



Treating mental health in the community A policy review



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1. Executive summary

Mental health – a 'burning injustice'

It is often said that mental health disorders affect one in four of the UK population at some point in our lives¹. The total social and economic cost to the nation is estimated at over £100 billion²; the impact on individual lives can be crippling.

Speaking at the Charity Commission in January 2017, the Prime Minister Theresa May promised to address 'the burning injustice' when people with schizophrenia, depression, anxiety and other mental health problems cannot access the treatment they need. She pledged 'to employ the power of government as a force for good to transform the way we deal with mental health problems right across society, and at every stage of life'.³

This included announcing a spectrum of measures – and up to £15 million funding – to transform mental health support through community clinics, crisis cafes, and other 'preventative services in the community'.

The Prime Minister's speech was the latest effort by successive governments to reform mental health policy.⁴ Increasingly, policy is directed towards helping people access support in the places where they live, as a community-focused alternative to institutionalisation and medication.

But how much do we know about the most effective ways for communities to support people with mental health problems? And does this latest tranche of spending match up with the evidence we have?

This paper reviews the quality of evidence available on the effectiveness of different community approaches to mental health. It looks at 48 reviews covering 827 primary experimental and non-experimental studies, published between 2004 and 2017, drawn from the UK and comparable high-income countries. The paper looks mainly at the highest-quality evidence, defined as evaluations drawing on randomised control trials (RCTs), meta-analyses or comparative longitudinal data.

This is done with an eye on the community business sector, which is backed by Power to Change and where we hope to see new mental health interventions developed. Using guidelines and definitions established by Public Health England, it assesses what we know about mental health support in the community and what we do not.

What we found and why it matters – working with the community and working in the community

We found evidence that some 'community-centred' projects, which draw on the support networks and skills already available in a community, have a positive impact on mental health. However, there is no high-quality evidence that 'community-based' projects, which simply deliver services in a local area, have a positive impact on mental health.

To put this another way, the evidence allows us to say with confidence that some mental health programmes working with a given community are effective. We cannot make the equivalent claim for mental health programmes which are based in a community but do not harness the social capital already there.

If we cross-reference this with announcements about the allocation of the £15 million mental health spending, there are questions to ask about the strength of the evidence that backs the effectiveness of these projects. Using the Public Health England definitions, many appear to resemble 'community-based' rather than 'community-centred' projects.

The political context – devolution and mental health support

This matters a great deal. National and local government, as well as charitable foundations and trusts, are making decisions about the best way to invest limited resources to help people who need mental health support. It is essential that these decisions are made on the best available evidence, and that evaluations and trials are commissioned where evidence is inadequate.

As devolution gathers pace, people will have more control over the sort of care they receive. There is an increasing move towards subsidiarity, with political decisions devolved to the most local level possible, and sometimes directly to individuals themselves. The highest profile example is through personal budgets, which will give people the right to decide on their own packages of support, rather than those decisions being made on their behalf by a local authority.

ONS (2009) Adult Psychiatric Morbidity in England, 2007: results of a household survey

²Mental Health Foundation (2015) Fundamental facts about mental health ³May, T. (2017) The shared society: Prime Minister's speech at the Charity Commission

³ May, T. (2017) The shared society: Prime Minister's speech at the Charity Commission annual meeting. Retrieved from https://www.gov.uk/government/speeches/the-shared-society-prime-ministers-speech-at-the-charity-commission-annual-meeting

Department of Health. Mental health service reform. Retrieved from

What next – testing the right solutions

There is a clear demand for effective, costefficient initiatives to support people in their
own communities when they face mental health
difficulties. There is also a political context
in which these initiatives are already being
considered and commissioned, by officials
keen to roll-out some of the promises already
made. And government departments, along
with independent experts, charities and think
tanks, have started looking at mental health
programmes in more detail than ever before.

What we lack, however, is enough information about 'community-centred' mental health interventions. There has been a spate of initiatives in this area, especially since this model was championed by Public Health England in 2015, but most of these have focused on locally-based discussions about the sorts of services people would like to see. There have been relatively few new projects launched on the ground.

Power to Change believes we need to see a move towards trialling new 'community-centred' projects in local places, with rigorous evaluations to assess the evidence that these projects are effective in helping people with mental health problems. These trials and evaluations could be funded by charities, or through commissioning and procurement processes by local authorities. We also believe that community businesses can, and should, be considered to trial or deliver these projects.

A stronger evidence-base is essential.

We cannot afford to spend the money we have without knowing whether it will do any good for the people who need it.



2. Background

2.1. Context

In 2014, Public Health England (PHE) published its report From evidence into action. This called for 'place-based' approaches to healthcare, which would develop local solutions for people by drawing on all the assets and resources of an area and building the resilience of local communities. 5 PHE followed this in 2015 with a guide to community-centred approaches for health and wellbeing, which published guidelines on how

community projects could have a positive impact on health,

including mental health.6

The 2015 report explicitly recommended 'community-centred' approaches, referring to interventions which would complement existing social networks, expertise and local experience to provide non-clinical support. This is distinct from 'community-based' approaches, which use a community as a setting for mental health support but do not necessarily draw on other local assets to do so.7

This is an interesting and important distinction to us at Power to Change. Our own work focuses on growing and supporting community businesses in England, with a focus on how communities can combine the assets on their doorstep and the skills of local people to build stronger, sustainable places. We also explore the way that public policy, by supporting local communities, can make progress preventing social problems before they arise, rather than waiting for those problems to surface and handling the fallout.

Better mental health and community approaches are also evidently important to the government. In January this year, the Prime Minister Theresa May announced a commitment to address the 'burning injustice' when people couldn't access the mental health support they needed. This included £15 million dedicated to funding 'preventative services in the community'.

But what will this money fund, and how strong is the evidence that it will have a positive impact?

⁵ Public Health England (2014) From evidence into action; opportunities

to protect and improve the nation's health. London: Public Health England
⁶ South, J. (2015) A guide to community-centred approaches for health and wellbeing.

London: Public Health England

For a discussion of the terms community-based and community-centred see section 3.1

⁸ Morgan, A., et al (2010). Health Assets in a Global Context: Theory, Methods,

Action. London: Springer

⁹ Milligan, C.; Dowrick, C.; Payne, S.; Hanratty, B.; Irwin, P.I Neary, D. and Richardson, D. (2013). Men's Sheds and other gendered interventions for older men: improving health and wellbeing through social activity - a systematic review and scoping of the evidence base. Lancaster: Lancaster University Centre for Ageing Research.

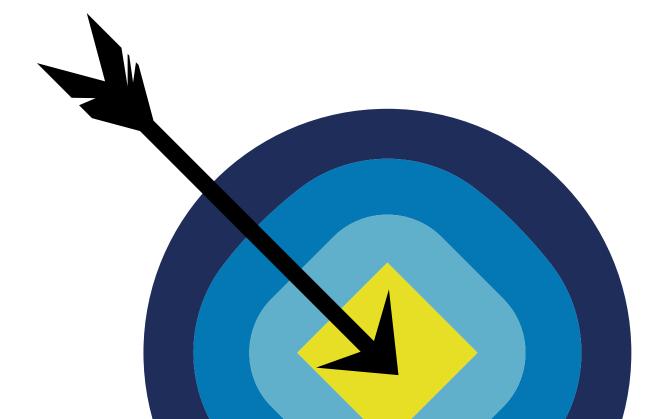
Firstly, high-quality evidence is worryingly sparse. Even in detailed, informative studies into the impact of community-centred mental health projects, some authors concede that the level of evaluation falls short of the quality they would like. One review of asset-based work says:

While it is justified to be very optimistic about the potential of the asset based approach, it will require a lot more groundwork in supporting the evidence base for the effectiveness of asset based interventions.⁸

Another, into the sort of 'men in sheds' initiatives which have attracted so much attention in recent years, concludes:

Future studies would benefit from taking a longitudinal and comparative dimension so that effects over time can be assessed and compared between different sites and types of intervention.⁹

We concur with this. It is essential that researchers, and people commissioning research into social programmes, help build a much stronger evidence base of community mental health projects. This means funding and publishing comparative longitudinal data in this area, which would allow organisations and researchers to track the quality and sometimes cost-effectiveness of different interventions across time. This is the best way to guarantee better-informed funding decisions in the future.



Nonetheless, this paper identified and reviewed 48 reviews covering 827 primary experimental and non-experimental studies, published between 2004 and 2017, drawn from the UK and comparable high-income countries. These evaluations looked at both 'community-centred' and 'community-based' initiatives, as defined by PHE, and drew on the highest-quality evidence available, through randomised control trials (RCTs) and / or comparative longitudinal data.

Broadly, we found there is high-quality evidence that some 'community-centred' projects have a positive impact on mental health. However, there is no high-quality evidence that 'community-based' projects do.

One worrying conclusion is that, looking at the public announcements made regarding how the Prime Minister's £15 million mental health spending will be allocated, this money may be concentrated in community-based rather than community-centred interventions.

For example, the first phase of spending made grants to refurbish existing 'places of safety', equip street triage vehicles for people suffering mental health crises and buy new vehicles for transporting people between mental health facilities. This may be essential work to patch-up the mental health system, but there is little evidence that this public money is being used to deliver the lasting community-centred solutions recommended as a priority by PHE just two years ago.

2.2. Aim

Considering the recent mental health policy developments, the overarching aim of this rapid evidence review is to help Power to Change understand the importance of community and place as a determinant of an individual's mental health. The primary purpose is to inform programme design and market development at Power to Change.

It delivers on its aim by:

- Presenting a typology of mental health interventions with a community component
- identifying a set of primary and secondary research studies that report on the effectiveness of mental health interventions with a 'community' component
- Assessing the quality of the evidence base of mental health interventions with a community component
- Describing and synthesising the data that were identified
- Writing up results
- Drawing conclusions, suggesting evidence gaps and future priorities

This review was conducted as a semi-systematic literature review, drawing primarily on systematic reviews of primary evaluation studies. It was considered an appropriate research approach for this topic due to a limited timeframe and the importance of verifying the quality of existing information. Sources were limited to those produced in the last ten years in English, though earlier literature informed the scope of the study. To ensure that the sources retrieved were both high-quality and relevant to the research question, sources from academic and grey literature were assessed for their quality using agreed criteria. During the retrieval process sources were also coded by intervention type, and the key outcomes were extracted to develop an overview of the evidence base from which to begin analysis. The review author extracted information relevant to the research questions and drew conclusions. See Appendix A: Review methods for a detailed description of methodology.

2.3. Review Questions

The overarching review question is:

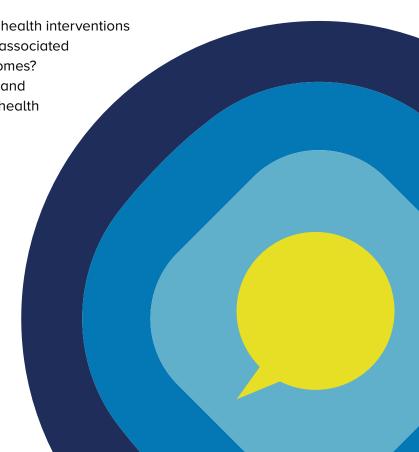
'What has been done to research the value of community-centred and community-based mental health services?'

To answer this question, the following, more focused research questions (RQs) form the basis of the enquiry:

– RQ1: Which approaches to mental health interventions with a community component are associated with improved mental health outcomes?

– RQ2: What is the range of models and approaches underpinning mental health interventions with a community component?

RQ1 is addressed through synthesis of the effectiveness data; and RQ2 through a map of the evidence and a theoretical synthesis of the models and mechanisms reported in the available literature.



2.4. Conceptual framework

There is general agreement among those affected by mental health problems, or working in the field of mental health, that there is no universally acceptable lexicon between all the people affected by the experience of mental health problems. The result is that language in this field is particularly contested and revisited.

For example, since 2008 the concept of wellbeing has revolutionised the way in which UK policy-makers (within the world of public mental health) approach the mental health of the population. However, in 2013 the Chief Medical Officer (CMO) in her annual report highlighted the definitional and methodological problems with the concept of wellbeing, as a field within mental health. Her critique focused on the absence of acceptable set of metrics, and lack of clarity on how concepts and measures that do exist relate to populations with mental illness.

Based upon independent scientific analysis and appraisal of the quality of the evidence base, the CMO delivered a robust critique of the current evidence base on wellbeing:

Contrary to popular belief, there is no good evidence I can find that well-being interventions are effective in primary prevention of mental illness...

The result is that the public health needs of approximately 1 in 4 of the population who have a mental illness, 75% of whom receive no treatment, risk being side-lined in the enthusiastic pursuit of a policy agenda that is running ahead of the evidence.

For the purposes of this RER, we are drawing on the CMO's model for the understanding of public mental health and well-being (Figure 2-1). The model was developed by the Department of Mental Health and Substance Abuse at the World Health Organization (WHO) and has been incorporated into the WHO's Mental Health Action Plan 2013–2020.



Using this framework,¹⁰ it becomes easy to understand how all interrelated parts - mental health promotion, mental illness prevention and treatment and rehabilitation - relate to the broader concept of public mental health. The intersection between 'mental health promotion' and 'mental illness prevention' in Figure 2.1 is where the evidence base requires strengthening to progress the 'wellbeing' agenda.

The purpose of this section is to consider the overall effectiveness of mental health interventions that incorporate a community component. This analysis will help us answer the first research question:

– RQ1: Which approaches to mental health interventions with a community component are associated with improved mental health outcomes?

3. Evidence Review I: Synthesis of effectiveness studies

3.1. Description of studies included in synthesis

Studies and quality of evidence

We searched for evaluation studies that aimed to deliver outcomes associated with mental health promotion and / or mental illness treatment and prevention.

Our initial search – based on screening abstracts across a range of evidence sources (academic databases and grey literature) identified 177 evaluation studies of interest¹¹. Careful consideration and quality assessment of evidence reduced the number to 66 eligible studies¹². Half of the eligible studies are mainly secondary methodologies that follow a systematic approach (51%).13 We also identified a small number of primary studies (29%) that are almost all are single case evaluations.

When considering the question of the overall effectiveness of mental health interventions, we decided to take a pragmatic approach. Therefore, we included both experimental and non-experimental evidence in the final synthesis of results. As this report outlines, there is a large and diverse range of approaches to supporting individuals to be active partners in their own mental health and care, and to supporting and developing communities that can help maintain and improve mental health and wellbeing. Unsurprisingly, this means that there is an equally broad and diverse range of evidence, from a range of sources including research trials and evaluations of programmes, as well as qualitative evidence and stories from patients, professionals and service managers.

The next section outlines the final synthesis. We included 48 out of 66 eligible studies (35 systematic reviews; 6 other reviews; 6 single case studies and 1 experimental primary study). In total, we synthesised evidence from 827 primary experimental and non-experimental evaluation studies from a range of high income countries.

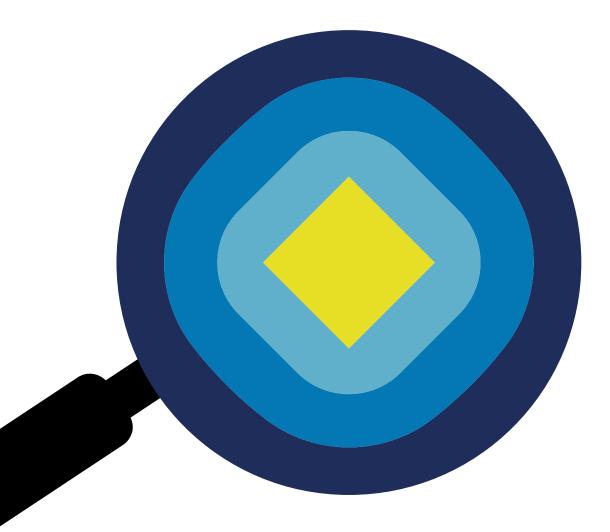
¹⁴¹ primary, 129 secondary and 5 conceptual and 2 journalistic

⁽See Table A-2 for types of evaluation studies)
²Studies satisfying our eligibility and quality criteria, see Appendix A

¹³See Table C-1 in Appendix C ¹⁴See Table C-2 in Appendix C

The synthesis did not include 18 eligible studies (10 primary studies and 7 other reviews and 1 conceptual paper). Their findings have informed the overall approach of this review but have not been included in the synthesis because of their poor evaluation or review designs.

Eligible studies were published between 2007 and 2017.



Participants

A quarter of the studies (26%) involved people with a diagnosis of schizophrenia or related disorders. 20% Of studies involved older people without known cognitive impairment and 17% of studies worked with people who live in supported housing. Smaller proportions focused on all / area populations (7.5%), parents and children of parents with serious mental illness (4%), workers with a major depressive disorder (8%), young people (4%).¹⁴

Intervention methods

Initiatives aiming to reduce mental health illness and promote mental health use a combination of intervention methods.¹⁵ We identified 29 interventions methods. The largest proportions of studies included in the review were public health interventions aiming to promote wellbeing (29%), and used volunteers / peers (10%) or 'green care' (10%). 7% studied community development interventions and collaborations, and 6% focused on exercise or physical activity. Smaller proportions employed a range of methods (behavioural, parenting, psychosocial, lifestyle, work-directed, gendered interventions etc.)

Settings

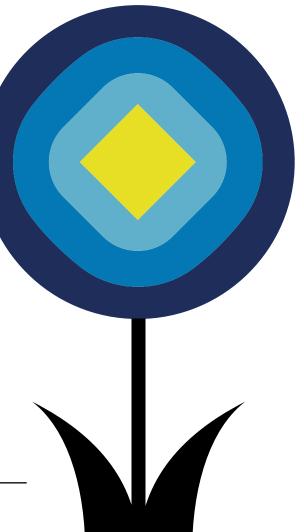
Interventions included in the review were delivered in a combination of 'community' and 'non-community' settings (inpatient, outpatient, hospital, primary, secondary, occupational, antenatal care, community mental health centre, university, school, home, workplace, farms, community allotments, sheltered workshops, telephone, supported accommodation in the community, crisis residential unit, refugee centre, online).

Duration

The duration of interventions included in the review ranged from 1 week to 52 weeks (1 year). In 40% (178) of studies the intervention lasted from 1 to 12 weeks.

Outcomes

The interventions included in the review delivered a range of outcomes. The promotion of mental health and/or treatment of a range of mental illnesses were the primary outcomes of almost all studies. Almost half (40%) reported on mental illness (mental state, depression, anxiety, mood disorders); More than half (47%) reported the results on quality of life or wellbeing measures. A similar proportion of studies also included social skills and social capital.¹⁶



¹⁵ See Table C-3 in Appendix C ¹⁵ See Table C-4 in Appendix C

3.2. Synthesis of results

This section reports on the synthesis of the results and considers what type of mental health interventions with a community component¹⁷ were generally effective.

Table 4-1 summarises effectiveness of the identified 29 intervention methods across seven key outcomes (Depression, anxiety, physical functioning, self-esteem, social / life skills, wellbeing and quality of life, and work functioning).

Table 4-1: Intervention effectiveness across 8 key outcomes

	Depression	Anxiety	Physical functioning	Self- esteem	Social/ Life skills	Wellbeing & quality of life	Work functioning
Wellbeing interventions			•	•	•	•	
Volunteers / peers	•	•	•	•	•	•	
Green care	•	•	•	•	•	•	•
Community development	•	•	•			•	
Exercise, physical activity, sports	•		•				
Community-based mental health							
Parenting programmes							
Gendered interventions			•		•	•	
Community-based - improving QoL							
Psychosocial (psychoeducation)				•			
Work-directed interventions	•						
Reducing psychological disorders	•	•			•	•	
Community Participatory Research	•		•				
Supported employment							
Advocacy interventions	•						
Reintegration/ harmful behaviour							
Telephone counselling							
Primary prevention of suicide							
Yoga					•	•	
Cognitive- Behavioural Therapy							
General physical health advice						•	
Healthy behaviour interventions	•			•		•	
Psychosocial (social networks)					•	•	
Respite care							
Dance movement therapy							
Oral health							
Dance therapy						•	
HIV prevention advice							
Smoking cessation advice							

Table 4-1 shows a group of 16 interventions (wellbeing interventions, volunteers / peers, Green care, community development, exercise, gendered, psychosocial, work-directed interventions, reducing psychological disorders, community participatory research, advocacy interventions yoga, general physical health advice, healthy behaviour interventions, psychosocial, dance therapy) that demonstrated positive effect on at least one outcome.

Green care is the only intervention method that is effective across all eight key outcomes. Interventions using volunteers or peers reported positive findings across seven outcomes.

It is worth noting that most of the evidence related to the following intervention types is not experimental. To determine effectiveness, we had to include non-experimental and qualitative evidence.

- Wellbeing interventions
- Volunteers / peers
- Community development
- Gendered interventions
- Community participatory research

This group of interventions do not have strong and experimental evidence base, although there is a long tradition of initiatives. The reasons may include: the complexity and timing of evaluations to understand how complex changes in community relationships affect health and wellbeing outcomes over time, lack of commitment or resource to evaluate interventions of this kind and the point that some forms of community organising are a response to situations and research opportunities have been missed. Critical appraisals highlighted some problems in the papers that were included, including lack of

clarity in the definition of outcomes, too much information on processes, disconnection between theory and findings, lack of attention to the contexts in which interventions were located, and lack of attention to wider aspects of social and economic forces that shape the take up of interventions. Finally, papers rarely reflected negative impacts.

4. Evidence Review II: Intervention models underpinning community mental health

This section answers the second RQ:

– RQ2: What is the range of models and approaches underpinning mental health interventions with a community component?

The purpose of this section is to discuss the intervention methods included in the synthesis (Section 3.2) utilising Public Health England's typology of community-centred mental health interventions.

4.1. Defining community-centred and community-based mental health support

A fundamental shift in the orientation of mental health practice has been unfolding for at least 30 years in the UK and other high income countries. Several converging factors have led to an emphasis upon community based and focused interventions for individuals with severe mental illnesses. These factors include deinstitutionalization, evidence of the limitations of pharmacological and psychotherapeutic interventions upon quality of life and community functioning, longitudinal research, and resulting mental health reform efforts.¹⁸

The shift has led to the implementation of a broad array of case management services and the development of a broad evidence base for interventions such as supported housing, and supported employment.¹⁹ The common goal of these interventions is to support people with severe mental illnesses in achieving the highest possible level of independent community functioning. In practice, it involves an array of disciplines, services, and combinations of interventions. This constellation of services and practices is variably referred to as community mental health intervention and psychosocial or psychiatric rehabilitation, among other terms.²⁰

Simultaneously, wellbeing and community engagement were becoming central to guidance and national strategy for promoting public health. Community engagement activities take many forms - service user networks, health-care forums or volunteering. Interventions are delivered by trained peers, and / or by involving communities in decision-making and in the planning, design, governance and delivery of services.

¹⁸Kidd, S. A., Virdee, G., & McKenzie, K. J. (2014). Mental health reform at a systems level: Broadening the lens on recovery oriented care. Canadian Journal of Psychiatry, 59, 243–249.
¹⁹Corrigan, P. W., & Mueser, K. T. (2012). Principles and practice of psychiatric rehabilitation: An empirical approach. New York: Guilford.

²⁰Kidd, S.A., Davidson, L. & McKenzie, K. J (2017). Common Factors in Community Mental Health Intervention: A Scoping Review.

The increasing policy focus on wellbeing and community engagement is based on the hypothesis that by improving social capital and reducing isolation, some social inequalities that underpin health inequalities could be reduced, and health improved. It is thought that community engagement is a useful strategy for improving – directly or indirectly – the health of disadvantaged groups. The hypothesis was supported by the findings of a NIHR systematic review on the effectiveness of community engagement activities. The review concluded that community engagement interventions are effective in improving health behaviours, health consequences, participant self-efficacy and perceived social support for disadvantaged groups.²¹

In 2015, and building on the findings of NIHR's systematic review, PHE published a guide to community-centred approaches for health and wellbeing and argued for a shift to more person and community centred ways of working in public health and healthcare. Through the guide PHE outlined a 'family of approaches' for evidence-based community-centred approaches to health and wellbeing.²²

Based on the core concepts of equity, control and social connectedness, the guide identified a diverse range of community interventions, models and methods that can be used to improve health and wellbeing or address the social determinants of health. The term 'community-centred' was used rather than 'community-based' because these approaches draw on community assets, are non-clinical and go beyond using a community as a setting for health improvement. Community-centred approaches complement other types of interventions that focus more on individual care and behaviour change or on developing sustainable environments.

²¹Community Mental Health Journal. O'Mara-Eves, A. et al. (2013) Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. London: National Institute for Health Research

²² South, J. (2015) A guide to community-centred approaches for health and wellbeing. London: Public Health England

PHE's guide identified the following four-strand²³ typology:

strengthening communities	building community capacity to take action on health and the social determinants of health.
volunteer/ peer roles	enhancing individuals' capabilities to provide advice, information and support or organise activities around health and wellbeing in their or other communities.
collaborations and partnerships	working in partnership with communities to design and/or deliver services and programmes.
access to community resources	connecting people to community resources, information and social activities.

The guide also outlined the following characteristics of community-centred approaches:24

- recognise and seek to mobilise assets within communities. These include the skills, knowledge and time of individuals, and the resources of community organisations and groups
- focus on promoting health and wellbeing in community settings, rather than service settings using non-clinical methods
- promote equity in health and healthcare by working in partnership with individuals and groups that face barriers to good health
- seek to increase people's control over their health and lives use participatory methods to facilitate the active involvement of members of the public

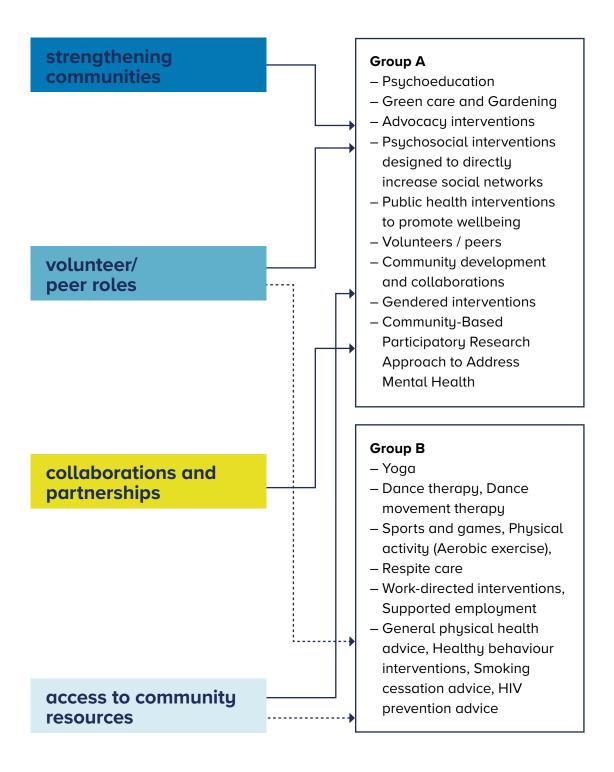
4.2. Summary of findings

In this section, we discuss the intervention methods included in the synthesis (Section 3.2) utilising PHE's typology.

Figure 3-2 outlines our findings. We found that 9 intervention methods - out of 29 intervention methods included in the synthesis²⁵ - are community-centred (group A in figure 3-2), and another six have the potential to be communitycentred if delivered under certain conditions (group B in figure 3-2). Almost half of intervention methods included in the synthesis are community-based rather than community-centred.

²³ Appendix B provides detailed description of each strand

²⁴ South, J. (2015) A guide to community-centred approaches for health and wellbeing. London: Public Health England
²⁵ See Table C-3



Our analysis identified that nine intervention methods included in the synthesis fulfil the definition of a community-centred intervention (drawing on community assets, are non-clinical and go beyond using a community as a setting for health improvement):

- Psuchoeducation
- Green care (social and therapeutic horticulture, environmental conservation, care farming) and gardening
- Advocacy interventions (providing informal counselling and support for safety planning and increasing access to different services)
- Psychosocial interventions (guided peer support, a volunteer partner scheme, supported engagement in social activity, dog-assisted integrative psychological therapy and psychosocial skills training) designed to directly increase social networks
- Public health interventions to promote wellbeing
- Volunteers / peers
- Community development and collaborations
- Gendered interventions (Men's Sheds & women's specialist organisations)
- Community-based participatory research approach to address mental health

All nine intervention methods aim to support communities to identify health and social issues and then devise and implement appropriate solutions, with the aim of creating more supportive and healthier environments. They focus on enhancing individuals' capabilities to provide support that can be emotional (providing empathy and care), instrumental (helping with practical tasks), informational (providing advice), and appraisal (offering feedback and reflection). Their premise is that people will use their life experience, cultural awareness and social connections to relate with other community members, to communicate in a way that people understand and to reach those not in touch with services or who are resistant to professional messages.

Therefore, the nine intervention methods can be allocated to all four PHE intervention types (strengthening communities, volunteer / peer roles, collaborations and access to community resources²⁷). These types of approaches seek to draw on and strengthen community capacity to take collective action that will in turn lead to changes in health or the social determinants of health; are characterised by partnership working with communities to improve planning and decision-making; use volunteers / peers who are usually drawn from the community they work in, and receive some training and support to undertake health promotion, early intervention and sometimes care in the community.

A pilot evaluation of the Wandsworth Model - a community-based mental health project in Wandsworth that canvassed partnerships with local faith-based and other community groups to co-produce responsive mental health services – found that co-production can be very rewarding for both public agencies and communities, if supported and implemented with a view to empowering people instead of making false economies for the welfare services.28 The evaluation concludes that supporting service users to become partners in managing their own health constitutes a major shift that requires a lot of experience and commitment in the co-production of services and, perhaps, it can only be possible when systemic barriers at community, public agency and state levels are removed. Nonetheless, the evaluation suggests that the 'Wandsworth model' of co-production appears to be a promising approach and should be further explored and supported to achieve its full potential.²⁹

Furthermore, an independent evaluation of the Rotherham Social Prescribing Mental Health Pilot³⁰ – a programme that intends to help users of secondary mental health services build and direct their own packages of support, by accessing tailored voluntary activity in the community, with a view to achieving sustainable discharges from mental health services – found that by the end of their involvement more than half of service users eligible for a discharge review were discharged from secondary mental health services, and more than

²⁶Knapp M, Bauer A, Perkins M, Snell T. Building community capital in social care

is there an economic case? Community Development Journal. 2013;48(2):313-31. ²⁷Appendix B provides detailed description

²⁸Hatzidimitriadou, E. et al (2012) Evaluation of co-production processes in a communitybased mental health project in Wandsworth. London: Kingston University/St George's University of London

²⁹It is worth noting that the evaluation study did not include the views of service users

³ºDayson C., Bennett E. (2016) Evaluation of the Rotherham Mental Health Social Prescribing Pilot. Centre for Regional Economic and Social Research Sheffield Hallam University

³¹It is worth noting that the evaluation study did not apply an experimental or quasi-experimental design and did not use valid and reliable measures

90 per cent of service users made progress against at least one well-being outcome measure and more than 60 per cent made progress against four or more measures. The evaluation also reported a range of other benefits (gaining employment, taking part in training, volunteering, taking-up physical activity and sustained involvement in voluntary sector activity once engagement with social prescribing was complete).³¹

In addition, our analysis identified six intervention methods - out of 24 included in the synthesis - that could potentially be allocated to the intervention groups, volunteer / peer roles and access to community resources, if delivered by qualified staff:

- Yoga
- Dance therapy, dance movement therapy
- Sports and games, physical activity (aerobic exercise),
- Respite care
- Work-directed interventions, supported employment
- General physical health advice, healthy behaviour interventions, smoking cessation advice, HIV prevention advice



5. Discussion

5

5.1. Summary of evidence

Initiatives aiming to reduce mental illness and promote mental health use a combination of intervention methods. Our search identified 66 eligible evaluation studies. Half of eligible studies are mainly secondary methodologies that follow a systematic approach (51%).³² We also identified a small number of primary studies (29%) that almost all are single case evaluations.

A quarter of the studies (26%) involved people with a diagnosis of schizophrenia or related disorders. 20% Of studies involved older people without known cognitive impairment and 17% of studies worked with people who live in supported housing. The largest proportions of studies included in the review were public health interventions aiming to promote wellbeing (29%) and used volunteers / peers (10%) or 'green care' (10%). 7% of the studies studied community development interventions and collaborations, and 6% focused on exercise or physical activity.

When looking at effectiveness across eight key outcomes (depression, anxiety, physical functioning, self-esteem, social / life skills, wellbeing and quality of life, and work functioning), we identified 16 out of 29 intervention methods included in the synthesis that demonstrated positive effects and can provide (experimental or non-experimental) evidence on at least one mental health-related outcome:

- Public health interventions to promote wellbeing
- Volunteers / peers
- Green care
- Community development
- Exercise
- Gendered
- Psychosocial (psychoeducation)
- Work-directed interventions
- Reducing psychological disorders
- Community participatory research
- Advocacy interventions
- Yoqa
- General physical health advice
- Healthy behaviour interventions
- Psychosocial designed to directly increase social networks
- Dance therapy

Interventions included in the review employed a range of models and approaches and were delivered in a range of 'community' and 'non-community' settings. Applying our quality criteria and drawing on PHE's typology of community-centred interventions, we identified that almost half of mental health intervention types included in the synthesis are community-based rather than community-centred.

Our search identified nine intervention methods that demonstrated effectiveness in at least one outcome and fulfilled the definition of a community-centred intervention type:

- Psychoeducation
- Green care
- Advocacy interventions
- Psychosocial designed to directly increase social networks
- Public health interventions to promote wellbeing
- Volunteers / peers
- Community development and collaborations
- Gendered interventions (men's sheds & women's specialist organisations)
- Community participatory research approach to address mental health

The analysis also identified six interventions - out of 29 intervention methods included in the synthesis - that could potentially be allocated to the intervention groups, volunteer / peer roles and access to community resources, if delivered by qualified staff (yoga; dance therapy, dance movement therapy; sports and games, physical activity; respite care; work-directed interventions, supported employment; general physical health advice, healthy behaviour interventions, smoking cessation advice, HIV prevention advice).

Green care is the only intervention method included in our synthesis that fulfils PHE's definition of a community centred intervention and seems to be effective across all eight outcomes.

Communities are part of our health system and have a vital contribution to make to preventing mental illness and improving mental health, along with individual-level approaches to health and care. Our search and analysis did not find robust (experimental and quasi-experimental) evidence to support most community-centred mental health interventions, as defined by recent government policy, although it did find interesting evidence that could be followed up with more robust, longer term research.

Community participation - the active involvement of people in formal or informal activities, programmes and/or discussions to bring about a planned change or improvements in community life, services and/or resources - has long been a central tenet of public health and health promotion. Evaluations of community-centred mental health interventions should now move from descriptive studies to more systematic data collection that would allow for a better understanding of the effects of community-centred work.

5.2. Next Steps

This review aimed to help Power to Change understand the importance of community and place as a determinant of an individual's mental health. The primary purpose was to inform programme design and market development. The recommendations laid out in this section have been formulated by identifying and assessing the strength of the evidence of effectiveness for a range of mental health interventions with a community component.

Considering aims, purpose and identified evidence we group our next steps under the following two headings.

Programme design

Mental health with a community component is most usefully framed according to the WHO model of 'mental health promotion', 'mental illness prevention' and 'treatment, recovery and rehabilitation'; and the PHE typology of community-centred interventions. There is a promising evidence base for effective community-centred interventions that can and should be strengthened as part of new funding and commissioning.

- 1. The design of new mental health-related programmes should be informed by robust evidence. This review identified nine community-centred intervention methods with high quality evidence. Power to Change can confidently support programmes that use any of the nine intervention methods.
- 2. There are also six intervention methods (yoga, dance, respite care etc.) that could be delivered using community-centred approaches. Power to Change should search the existing evidence base in more depth, and subsequently support new pilots that use any of the six intervention methods.

There is a range of innovative mental health interventions with a community component that currently take place and do not apply high quality evaluation

standards (experimental, quasi-experimental, randomised trials, longitudinal and comparative data collection) and therefore were not included in this review. However, good community-centred mental health support and initiatives should always be based on high quality and accurate data and there is scope to collect far better longitudinal and comparative data on community-centred interventions that would not distort delivery.

3. Power to Change should support new community-centred mental health interventions to evaluate effectiveness in a robust and appropriate manner.





Appendices

Appendix A: Review methods

Appendix B: Community-centred intervention groups

Appendix C: Tables

Appendix C: Measurement tools

Appendix D: Bibliography

Appendix A: Review methods

Design

This RER was conducted as a semi-systematic literature review, drawing on primary and secondary evaluation studies. An RER was considered an appropriate research approach for this topic due to a limited timeframe and the importance of verifying the quality of existing information.

An RER is an efficient way of reviewing the content and quality of current knowledge on a topic and identifying questions which require further research. The research process includes a clear review question, a structured literature search with a clear protocol and rationale for how the search is conducted, appraisal of the quality of evidence, data extraction and a synthesis of the evidence base. Based on these requirements, the methodological approach taken combines elements of a systematic evidence assessment with a more reflexive form of evidence-focused literature review.

This approach involves several stages, as outlined in Table A-1 below

Table A-1: Research and analysis process

1 Search	Sources assigned. Search conducted. Downloads.
2 File	Assess type, design and quality of study. Pre-screen against inclusion criteria. File in reference database.
4 Coding	Record type, design and quality of study in Excel spreadsheet.
5 Analysis	Reading and analysis of studies/data, recording strength of evidence from which conclusions are drawn. Discuss key messages with Power to Change staff.
6 Review	Review and finalisation of report.

The evidence retrieval is streamlined by a focus on literature that, in line with the research questions, has as its primary focus the evaluation of interventions with a community component that deliver mental health outcomes. Sources are limited to those produced in the last ten years in English, though earlier literature informed the scope of the study. To ensure transparency of the search process, the search strings used and the databases accessed were recorded during evidence retrieval. To ensure that the sources retrieved were both high-quality and relevant to the research question, sources from academic and grey literature were assessed for their quality using agreed criteria — described in the next section. This meant that documents which were found to be high quality could be prioritised during the analysis. The quality assessment protocol used is described in the following section. During the retrieval process sources were also coded by intervention type, and the key outcomes were extracted to develop an overview of the evidence base from which to begin analysis. The review author extracted information relevant to the research questions and drew conclusions.

Search strategy

Searching across such a broad topic raises challenges. Approaches to community-based mental health services cut across many disciplines, topic areas and outcome domains including, for example, housing, employment, social inclusion, prevention and substance abuse. Searching broadly requires the location and screening of many reports to identify a much smaller amount of research evidence that is specifically relevant. This can make exhaustive searching costly and time-consuming.

A further challenge relates to identifying different types of evidence. During initial conversations, we aimed to find outcome, process and economic evaluations, and the theoretical literature that applied to them. Not only are these often reported in different sources, which broadens the search scope, but also, they use diverse terminology that can make recognition of their relevance difficult.

Given the above challenges, this RER used a practical strategy for identifying relevant studies. The first stage of the research and evidence retrieval involved developing search strings for Google and Google Scholar³³. The process was guided by internal stakeholders to ensure that key literature was included.

Finally, a decision was made to capitalise on the systematic searches that have already been carried out for other reviews by identifying relevant primary studies. As a result, systematic reviews were identified through searching various websites and databases devoted to systematic reviews.

Identifying systematic reviews

We searched the main databases of systematic reviews relevant to our research questions:

- Cochrane Database of Systematic Reviews (CDSR). CDSR includes all Cochrane Reviews (and protocols) prepared by Cochrane Review Groups in The Cochrane Collaboration; Date of search: 15 February 2017
- The Campbell Library. The Campbell Collaboration's library of systematic reviews includes reviews and protocols prepared by Campbell review groups under any of the six co-ordinating group themes: crime and justice, education, international development, methods, social welfare and review users; Date of search: 15 February 2017
- PsyInfo. This database is one of the largest resources devoted to peer-reviewed literature in behavioural science and mental health; Date of search: 20 February 2017

Selection and eligibility criteria

The outcome of the search was a database of references and documents that were screened using the review's inclusion criteria. The inclusion criteria are a list of statements about what the study should contain to be relevant to the review question; studies must meet all the criteria to be eligible for inclusion in the review. The following criteria were applied twice: first, to identify systematic reviews and, second, to identify relevant primary studies.

- I. 10 years
- II. In English
- III. Must discuss interventions reporting primarily on mental health-related outcomes and include a community component
- IV. Must be rated 'medium' or 'high' quality

Quality criteria

The evidence retrieved was coded according to the research type (primary, secondary, or conceptual) and its quality was assessed using four key dimensions:

- A. Relevance of the study to the research questions:
 - RQ1: What is the range of models and approaches underpinning mental health interventions with a community component?
 - RQ2: Which approaches to mental health interventions with a community component are associated with improved mental health outcomes?
- B. Methodological transparency
- C. The validity of the findings
- D. Conceptual framing

Primary and secondary sources were assessed using specific indicators of quality and four inclusion criteria, as detailed below. Any sources not meeting the criteria were excluded from analysis. The indicators used to assess evidence quality were discussed and agreed with internal stakeholders. The author also discussed with Power to Change the nature of the evidence body in aggregate, and this report describes his findings with respect to the size, quality, and applicability of the body of evidence.

Table A-2: Study types and designs

Туре	Design
Primary	Experimental or Quasi/Natural Experiment [PE] Comparative [PC] Single Case Study or Evaluation [PS]
Secondary	Systematic [SS] Other review [SO]
Conceptual	[C]
Journalistic	[J]

Table A-3: Assessing quality – primary studies

Principles	Questions	Scoring
Conceptual framing	a. Does the study have a conceptual framework and clear research question?b. Does the study appear to draw conclusions based on its results rather than theory or policy?	0 Neither 1 One 2 Both
Methodological transparency	a. Does the study explain its research design and data collection methods?b. Does the study present or link to data sources?c. Does it demonstrate a clear link between the original research questions and data?	O Neither 1 One 2 Both 3 All three
Internal and external validity	a. Is the study internally valid?Or, are alternative causes of impact or the study's limitations considered?b. Is the study externally valid?Or, can findings be generalised to other contexts and populations?	0 Neither 1 One 2 Both
Journalistic	a. How relevant is the study to the research topic?	1 Partially 2 Directly
Score (Sum)		0-8

Scoring: 0-4 Low [Excluded], 5-6 Medium, 7-9 High

Table A-4: Assessing quality – secondary studies

Principles	Questions	Scoring
Relevance	a. Does the study directly address the research topic?	0 No 1 Yes
Methodological transparency	a. Does the study describe where and how studies / data were selected for inclusion?	0 No 1 Yes
Internal and external validity	a. Does the study assess the quality of the studies / data included?b. Does the study use the Cochrane protocol or another of similar rigor?	0 No 1 Yes one 2 Yes both
Journalistic	 a. Does the study draw conclusions based on the studies/data reviewed and consider alternative conclusions and / or limitations to the conclusions? 	0 No 1 Yes
Score (Sum)		0-5

Scoring: 0-2 Low [Excluded], 3-4 Medium, 5 High

Validity was considered with respect to whether a study considered the limitations of the conclusions drawn and/or whether other variables could have influenced the findings. This applied to all studies that were retrieved, whether they made claims of causal impact or only presented correlations and links between phenomena. Assessing the validity of the evidence was challenging and relied on the author's own judgment.

Appendix B: Community-centred intervention groups

Strengthening communities

This type of approaches seeks to draw on and strengthen community capacity to take collective action that will in turn lead to changes in health or the social determinants of health. Approaches can be applied at a neighbourhood level and may include:

- Community development includes community empowerment models and community organising
- Asset-based approaches includes asset mapping, asset-based community development, appreciative inquiry and world café
- Social network approaches includes mutual aid, neighbourhood network models that coordinate informal support to older people, self-help, time banking schemes

The central premise is that communities can be enabled to identify health and social issues and then devise and implement appropriate solutions, with the aim of creating more supportive and healthier environments.

Volunteer/peer roles

This group of approaches focus on enhancing individuals' capabilities to provide advice, information and support and to organise activities around health and wellbeing in their own or other communities. PHE grouped these approaches are into three categories:

- Bridging roles. These involve community members being connectors, signposting to services and information and supporting people to improve their health and wellbeing. Volunteers are often embedded in the community and are already 'natural helpers', but they are not necessarily peers
- Peer-based interventions. These aim to recruit and train people on the basis of sharing the same or similar characteristics as the target community, often with the aim of reducing communication barriers, improving support mechanisms and social connections.
- Volunteer health roles. Within an extensive range of formal volunteer health roles in the UK many of these are focused on reducing health inequalities.
 Common health improvement models include walking for health, befriending and environment and health volunteering projects. Volunteers typically receive training and support to undertake a heath role.

Collaborations and partnerships

This group of approaches is characterised by partnership working with communities to improve planning and decision-making. There is a long tradition of participatory and collaborative approaches in health promotion and public health with links to patient and public involvement in health and care services. Collaborative approaches involve communities and local services working together at any stage of the planning cycle: identifying needs and agreeing priorities, planning and programme design, decision-making, implementation and evaluation. These approaches are grouped into four broad categories:

- Community-based participatory research. It involves partnerships between communities, services and academic researchers, usually with the purpose of identifying community needs and then working together to develop programmes.
- Area-based initiatives. They tackle social or economic disadvantage at an area or neighbourhood level through partnership working and multi-faceted programmes where health is often a strand alongside economic development, urban regeneration, access to services and education.
- Community engagement in planning. Multiple approaches exist for involving communities in planning and decision-making in local government and the NHS.
 Community engagement methods include area forums, open space events, planning for real, user panels, deliberative polling, residents' committees and citizens' juries, fairness commissions and participatory budgeting.
- Co-production projects. Co-production approaches seek to develop equal, reciprocal partnerships between professionals and those using health and care services. They share many of the features of other collaborative approaches but with more focus on people with long term conditions or needing social care.

The premise is that involving communities in assessment, design and development of solutions will result in services and health programmes that are better matched with needs

Access to community resources

This group is about connecting individuals and families to community resources – information, services, practical help, and group activities and volunteering opportunities – to meet health needs and enhance wellbeing. Tapping into the assets of voluntary and community organisations (sometimes referred to as non-traditional providers) these approaches establish referral routes, reduce barriers to accessing services and social participation, and commission and coordinate group activities. Approaches are grouped into:

- Pathways to participation. This covers social prescribing and other types of non-medical referral systems including arts on prescription, green gyms, referral systems for food banks, welfare advice in primary care and interventions which widen volunteering opportunities for people with specific health needs. The broad aim is to connect individuals with non-clinical or social needs or those with mild to moderate mental health problems to opportunities for social interaction, support, learning and healthy living activities. Pathway approaches are often based within general practice and/or involve primary care teams, but use a social determinants rather than a clinical model of health.
- Community hubs. These are community centres or community anchor organisations focused on health and wellbeing that can be either locality based or work as a network. Community hubs typically provide multiple activities and services that address health or the wider determinants of health, most of which are open to the wider community. Some hubs layer health into an existing community resource such as faith settings or libraries, others build social activities and support services within a primary health care setting. There are often outreach projects, social prescribing and volunteering schemes nested within a community hub, and some include co-located health services.
- Community-based commissioning. It uses a social determinants approach and recognises that individuals, particularly from vulnerable groups, have a range of health and social needs which cannot be met solely by health services.

Appendix C: Tables

Table C-1: Nature of evidence base

Quality	Primary		Secondary			Total		
	Experimental	Comparative	Single Case	Systematic	Other	Conceptual	Journalistic	
High	1	0	8	23	1	1	0	33
Medium	0	0	7	12	13	0	0	21
Total	1	0	15	35	14	1	0	66

Table C-2: Participants (n=827)

Participants	No. of studies	%
People with a diagnosis of schizophrenia or related disorders	218	26%
Older people without known cognitive impairment	163	20%
People who live in extra care housing	141	17.1%
All / area populations	62	7.5%
Parents and children of parents with serious mental illness (SMI) and severe depression	45	5%
Workers with a major depressive disorder or a high level of depressive symptoms.	37	4%
Low-Income Urban Youth	33	4%
Adolescents or young adults aged between 12 and 25 years with or without mental health problems	28	3%
Refugee and asylum-seeking children	21	2.5%
Minority populations	20	2.4%
Abused women with no care or usual care	13	2%
Homeless young people (street-connected)	11	1%
Informal carers of people with dementia	9	1%
Post-secondary undergraduate students	8	1%
Young people who misuse non-opioid drugs	7	1%
Women	5	0.6%
People with dementia and their caregivers	4	0%
Siblings of people with severe mental illness	1	0%
People who have been diagnosed with Post Traumatic Stress Disorder	0	0%

Table C-3: Intervention Method (n=827 studies)

Intervention Method	No. of studies	%
Public health interventions to promote wellbeing	238	29%
Volunteers / peers	84	10%
Green care ³⁴	80	10%
Community development and collaborations	60	7%
Exercise, Physical activity, Sports and Games	51	6%
Community-Based Mental Health and Behavioral Programs ²⁵	33	4%
Parenting programmes	31	4%
Gendered interventions (Men's Sheds & Women's specialist organisations)	30	4%
Community-based interventions for improving QoL ³⁶	29	4%
Psychosocial ³⁷	29	4%
Work-directed interventions	23	3%
interventions aimed at reducing psychological disorders38	21	3%
Community-Based Participatory Research Approach (mental health)	20	2%
Supported employment ³⁹	14	2%
Advocacy interventions ⁴⁰	13	2%
Interventions for promoting reintegration and reducing harmful behaviour	11	1%
Telephone counselling	9	1%
Interventions for primary prevention of suicide	8	1%
Yoga	8	1%
Cognitive- Behavioural Therapy	7	1%
General physical health advice	6	1%
Healthy behaviour interventions	6	1%
Psychosocial interventions designed to directly increase social networks ⁴¹	5	1%
Respite care	4	0%
Dance movement therapy	3	0%
Oral health education	3	0%
Dance therapy	1	0%
HIV prevention advice	0	0%

³⁴Social and Therapeutic Horticulture, Environmental conservation, Care farming ³⁵Externalizing/sexual health, broad social/emotional/behavioural, alcohol/substance

²⁸ Cognitive and behaviour, productions obtained behaviour, family focused programs

29 Cognitive and behaviour, parenting behaviour, family function

29 Psychotherapy, CBT, DBT, problem solving therapy, psychoeducation or community treatment or support, suicide prevention interventions

28 Verbal processing of past experiences, array of creative art techniques and others used a combination

28 Individual Placement and Support and Augmented Supported Employment

³ºIndividual Placement and Support, and Augmented Supported Employment 4ºProviding informal counselling and support for safety planning and increasing

access to different services

4Guided peer support, a volunteer partner scheme, supported engagement in social activity, dog-assisted integrative psychological therapy and psychosocial skills training

Table C-4: Outcome Types (n=827 studies)

Outcome	No. of studies	%
Wellbeing & quality of life	388	47%
Mental state	332	40%
Social/ General functioning / Life skills	321	39%
Depression / Mood disorders	224	27%
Physical functioning / Physical fitness & health	223	27%
Self-esteem	162	20%
Anxiety	102	12%
Work functioning	92	11%
Service utilisation / resource use / Hospital admissions	80	10%
Alzheimer's	75	9%
Self-perceived changes in overall health	59	7%
Family function	55	7%
Satisfaction with care: patients/carers	54	7%
Cognitive function	52	6%
Education involvement	40	5%
Risk behaviour	40	5%
Acceptability of treatment	39	5%
Suicide related (knowledge, prevention, self-efficacy)	36	4%
Problem-based coping skills	29	4%
Post traumatic disorder	27	3%
Adverse effects: including mortality	27	3%
Days of sickness absence	23	3%
Employment status	14	2%
Fatigue	14	2%
Substance misuse	13	2%
Sleep	8	1%
Eating disorder	6	1%
Smoking cesssation	6	1%
Burden (caregivers)	5	1%
Dental state	3	0%

Appendix C: Measurement tools

Outcome	Measurement tool
Depression / Mood disorders	Center for Epidemiologic Studies Depression Scale Geriatric Depression Scale Depression Anxiety Stress Scale Hospital Anxiety and Depression Scale Beck Depression Inventory Brief Symptom Inventory Hamilton Depression Scales Symptom Check List-90-Revision
Social/ General functioning / Life skills	Socio-Occupational Functioning Scale Tool for Recognition of Emotions in Neuropsychiatric Disorders (TRENDS) Accuracy Score Functional Assessment for Comprehensive Treatment of Schizophrenia SCL-90-R scale Global Assessment Scale - GAS or Global Assessment of Functioning - GAF Work Behavior Assessment UCSD Performance-based Skills Assessment Nurses' Observation Scale for Inpatient Evaluation Scale of Social-skills for Psychiatric Inpatients Social Skills Performance Assessment The Medication Management Abilities Assessment
Mental state	Depression Anxiety Stress Scale Positive and Negative Syndrome Scale Schedule for Assessment of Negative Symptoms Schedule for Assessment of Positive Symptoms Calgary Depression Scale 25-Item Resilience Scale Hamilton Rating Scale for Depression Zung Self-Rating Depression Scale Profile of Moods State Future Outlook Inventory
Wellbeing & quality of life	Personal Wellbeing Index World Health Organization Quality of Life BREF questionnaire Medical Outcomes Study (MOS) Short Form Health Survey (SF-36) EuroQoL 5 Dimensions Manchester Short Assessment of Quality of Life Quality of Well-Being Scale General Quality of Life Inventory Quality of Life Scale Quality of Life Interview - QOLI

Physical functioning / Physical fitness & health	SF-36 physical functioning subscale		
Self-esteem	Rosenberg scale		
Anxiety	Spielberger State-Trait Anxiety Inventory Hamilton Anxiety Rating Scale Depression Anxiety Stress Scales Hospital Anxiety and Depression Scale Beck Depression Inventory		
Cognitive function	A neuropsychological test (sensitive to changes in cognitive function in adults)		
Acceptability of treatment	Attendance at interventions Number of participants completing the interventions		
Service utilisation / resource use / Hospital admissions	Contacts with neurologist, psychiatrist or other specialists Numbers of inpatient days Numbers of admissions Mean days in hospital		
Adverse effects: including mortality	Extrapyramidal Symptom Scale Serious adverse reactions (SARs)		
Days of sickness absence	Employee attendance records. Files of a compensation board Self-reported		
Employment status	Days in competitive employment (long term, i.e. over one year of follow-up)		
Fatigue	Fatigue Scale Fatigue Severity Scale Brief Pain Inventory		
Self-perceived changes in overall health	Global Impression Scale		
Sleep	Pittsburgh Sleep Quality Index		
Burden (caregivers)	Caregiver Burden Hamilton-Depression Hamilton Anxiety Global Severity Index from the Brief Symptom Inventory Social Support-Affective Support Social Support-Confidant Support Perceived Stress Scale Center for Epidemiological Studies - Depression Scale Penn State Worry Questionnaire SF-36 Mental and Physical component summary Family Burden Interview Schedule (FBIS)		
Dental state	Modified Quigley-Hein Plaque Index		
Satisfaction with care: patients/carers	Client's Assessment of Treatment Scale Participant attrition rates		

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