONCLUSION: Summing it up

How 'peer-ness' and 'peer support' is defined impacts on the design and implementation of a peer support intervention. While there were many important differences between the systematic reviews, all stressed the importance of reciprocal sharing of experience. The role this experiential knowledge plays in the implementation of a peer support intervention depends on whether an 'empowerment model' or 'a behaviour change model' is used.

The reviews reported on a range of, mostly positive, outcomes but adverse effects were also noted. Augmenting the social relationship that is at the heart of peer support can influence results positively and minimise harm.

It is worth investing in peer support but what is being done needs to be underpinned by an explicit programme logic. Its implementation needs to be supported by competency building, supportive supervision and appropriate reflective practice.

IMPLICATIONS: What can be done within the NDIS context in Australia?

Implications for NDIA as funders of peer support groups

- Allow for diversity of approaches but require transparency about the programme logic underpinning the peer support offered.
- Require a monitoring and evaluation approach that supports reflective practice and continuous improvement. Obtaining the perspectives and experiences of those involved in peer support, and gathering information about implementation processes and context, should be included.
- Invest in cumulative knowledge building, drawing on learnings from practices within the NDIS but also from international practice. Maintain a community of practice among organisations supporting peer support practice so learnings can be shared timely and additional support can be provided where needed.

Implications for organisations helping peer support groups

- Make explicit what peer support is offered based on a clear programme logic. This can build on an empowerment or behaviour change model and needs to provide a coherent explanation of: what we want to change, and why; what we know about what we want to change; our assumptions; how we will act to generate this change; and, why we will act in this way. Focus on augmenting the social relationship between peers and provide the necessary support to do this well – both for the peers and those supporting them.
- Implement regular feedback mechanism for assessing benefits but also unintended consequences. Document findings and act on the learnings in a timely fashion as a key requirement for accountability to those supported.
- Share learnings with other ‘providers’ for problem solving and support for practice improvement across all peer support groups.

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Note: All cited reviews are in the lists provided below.

List of systematic reviews focused on substantial peer support

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Reviews of qualitative and/or quantitative research

1. Embuldeniya G, Veinot P, Bell E, Bell M, Nyhof-Young J, Sale, Britten N (2013). The experience and impact of chronic disease peer support interventions: a qualitative synthesis. *Patient Education and Counseling* 92(1): 3-12.
2. King A, Evans M, Moore T, Paterson C, Sharp D, Persad R, Huntley A (2015). Prostate cancer and supportive care: a systematic review and qualitative synthesis of men's experiences and unmet needs. *European journal of cancer care* 24(5): 618-34.
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4. Pomery A, Schofield P, Xhilaga M, and Gough K (2015). Skills, knowledge and attributes of support group leaders: A systematic review. *Patient education and counseling* 99(5): 672-88.
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List of systematic reviews that met the inclusion criteria

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ANNEX 1. Stakeholder consultation on the focus and scope of the literature review

A written consultation was conducted with representatives from the NDIA and DSOs in January-February 2018. The purpose and focus of the review were explained and details about the review process provided. Feedback was invited on:

(1) The definition of peer support

Why is consultation on the definition of peer support important?

Peer support is a commonly used term but different definitions of what constitutes peer support exist. This term needs to be clearly defined for the literature review so the review team is able to search for the right type of studies and describe and analyse the findings from these studies in ways that make sense to the primary users of the review.

(2) Priority review questions

Why is consultation on review questions important?

Different stakeholder groups, typically, have different information needs and thus, different priorities for seeking evidence to inform their decisions. Such differences influence the focus of the literature review and, thus, what is considered relevant for inclusion and what different stakeholders can expect in terms of utility of the review.

(3) Important inclusion and analysis considerations

Why is consultation on inclusion and analysis important?

The review team needs to make sure that the review is focused on what is most important to peer support practice within the NDIS context but also that the review questions are answerable with a manageable review (within time and resource limitations). Hence, we want to as focused as possible but without excluding anything that is important to working with peer support in the disability sector.

The full consultation document and responses can be obtained from the first author on request.

ANNEX 2. Detailed review methods

2.1 Locating relevant reviews

We conducted extensive and thorough searches on specialist databases of systematic reviews using a wide range of alternative terms for peer support. We also systematically checked the reference lists of identified reviews for other relevant reviews. We conducted broad Google searches for unpublished systematic reviews and other information (such as standards, 'how to' guides, training materials) for implementing peer support and for conducting monitoring and evaluation of peer support.

The following databases were searched for systematic reviews published between January 2000 and March 2018: International Initiative for Impact Evaluation Database, the Campbell Collaboration Database, the Centre for Reviews and Dissemination Database, the Epistemonikos database, the Journal of Systematic Reviews, Cochrane Collaboration Database, DoPHER databases.

We searched the databases for the papers with the following terms in either the title or the abstract: "peer support" or "peer group*" or "peer coach" or "peer mentor" or "peer education" or "peer advocacy" or "peer tutoring" or "self-management" or "self-help group" or "support group" or "mutual" or "mutual support" or "peer provided service" and where possible, the results were restricted to systematic reviews.

Full details of these searches are presented below.

Search terms for each database used

Database	Search terms
Campbell Collaboration Library	in title: peer support OR in title: peer group OR in title: peer groups OR in title: peer coach OR in title: peer coaches OR in title: peer mentor OR in title: peer mentors OR in title: peer education OR in title: peer training OR in title: peer tutoring OR in title: self-management OR in title: self management OR in title: self-help group OR in title: self help group OR in title: support group OR in title: mutual OR in title: mutual support OR in title: peer provided service OR in title: peer advocacy
Centre of Reviews and Dissemination	Used the two MeSH searches suggested coupled with a restriction to the DARE database and to years 2000-2018. Choice was made to "not explode" the tree. Then a free-text title search was conducted to capture any studies which were not covered by the two MeSH searches. MeSH DESCRIPTOR Peer Group IN DARE MeSH DESCRIPTOR Self-Help Groups IN DARE title search: peer support OR peer group OR peer coach peer mentor OR peer education OR peer training peer tutoring OR self-management OR self-help group self-help group OR support group OR mutual mutual support OR peer provided service OR peer advocacy
Cochrane Collaboration Library	MeSH DESCRIPTOR Peer Group MeSH DESCRIPTOR Self-Help Groups "peer support" OR "peer group*" OR "peer coach*" OR "peer mentor*" OR "peer education" OR "peer tutoring" OR "self-management" OR "self-help group*" OR "support group*" OR "mutual" OR "mutual support" OR "peer provided service" OR "peer tutor*" OR "peer advocacy" These searches were filtered by year (2000-2018) and only selecting reviews.
DoPHER	"peer support" OR "peer group*" OR "peer coach*" OR "peer mentor*" OR "peer education" OR "peer tutor*" OR "peer advocacy" OR "self-management" OR "self-help group*" OR "support group*" OR "mutual" OR "mutual support" OR "peer provided service" These searches were conducted using the free text search with the 'title only' filter selected. In addition, a free text search was conducted for use of these terms in the 'abstract'.

Epistemonikos	<p>((title:(\"peer support\") OR abstract:(\"peer support\")) OR (title:(\"peer group\") OR abstract:(\"peer group\")) OR (title:(\"peer groups\") OR abstract:(\"peer groups\")) OR (title:(\"peer group*\") OR abstract:(\"peer group*\")) OR (title:(\"peer coach\") OR abstract:(\"peer coach\")) OR (title:(\"peer coaches\") OR abstract:(\"peer coaches\")) OR (title:(\"peer coaches*\") OR abstract:(\"peer coaches*\")) OR (title:(\"peer mentor\") OR abstract:(\"peer mentor\")) OR (title:(\"peer mentors\") OR abstract:(\"peer mentors\")) OR (title:(\"peer mentors*\") OR abstract:(\"peer mentors*\")) OR (title:(\"peer education\") OR abstract:(\"peer education\")) OR (title:(\"peer training\") OR abstract:(\"peer training\")) OR (title:(\"peer tutoring\") OR abstract:(\"peer tutoring\")) OR (title:(\"self-management\") OR abstract:(\"self-management\")) OR (title:(\"self management\") OR abstract:(\"self management\")) OR (title:(\"self-help group\") OR abstract:(\"self-help group\")) OR (title:(\"self-help groups\") OR abstract:(\"self-help groups\"))</p> <p>This search string was entered into the advanced search section, with the year of publication restricted from 2000 to 2018. Subsequently, the following filters were applied to exclude primary studies: broad synthesis, structured summary and systematic review. It should be noted that the advanced search function excludes foreign-language reviews.</p>
DoPHER	<p>"peer support" OR "peer group*" OR "peer coach*" OR "peer mentor*" OR "peer education" OR "peer tutor*" OR "peer advocacy" OR "self-management" OR "self-help group*" OR "support group*" OR "mutual" OR "mutual support" OR "peer provided service"</p> <p>These searches were conducted using the free text search with the 'title only' filter selected. In addition, a free text search was conducted for use of these terms in the 'abstract'.</p>
International Initiative for Impact Evaluations (3ie)	<p>title:"peer support" OR title:"peer group*" OR title:"peer coach*" OR title:"peer mentor*" OR title:"peer education" OR title:"peer tutoring"</p> <p>title:"self-management" OR title:"self-help group*" OR title:"support group*" OR title:"mutual" OR title:"mutual support" OR title:"peer provided service"</p> <p>These searches were conducted from the Title Search box with "Status" field restricted to "Review" and the date fields were restricted such that "From"=2000 and "To"=2018. The title field could only accommodate a limited number of characters, hence two searches were conducted.</p> <p>Full text search</p> <p>"peer support" OR "peer group*" OR "peer coach*" OR "peer mentor*" OR "peer education" OR "peer advocacy" OR "peer tutoring" OR "self-management" OR "self-help group*" OR "support group*" OR "mutual" OR "mutual support" OR "peer provided service"</p>

2.2 Screening of search results

First, the titles and abstracts of references were screened based on the above inclusion and exclusion criteria. Full-text papers were retrieved for all included references as well as all references for which inclusion or exclusion was 'unclear' because of lack of information. All full-text papers were screened again to confirm their inclusion or exclusion.

The screening was done by the researchers individually. Any queries about inclusion/exclusion were discussed and resolved with the lead researcher (GP). The lead researcher also conducted a 10% random sample spot-check on the screening of references.

The screening results are presented in **Annex 3**.

2.3 Standardized coding and data extraction

A standardized coding strategy was developed by the lead researcher (GP). This consisted of:

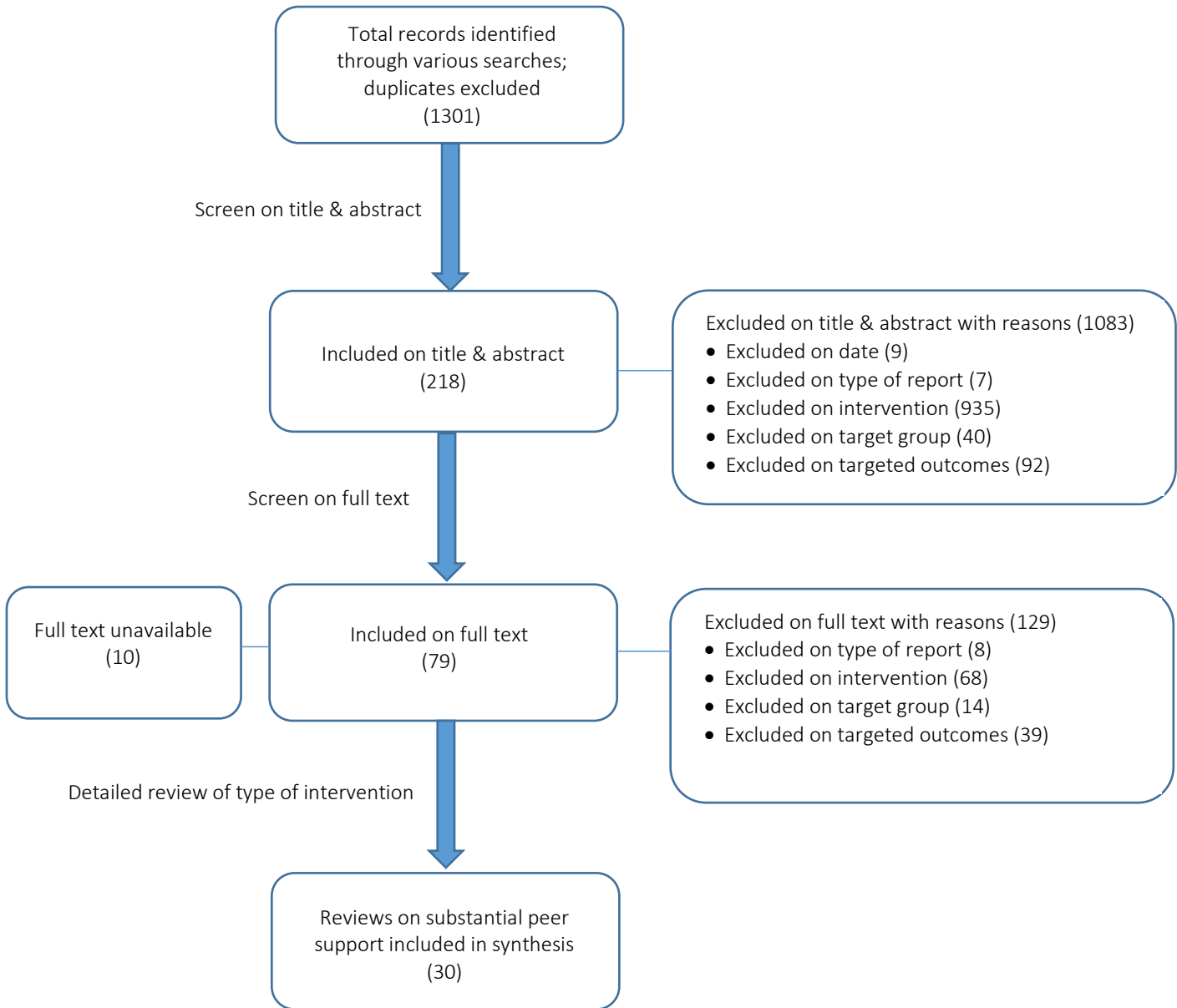
- (1) Keywording guidance²⁶ - This coding was done on the full reports to be able to describe the literature in a descriptive mapping according to a limited number of characteristics of reports/studies including: type of report; types of studies included in the review, topical focus, geographical focus; study population characteristics (age, sex, ethnicity, disability, other); definition of peer support; intervention provider, type and setting; outcomes targeted.
- (2) Data extraction guidance and tool²⁷ focused on:
 - a. Describing the review and its findings in detail
 - b. Identifying concerns with the review process
 - c. Judging risk of bias in the review

The full keywording and data extraction guidance and tools can be obtained from the first author on request.

²⁶ Based on: Peersman G, Flores S, Eke A, Tate R (2001). Coding rules for bibliographic register. Atlanta: Global AIDS Program, US Centers for Disease Control and Prevention.

²⁷ Based on: Peersman G, Flores S, Eke A (2003). *Systematic Review on Interventions for Preventing HIV-Infection in Developing Countries. Review Guidelines for Evaluation Studies*. Atlanta: Global AIDS Program, US Centers for Disease Control and Prevention; Gough D, Oliver S, Thomas J (Eds) (2017). *An introduction to systematic reviews*. 2nd Edition. London: Sage Publications Ltd; earlier work by Greet Peersman, Sandy Oliver, James Thomas and Ann Oakley at the EPPI-Centre, Social Science Research Unit, Institute of Education, University of London; and, ROBIS – a methodological standard for assessing Risk Of Bias In Systematic Reviews.

ANNEX 3. Search and screening results



ANNEX 4. Descriptive mapping of systematic reviews that met the inclusion criteria

Based on the standardized coding strategy and data extraction –described in Annex 2–, the following tables provide an overview of key characteristics of all systematic reviews that met the inclusion criteria (N=79).

The topical focus of the 79 included reviews is provided in **Table 1** and the focus on people with a disability and/or their carers is provided in **Table 2**. Most of the reviews were focused on chronic diseases; the majority of reviews related to people with disabilities were about mental health.

Table 1. Topical focus of included systematic reviews

Topical focus	Nr (%) of reviews [N=79]
Aged care	5 (6%)
Chronic disease	41 (52%)
Disability	34 (43%)
Other topical focus	30 (38%)

[Note: does not necessarily add up to 100% as some reviews have multiple foci]

Table 2. Disability focus of included systematic reviews

Disability focus	Nr (%) of reviews [N=34]*
People with a disability	24 (71%)
Intellectual, cognitive or learning disability	5 (21%)
Physical disability	5 (21%)
Psychological disability or mental health	21(88%)
Sight, hearing or speech	2 (8%)
Disability not specified	5 (21%)
Carers of people with a disability	10 (29%)
Relative	5 (50%)
Non-relative	0 (0%)
Carer not specified	7 (70%)

*34 reviews with a focus on disability were identified

[Note: does not necessarily add up to 100% as some reviews have multiple foci]

Table 3 provides an overview of the types of primary studies that included systematic reviews focused on and synthesised. As can be noted, most reviews were focused on effectiveness of peer support (i.e., evaluated in terms of outcomes). Only two reviews focused on cost effectiveness of peer support (Pennington et al., 2013; South et al., 2014).

Reviews that focused on other types of research focused on: levels of participation in support groups, experiences of participants in relation to different types of peer support interventions, role and relationships issues etc.

Table 3. Types of primary studies synthesised in the included systematic reviews

Types of primary studies synthesised	Nr (%) of reviews [N=79]
Reviews of intervention studies	69 (87%)
Outcome evaluations	66 (96%)
Process evaluations*	8 (12%)
Economic evaluations	2 (3%)
Reviews of non-intervention studies	19 (24%)
Qualitative research	18 (95%)
Quantitative research	3 (16%)

[Note: does not necessarily add up to 100% as some reviews included different types of studies and some included types of studies not listed in the table]

Table 4 provides an overview of the types of evaluation studies that included systematic reviews focused on and synthesised. Most reviews synthesised the findings related to specific outcomes. RCTs or quasi-experimental studies were favoured for inclusion due to their ‘perceived’ rigor. A good systematic review includes an assessment of the quality of primary studies and conducts some weighting of the evidence according to the quality. Many reviews noted quality issues with the primary studies, including those of RCTs, and rated the evidence base as ‘moderate’ or ‘lacking’.

Eight reviews synthesised findings from process evaluations and only 4 reviews incorporated findings from both outcome and process evaluations.

Table 4. Types of evaluation studies synthesised in the included systematic reviews

Types of evaluation studies synthesised	Nr (%) of reviews [N=79]
Outcome evaluations	69 (87%)
Experimental design	69 (100%)
Quasi-experimental design	39 (57%)
Other designs	31 (45%)
Process evaluations*	8 (10%)

[Note: does not necessarily add up to 100% as some reviews included different types of studies]