ImROC

Supported by

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

18. Peer Support for People with Physical Health Conditions

Authors: Julie Repper and Liz Walker (ImROC)

ACKNOWLEDGEMENTS

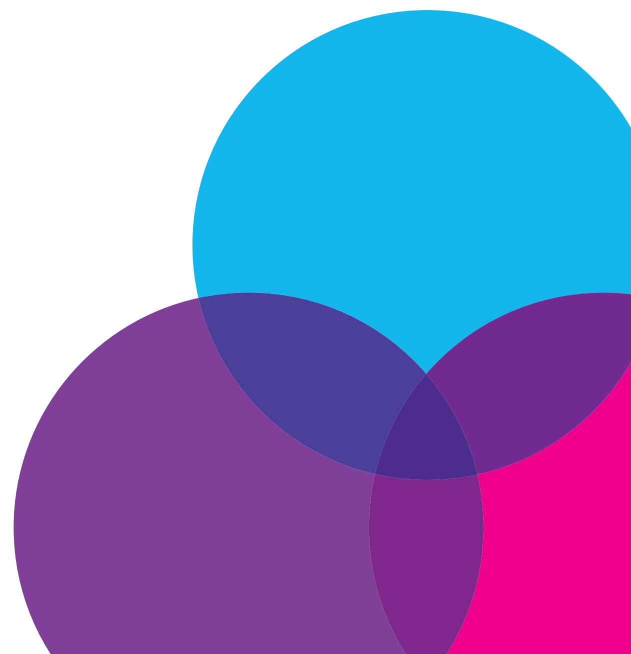
We would like to thank Heath Education England (HEE) for funding the coproduction and writing of this paper.

ImROC has previously written on this subject in our earlier Briefing Papers: Briefing Paper 5 Peer Support Workers Theory and Practice and Briefing Paper 7 Peer Support Workers: A Practical Guide to Implementation

INTRODUCTION

The development and expansion of new roles to support the mental health workforce was set out in the NHS Long Term Plan and Health Education England's report, Stepping Forward to 2020/21: The Mental Health Workforce Plan for England. A significant area of expansion is the development and implementation of the peer support worker role, in which people with lived experience of mental health problems and services provide support and deliver interventions to others who are experiencing similar problems (UCLP/NCCMH 2019, Peer Support Competency Framework - Background Information).

Whilst most peer support practice, research and publications have focused on peer support by and for people with mental health problems, informal support between people who have shared experiences has always occurred across the whole spectrum of health and social care settings.



A brief scan of any community newsletter reveals countless examples of peer support initiatives from carers groups offered at a hospice to meetings for siblings of bereaved children, from Al-anon meetings for families of people with drinking problems to the Parkinson's Disease Society…. shared experience clearly provides a strong foundation for mutual support in all areas of life.

There is, however, no existing guidance for the employment, training or role definition of peer support workers who focus on physical health problems either in physical health settings, or with people who also have mental health conditions.

The questions that this paper seeks to address are:

- Whether and how mental health peer support can be extended to address the physical health of people with mental health problems.
- Whether formal or intentional peer support has been introduced in physical health services (statutory, voluntary or private), whether it is beneficial, how it differs from mental health peer support and what additional training might be required.

BACKGROUND

Support offered by peer workers is distinct from that provided by other professionals. Rather than relying on a professional knowledge/theory base, peer support is based on experiential knowledge: knowing what these experiences can feel like and the impact they can have on your life; having experience of gaining an understanding of what has happened and working out ways of understanding, coping and recovering a life with or without ongoing difficulties.

Rather than focusing on directing, prescribing or fixing a person, peer support is about 'being with': offering support within an equal and reciprocal relationship, providing space, time and opportunity to share with someone who can provide a level of empathy and understanding based on their own lived experience.

And peer support goes beyond simply listening and sharing, to demonstrating the possibility of self-management and recovering a meaningful life; working with people to enable them to find their own solutions, to identify their own goals and to work out how to achieve these; addressing personal, social and relational barriers in a manner that fits the individual, their resources and their background – culture, religion, sexuality, childhood experiences, social situation etc.

Peer support can occur in an **informal** relationship between people who have experiences or goals in common, it can occur in community settings – like self-help groups, voluntary sector support groups, in groups of people with similar interests, using similar services or seeking similar solutions. It can also occur in a more **intentional** and formal manner, through the employment of people with similar experiences as peer support workers or peer specialists in services on an unpaid or paid basis.

Research into peer support consistently demonstrates the importance of particular values to underpin and inform effective practice. It is these values that define peer support, distinguish it from other forms of support, and that appear to be associated with the effectiveness of peer support (see Box 1).

Box 1. The Values Underpinning Peer Support (Adapted from Repper 2013)

Empathy and respect Understanding another's experience from their perspective and being genuinely interested in them as a person. Being non-judgemental, not making assumptions about or pathologising the person's experiences or beliefs.	**Inclusive** Respecting the diversity of each person's experience and their particular back-ground or culture that might influence this. Ensuring support is available to everyone.
Mutual Each person's experience is of equal value; both people can learn from each other within an equal, accepting, and respectful relationship (based on sharing and shared experiences)	**Non-directive** Helping people to find solutions which work for them (rather than suggesting solutions). Validating people's experiences; acknowledging that each person is the expert in their own experience.
Progressive Helping people to learn from their experience and to equip themselves to move forward.	**Reciprocal** Both people benefit from sharing their experience; everyone learns from one another and everyone's contribution is considered to have equal value
Strengths based Focusing on a person's strengths, helping them build them up and develop their ability to make use of the resources available to them.	**Community facing** Working with assets and resources in local communities to build their confidence and capabilities and develop initiatives where they are needed. Supporting people to engage in communities of their choice**.**
Recovery-focused Creating hope and a sense of control, empowering the person to define, lead and own their recovery,	**Safe** Offering support that is safe and non-judgmental, sharing personal experience in a safe, appropriate, and effective manner, working in a safe, supportive environment.

It is among people with mental health conditions that most peer support development, research and evaluation has taken place. Within the UK, many communities-based and voluntary sector services are either peer-led or coproduced and co-delivered with both support workers and professionally qualified staff.

Peer support occurs within these groups in a less structured, ‘rule-bound’ and professionalised manner than within statutory services, often providing a sense of solidarity and a shared voice, a feeling of belonging to a movement, of empowerment and community (Faulkner and Kalathil 2012).

In contrast, although many statutory mental health services now employ peer workers, their role is generally to support people using those services on a one to one or group basis alongside professionals. Research into mental health peer support has demonstrated that, when provided in services, it is at least as effective as support provided by other workers. Peer support has been shown to benefit those supported by reducing the incidence of crises, reducing the length and frequency of inpatient stays, improving engagement with community resources and increasing sense of empowerment and hope for the future (Slade et al, 2019).

PEER SUPPORT FOR PEOPLE WITH PHYSICAL HEALTH CONDITIONS

There are two interlinked sources of evidence/research underpinning peer support for people with physical conditions. The first refers to peer support focusing on the physical health of people with mental health problems. The second concerns peer support by and for people with physical health conditions.

There is inevitable overlap between these two subject areas owing to the high levels of mental health problems experienced by people with physical conditions and the poor physical health of many people with serious mental health problems.

This paper does not provide a systematic review of the literature but seeks to summarise the evidence in both of these areas to address the question: what is the role of peer support for people with physical health conditions?

Peer support to improve the physical wellbeing of people with mental health problems

It has been well established that people with serious mental health problems die between 10 and 20 years earlier than the general population due mainly to cardiovascular, respiratory, and metabolic diseases. This population is also less likely to have a primary care provider, and attendance at primary care appointments is lower than the general population (see Box 2).

There is some evidence that one to one peer support interventions with people who have more serious mental health problems can improve self-management and physical wellbeing. Stubbs et al (2016) conducted a systematic review of research into peer support interventions to improve the physical health of people with mental health problems to establish whether peer support improved physical health, appointment attendance and adherence to a healthier lifestyle. They identified 7 studies (only 2 of these were RCTs), all conducted in the US, totalling 220 participants receiving formal peer support which involved sharing personal experience and delivering an intervention. These studies

describe a number of different approaches: weight loss, personalised fitness, confidence in primary care appointments and broad-based self-management (including exercise, healthy eating, medication management, sleep and behaviour management).

Outcomes were generally positive with significant improvement in attendance at outpatient appointments (2 studies) and increased fitness and physical activity (1 study). Although there were also improvements in weight loss, reporting of physical symptoms, physical health related quality of life, physical functioning, and pain, these were not statistically significant.

Whilst this review is cause for some optimism, it demonstrates the need for more high-quality research into peer support. Variation in the interventions offered raises questions about the nature of peer support for physical health conditions. Not one of these interventions offered support based on experiential knowledge alone. Instead peer support workers offered professionally designed interventions which, arguably could have been provided by workers without lived experience.

Further evidence suggests that peer-led education and groups for people with mental health problems lead to benefits in self-management. Research conducted, once again, in the US, reports improvements in; self-management attitudes; skills and behaviours using group based Wellness and Recovery Action Planning (Cook et al, 2010); and the provision of group based information, skills and support can lead to increased engagement in physical health care (Pickett et al, 2012).

Within the UK, coproduced (peer and professionally led) education, delivered in Recovery colleges has been shown to enhance sense of hope, reduce use of services, improve engagement in community activities including work, volunteering and mainstream education (Perkins et al, 2018).

Although these interventions are offered by peers – either alone or in combination with professionals – none of them are strictly speaking 'peer support' because they involve the delivery of a specific intervention or training. Rather, they are peer delivered interventions or peer led/coproduced education.

Peer support for people with physical health problems

Where peer support is offered for physical health conditions, it appears to focus on those with long term or complex physical conditions. Interest in the feasibility and efficacy of peer support for this population is highly relevant given the prevalence and high levels of need among those with long-term conditions.

More than 15 million people - 30% of the UK population - live with one or more long-term conditions, and more than 4 million of these people will also have a mental health problem. People with cancer, diabetes, asthma and high blood pressure are at greater risk of a range of mental health problems such as depression, anxiety and Post Traumatic Stress Disorder.

A systematic review of the literature was undertaken by The Chronic Illness Alliance in Victoria, Australia (2011) to identify effective models of peer support for 'chronic conditions' and their effectiveness. 55 articles were included describing seven different models of peer support: professionally led groups; peer-led groups; peer coaches; community Health Workers; support groups; telephone-based peer support; internet and email peer support.

These were offered to people with a range of long-term conditions including musculoskeletal, respiratory, endocrine, pulmonary, renal, and cardiac conditions. Although the nature of the support provided was poorly defined and effectiveness was difficult to assess, the most commonly cited benefit was improved self-efficacy, and greater effectiveness was reported in socially disadvantaged groups or in culturally specific services. The main conclusion of this paper was a plea for more research of a higher quality.

One UK based qualitative study of one to one peer support, designed to help people at the stage of adapting to chronic renal illness and making treatment choices, reported benefits similar to those found in mental health peer support: talking to someone 'who's gone through what you're going through'; answers to questions and practical information; reassurance, encouragement and increased confidence; support with coming to terms with starting treatment; help making or confirming treatment decisions; hope for the future.

Respondents contrasted peer support favourably with clinical consultations: the encounter itself was perceived as not subject to constraints imposed by limited time or differences in status; interaction was facilitated by the peer supporter's empathy; and respondents felt more in control. These findings have been echoed in studies of peer support for diabetes (Smith, 2011), breast feeding mothers (Ingram, 2013) and in cancer care (Hoey, 2014) and terminal care (Samuels, 2014).

Most studies of peer support in physical health conditions report *groups* run by peers. Similar benefits to those above are reported by participants in cancer and HIV support groups, who found peer supporters to be positive role models who helped to normalise illness and demanding treatment regimes - this appears to have increased their sense of empowerment and agency.

Perhaps the best-known peer-led intervention is the Chronic Disease Self-Management Programme (CDSMP) or the Expert Patient Programme (EPP). This comprises peer led education for people with a range of long-term conditions utilising a Programme originally licensed from Stanford University, US. Currently running as a Community Interest Company, the Programmes offered are delivered either by voluntary sector organisations or NHS providers commissioned through CCG's, or local Public Health Departments.

The EPP and CDSMP seek to enable people to understand and gain confidence and skills to manage their own condition. It is estimated that over 5,000 courses have been delivered to over 70,000 participants through contracts with NHS Primary Care Trusts and other commissioning bodies across England. Many of its service users go on to become accredited tutors, some paid and some volunteers. Evaluation of reports improvements in self-efficacy and quality of life are likely to be cost effective.

Recovery College courses focusing on physical health differ from EPP in that they are coproduced and co-facilitated by people with physical health conditions and professionals, they are more flexible and experiential in content. They report similar findings to those of the EPP (Perkins et al, 2018). However, such group and educational initiatives are examples of peer led interventions rather than peer support *per se*.

Whilst there is no shortage of examples of peer support for people with physical conditions, the quality of published research is varied so it is not possible to draw conclusions. It is not always clear how the support offered is distinct from that offered by non-peers. In many of the published reports, peers are employed to provide professionally designed and developed interventions with little description of how they draw on their own lived experiences. Yet studies reporting peer support based on sharing of personal experience (such as EPP and one to one peer support for renal disease) describe the benefits derived from mutuality and reciprocity including normalisation of experiences, increased sense of agency and control, and improved hope.

More detailed information about the evidence for EPP/ CDSMP can be found on the Talking Health Taking Action website (https://www.talkinghealth.org/)

PEER SUPPORT: A HOLISTIC APPROACH

Given the co-existence and interactive effect of mental health problems and long term physical conditions (see Box 2), it is not surprising that the findings from research into peer support are much the same whether services focus primarily on people with mental health problems or people with long term physical conditions. The benefits reported for both groups are primarily improved levels of self-efficacy and engagement in care; with additional benefits of improved acceptance, hope and agency where peer support is based on sharing lived experience and building coping strategies together.

These findings corroborate the findings of research into mental health peer support. Taken together they suggest that the provision of support based on common experiences and focusing on working together to find ways of understanding, coping, and living well can be helpful whatever the shared experiences are. This makes sense particularly since research into community-peer support suggests that shared cultural backgrounds, shared experiences of trauma, adverse childhood experiences and/or bullying and exclusion also provide a basis for effective peer support (Faulkner and Kalathil).

Indeed, peer support workers appear to be well positioned to bridge the gap between physical, mental, social and community based services and resources as part of a whole person, integrated, place based, recovery orientated system of care as envisioned in the NHS Five Year Forward View (2014), the NHS Five Year Forward View for Mental Health (2016) and the General Practice Forward View (2016), and as recommended by Naylor et al (2012) see Box 2.

The Local Government Association guide to community capacity and peer support (LGA/ NHSE, 2019) envisages peer support as an integral part of an asset-based approach to supporting people as valued and active citizens in their communities. It provides a summary of the functions of (largely unpaid) peer support accessible for all local citizens, whether they have physical, mental or social needs, including: assistance in daily management (via skills development sessions, support to overcome personal barriers, and regular prompts and reminders); social and emotional support (via space to talk about worries, wellbeing and motivational issues); linking to community and clinical resources (via signposting to community resources, locating projects in community settings, referring to/'pulling in' practitioners as appropriate); and ongoing support (via setting up support groups that are flexible and convenient, offering informal support between meetings, and evolve according to participants' wishes and motivations).

Mind provides an online toolkit to support community-based peer support to develop in flexible ways to meet the needs or mutual experience of group members. The values that they coproduced to underpin any peer support include: experience 'in common'; safety; freedom to be oneself; human connection; and choice and control. These are not only very similar to those given in Box1, but also apply equally to mental and physical health conditions. Crepaz-Keay (2017) reflects on his experiences of peer support in community settings and sees it as having the "capacity to address social isolation, build skills and self-esteem, and give individuals a better quality of life – it can also add value to whole communities and reframe the way entire groups are considered within them".

This reflects the findings of many social prescribing services initially set up to meet the emotional/mental health needs of people using primary care services, and increasingly finding themselves working with people who have multiple long-term conditions (both mental and physical), and who are often inactive and isolated. Increasingly, social prescribing services are employing staff (link workers) who themselves live with long term conditions, and training them to provide active listening, problem solving, coaching and empowerment. (Repper, 2019).

In the US, the National Academy for State Health Policy (2016) proposes employment of peer support to promote physical and mental health integration by: linking to community resources; group facilitation; skills building; mentoring; goal setting; and individual wellness planning. In three states Medicaid health insurance funds integrated peer support. Interestingly, funding guidance for these services includes key service design components including peer supervision, individualised care plans including specific personal goals, and competency-based peer training.

Box 2. The mental health of people with long-term physical conditions (Naylor et al, 2012)

Many people with long-term physical health conditions also have mental health problems. These can lead to significantly poorer health outcomes and reduced quality of life.

Costs to the health care system are also significant – by interacting with and exacerbating physical illness, co-morbid mental health problems raise total health care costs by at least 45 per cent for each person with a long-term condition and co-morbid mental health problem.

This suggests that between 12 per cent and 18 per cent of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing – between £8 billion and £13 billion in England each year. The more conservative of these figures equates to around £1 in every £8 spent on long-term conditions.

People with long-term conditions and co-morbid mental health problems disproportionately live in deprived areas and have access to fewer resources of all kinds. The interaction between co-morbidities and deprivation makes a significant contribution to generating and maintaining inequalities.

Care for large numbers of people with long-term conditions could be improved by better integrating mental health support with primary care and chronic disease management programmes, with closer working between mental health specialists and other professionals.

Collaborative care arrangements between primary care and mental health specialists can improve outcomes with no or limited additional net costs. Innovative forms of liaison psychiatry demonstrate that providing better support for co-morbid mental health needs can reduce physical health care costs in acute hospitals.

Clinical commissioning groups should prioritise integrating mental and physical health care more closely as a key part of their strategies to improve quality and productivity in health care.

Improved support for the emotional, behavioural, and mental health aspects of physical illness could play an important role in helping the NHS to meet the Quality, Innovation, Productivity and Prevention (QIPP) challenge. This will require removal of policy barriers to integration, for example, through redesign of payment mechanisms.

CONCLUSIONS

Whilst reports of peer support for physical health conditions are promising, as with all types of peer support further research is needed. The evidence on specific outcomes is mixed and hampered by the lack of a consistent definition of the intervention and a lack of high-quality research.

The principles of peer support (see Box 1) developed within mental health services would appear to have relevance for peer support offered within all services. Sharing experiences, feelings and coping strategies, taking time to understand each other, demonstrating possibilities, and finding ways forward together, are as relevant for people with physical conditions as they are for people with mental health problems.

Much of the research into peer support for people with serious mental health problems and physical conditions appears to focus on peer delivery of professionally designed interventions with little mention of the way that peers offer anything different from non-peer staff. Whilst these interventions may be helpful, this is not peer support per se. We would recommend that all peer support services are clear about the role that lived experience plays in peer support.

There are many tools available to help peer workers to structure and focus the support that they provide without resorting to the models, theories and interventions designed by other professionals. We recommend that peer worker training includes the skills to use tools that are consistent with the non-directive, recovery focused and strengths-based approaches of peer support. (For example, personal wellness planning, problem solving, coaching skills, goal setting, action planning, five ways to wellbeing).

Given the notable co-occurrence of physical and mental health problems, it makes sense for peer support workers to offer a holistic goals-orientated approach in all of their work - working alongside people to support them to identify and achieve their life goals, and to address psychological, social and physical challenges that might impede their progress. This is utterly consistent with the underpinning principles of peer support.

However, the distinction between community based peer support (which develops organically to meet the needs of people with shared experiences, and places greater emphasis on collective voice/action, and solidarity) and intentional peer support (via the employment of trained peer support workers in statutory services) needs to be recognised.

Knowledge pertaining to specific diagnoses, whether relating to physical or mental health conditions may be relevant when training peer workers for employment in particular services, but it is not a requirement as peer support is not about providing expert knowledge (other professional experts can do that). It is about; working together to find explanations that accord with the individual's culture, background, beliefs and experiences; researching solutions and potential treatments and therapies together; and active listening to reach decisions about what is best for the individual - rather than offering a standard medical response or delivering a standardised intervention.

Although more research is needed, this summary of peer support in physical health care suggests that peer workers have an important role to play in improving the quality of life and community engagement of people who have long term physical and/ or mental health problems.

It appears to be helpful in building understanding, confidence, control, hope and rebuilding meaningful roles, relationships, and activities. It offers a place where people can feel a sense of belonging and acceptance, within diverse communities of their choice. It can support people to recognise their rights and fight social injustice.

As numbers of people living with long term physical and mental health conditions increase, and current policy emphasises place based systems of care with integrated services built around more inclusive communities, there is a clear role for peer support (based on shared experiences of mental and/or physical health conditions, similar life experiences, and common cultural and/or social backgrounds) both within services, in the community - and in navigating the system.

REFERENCES

Cook, J., Jonikas, J., Hamilton, M., Goldrick, V., Steigman, P., Grey, D., Burke, L., Carter, T., Razzanio, L., Copeland, M.A. (2013) Impact of Wellness Recovery Action Planning on service utilization and need in a randomized controlled trial. Psychiatric Rehabilitation, 36,4,250-257.

Crepaz-Keay, D. (2017), "Peer support in community settings: getting back to our roots", *Mental Health and Social Inclusion*, Vol. 21 No. 3, pp. 184-190.

DoH (2014) NHS Five Forward View. London: NHS England

DoH (2016) NHS Five year Forward View for Mental Health. London: NHS England

DoH (2016) General Practice Forward View. London: NHS England

Faulkner A, Kalathil J (2012) The freedom to be, the chance to dream: preserving user-led peer support in mental health. London: Together for Mental Wellbeing.

Hoey, L., Leropoli, S., White, V., Jefford, M. (2008) Systematic review of peer-support programs for people with cancer. *Patient Education Counselling,* 70,3,315-37

Ingram, J. (2013) A mixed methods evaluation of peer support in Bristol, UK: mothers', midwives' and peer supporters' views and the effects on breastfeeding. *BMC Pregnancy Childbirth* **13,** 192

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M. and Galea, A. (2012) "Long-term conditions and mental health: The cost of co-morbidities". Kings Fund and Centre for Mental Health, London.

Perkins, R., Meddings, S., Williams, S., Repper, J. (2017) Briefing Paper 17. Recovery Colleges 10 years on. Nottingham: ImROC.

Pickett, S., Diehl, S., Steigman, P., Prater, J., Fox, A., Shipley, P., Grey, D., Cook, J. (2012) Consumer empowerment and self-advocacy outcomes in a randomized study of peer-led education. *Community Mental Health* 48, 4, 420-430.

Repper, J (2012) *Peer Support: Theory and Practice*. Briefing Paper 5. Nottingham: Imroc

Samuel, M. (2014) "You don't come here to die but to learn about living " The importance of peer support in palliative care*" Community Care*, February 17, 2014

Ingram, J. A mixed methods evaluation of peer support in Bristol, UK: mothers', midwives' and peer supporters' views and the effects on breastfeeding. *BMC Pregnancy Childbirth* **13,** 192 (2013). https://doi.org/10.1186/1471-2393-13-192

Slade M, McDaid D, Shepherd G, Williams S, Repper J (2017) *Recovery: The Business case*. Briefing Paper 14. Nottingham: ImROC.

Smith, S., Paul, G., Kelly, A., Whitford, D., O'Shea, E., O'Dowd, T. (2011) Peer support for patients with type 2 diabetes: cluster randomised controlled trial. BMJ, 342:d715

Stubbs B, Firth J, Berry A et al (2016a) How much physical activity do people with schizophrenia engage in? A systematic review, comparative meta-analysis and meta-regression. Schizophrenia Research. 2016 Oct;176(2-3):431-40.

ImROC's Vision

For systems, services and cultures to support Recovery and wellbeing for all locally, nationally and internationally.

ImROC's Mission

ImROC works in partnership with communities to develop systems, services and cultures that support recovery and wellbeing for all. ImROC has been leading the way in recovery-oriented service and practice improvement since 2011.

Originally established on behalf of the Department of Health to champion its 'Supporting Recovery' initiative, through a collaboration between the Centre for Mental Health and the NHS Confederation's Mental Health Network, ImROC is now hosted through Nottinghamshire Healthcare NHS Foundation Trust. This innovative new partnership allows us to cement our close working relationship with frontline providers of care, ensuring that our work remains relevant and useful to practitioners, managers, system leaders, local communities and ultimately, the people who access services.

Our role is about enabling people (who use services, work in services and live in communities) to unlock and pool the strengths and talents they take for granted, explore new ways to make use of them, share knowledge and learning, and facilitate recovery-oriented improvement in the outcomes and experience of health and social care. We rely on and embrace the expertise, experience and collective wisdom of everyone we work with, and encourage communities to develop as a result. Our job is about using our expert knowledge to inspire others to believe that change is possible; pursue their dreams, and most importantly to act: changing attitudes and behaviours. This ethos of working in co-production is at the heart of our organisational work, and role models what we seek to achieve at a practice level too.

Contact:

ImROC
c/o Learning and Development
Nottinghamshire Healthcare NHS Foundation Trust
Duncan Macmillan House
Porchester Road
Mapperley
Nottingham
NG3 6AA

imroc@imroc.org
07973665472

Citation: Perkins R, Meddings S, Williams S, Repper J (2018)
Recovery Colleges 10 Years On, Nottingham, ImROC.

™012136248