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Evaluation of the Building a Healthy Future programme

Final report

April 2016

Authors

This report has been jointly authored by Mark Robinson, Esmee Hanna, Gary Raine, and Steve Robertson from the Institute of Health and Wellbeing at Leeds Beckett University and Jacob Diggle from Mind's Research and Evaluation team.

Leeds Beckett University conducted an independent evaluation of the Building a Healthy Future programme – including analysis of outcomes, qualitative interviews with service users and stakeholders, and case studies. Mind's Research and Evaluation team conducted an economic evaluation of the programme.

The report presents the integrated findings of Leeds Beckett University and Mind. It has been approved by all authors. Detailed findings and recommendations from the two research projects are presented separately in the appendices of the report.

The report is intended to:

- gain an understanding of the impact of the Building a Healthy Future programme
- identify the economic benefits that implementing a programme such as this can have
- establish what works and what learning should be taken forward by anyone developing/ implementing a similar service
- identify questions for further investigation.



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The authors would like to thank Mind's Service Development Manager, Birmingham Mind and Manchester Mind for their invaluable support, and the stakeholders who gave valuable feedback via interviews. We would also like to thank the Department of Health who provided funding and support for the programme. We owe the greatest thanks to all the service users who were so generous with their time and ideas.

Mind would also like to thank Oxfordshire Mind, British Heart Foundation, Diabetes UK and Arthritis Research UK for their support throughout the programme.

Foreword



Having hope, confidence and good self-esteem can help us stay mentally healthy.

If we can adapt well to change, have a strong sense of purpose, and supportive relationships and social networks, then we're more likely to cope in the face of adversity.

However, our research in this area shows that people most at risk of developing mental health problems are often less equipped with the resources they need to stay well – particularly when experiencing long-term physical health conditions.

Mind believes that with the right resources and support, we can change this, so that people can develop this capacity for resilience and stay well.

In 2012 we therefore set ourselves an ambitious four-year goal to support people at risk of developing mental health problems to build strong peer relationships, learn tried and tested psychological coping strategies and make positive changes to their lives.

Thanks to funding from the Department of Health, our Building a Healthy Future programme has been a key part of this work. We know from our research that people with long-term physical conditions are the most frequent users of health care services and commonly experience mental health problems such as depression and anxiety. As a result, the quality of life they experience and their overall health can deteriorate rapidly.

By bringing together the support of local Minds with social networks and specialist partners such as British Heart Foundation, Diabetes UK and Arthritis Research UK we set out to address this challenge.

Thanks to Leeds Beckett University and Mind's Research and Evaluation team, we've measured the success, economic and social impact of this work to support people with arthritis, diabetes and heart disease.

The evidence shows that most people participating in the programme were more resilient and felt more confident in managing their long-term condition as a result of this Mind delivered programme.

We still have work to do. People with long-term conditions continue to face significant challenges in relation to their mental health.

Mind is committed to working in partnership so that we are able to build on the success of this initial work to reach and support many more people living with long-term conditions towards a healthy future.

A handwritten signature in black ink that reads "Paul Farmer". The signature is written in a cursive, flowing style.

Paul Farmer
Chief Executive, Mind

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Executive summary

Project summary

At Mind, we define resilience as an individual's ability to deal with and adapt to challenging circumstances, and stay mentally well. We've identified three elements we believe lie at the heart of resilience: wellbeing, social connections and having ways to cope with difficult events.

It is well established that people with long-term physical health conditions (LTC) are at greater risk of developing mental health problems than the general population. Building on its work to increase the resilience of other at risk groups, Mind has developed a six-week course that aims to improve the wellbeing, resilience, and confidence to self-manage of people with heart conditions, diabetes, and arthritis.

Funded by the Department of Health's Innovation, Excellence and Strategic Development fund (IESD), a pilot of the programme was delivered in two locations – Birmingham and Manchester – between September 2014 and March 2016. 248 participants completed all six sessions of the course and a further 220 attended at least one session but did not complete the whole course. Manchester Mind recruited almost double the number of participants of Birmingham Mind (340 and 128 respectively). However, a lower proportion of participants completed the course in Manchester (46%) than in Birmingham (72%).

Evaluation

Leeds Beckett University conducted an independent impact evaluation of this pilot programme ('impact evaluation'). They sought to identify changes in the perceived resilience of service users, examining how the programme processes work for participants, under what circumstances, for which particular groups (taking account of condition, gender, and age); and exploring issues concerning the sustainability of the resilience programme.

In order to supplement Leeds Beckett's evaluation, Mind's Research and Evaluation team conducted a formative economic evaluation of the programme ('economic evaluation'). They modelled the potential health and non-health cost savings of the intervention, using case studies and outcomes data collected as part of the impact evaluation. They also began to identify enabling factors and barriers that affect the economic impact of the intervention.

This report presents their integrated findings. Detailed findings and recommendations from each of the two research projects are presented in the appendices.

Methodology

Leeds Beckett University's impact evaluation involved mixed quantitative and qualitative methods:

- A before and after questionnaire survey was administered (on three occasions, including three-month follow-up) to all participants on both projects. The resilience measurement questionnaire consisted of three scales concerning wellbeing, social efficacy (problem-solving/achieving goals) and social networks; and further related items about managing a LTC.
- Semi-structured interviews were held during project visits with 24 participants between 12 and 15 months into the intervention. The sample was purposive, to include female and male participants, and those with the main conditions represented on the courses. 18 female participants were interviewed, and six male participants. 13 participants had type 2 diabetes, one had a heart condition and type 2 diabetes, two had heart conditions, six had arthritis, one had arthritis and type 2 diabetes, and one had arthritis with type 2 diabetes and a heart condition. 11 Interviews were held with stakeholders. Eight

participants kept an anonymous brief narrative record of their progress in the three months following the course.

The quantitative data was analysed using the statistical software package SPSS. Three sets of analyses were conducted for Manchester Mind and Birmingham Mind separately and then for both areas combined:

- the first assessed change between baseline and the end of the course (post-stage) only
- the second assessed change between baseline and follow-up (three-month follow-up)
- a repeated measures analysis was then conducted to provide a comparison of change over the three time points. (Baseline, post course and three-month follow-up).

The qualitative interview data was analysed thematically using NVivo software. The evaluation team synthesised results from the different components of data analysis to inform conclusions and recommendations.

The economic evaluation involved three strands:

- an initial review of published and grey literature on the impact of co-morbid physical and mental health problems
- identifying the resources required to deliver each element of the programme
- conducting 16 semi-structured interviews with a diverse sample of project participants.

Mind's Research and Evaluation team used these data to develop case studies to understand the potential economic impact of the programme.

Findings

- Overall, course participants in both Birmingham Mind and Manchester Mind were found to have medium to large improvements for the four outcomes: wellbeing, problem solving and achieving goals, social support, and the management of LTC.
- All improvements were maintained at the three-month follow-up period.
- Significant improvements were found for both males and females and individuals with diabetes and arthritis.

- Most participants on the programme recorded an improvement in scores.
- Baseline to end combined scores across both programmes showed a statistically significant improvement over this period for all four outcomes and the 'overall combined score'.

Interviews

Responding to challenges of high recruitment targets and unclear boundaries, the two programmes approached recruitment in different (medical and community-based) ways. Participants benefited from the opportunity to meet with other people with similar experiences around various LTC and strongly valued the peer support that they received. The skilled facilitation, and experiences in peer groups established a safe space, in which participants could receive support and explore coping skills in a comfort zone which might be extended as the programme progresses. Potentially life-changing impacts were reported by participants.

However, a number of issues were also identified. Firstly, the lack of clarity about boundaries for referral and recruitment led to very distinct client groups emerging. Secondly, in the early stages of the programme, coordinators were effectively lone-working on a project that placed great demands on them. Thirdly, peer support among course participants was very highly valued, but there was little preparation for participants to become peer supporters with expertise after the programme. Fourthly, the language of everyday experience was effective in engaging participants, but the specific term 'resilience' had not been explored by the end of the course. Fifth, it is not clear that the course as designed would be consistently beneficial or suitable for people across an uncontrolled diverse range of conditions and of severity around mental health. Sixth, despite impressive participant recruitment numbers, there was high participant dropout. Finally, uneven engagement from different community groups requires further thought about diversity.

Economic evaluation

The economic evaluation indicates that the Building a Healthy Future programme has a positive economic impact, in addition to the positive effect on individual's wellbeing and resilience. However, the majority of the savings produced are non-cashable (i.e. avoided costs/prevention).

Our case studies suggest that the intervention could produce overall savings between £718.07 and £20,632.07 per participant per year (PPPY). However, most of these savings are non-cashable and distributed across a range of funders, commissioners, and service providers. The largest savings were produced by new employment and job retention.

The intervention appears to have a positive impact on the mental health of participants. The high costs and poor individual outcomes associated with co-morbid physical and mental health problems mean that this intervention may produce considerable non-cashable savings if it can help to prevent the development of mental health problems in the longer term. However, the intervention leads to little change in health service use in the short to medium term.

Benefits are not evenly distributed across different groups of service users. People who are already confident in self-managing their condition

may still receive positive mental health benefits from the course. However, the economic impact of their participation will be significantly lower than their peers. The majority of service users were not in work but participants who were supported to gain or retain their employment through the course had significantly higher economic impact. There are some indications that the intervention could lead to large cost savings for service users with higher levels of mental health need. The continued support provided by regular follow-up sessions appears to improve the sustainability of participants' improved outcomes. This service, particularly if predominantly peer-led, does not require large investment and it appears to offer very good value for money.

Based on the data collected through case study interviews, we have assumed that the reported positive effects on individual outcomes are maintained for 12 months and calculated savings for primary and secondary mental health services accordingly. However, this research only monitored outcomes for three months and so these assumptions should be tested with further research. More systematic collection of service use data and long-term monitoring of participant outcomes is required to make more confident conclusions about the impact and value of the intervention.

It has allowed me to look forward and really plan what I want for my future and not to feel as if I'm limited because of my health.



Key recommendations

Based on the integrated findings of the impact and economic evaluations, the authors make a number of key recommendations:

Impact

- The intervention has been shown to have significantly positive effects on participants' outcomes. It also provides good value for money. With minor revisions, this intervention could have a very positive effect if rolled out more broadly.
- Further development work is required to refine the targeting of the intervention for group(s) or participant characteristics who will benefit most from the intervention. This report provides detailed analysis of the impact of the course on a range of participants – including diverse mental health needs and severity of LTC.
- More careful screening of potential participants in the intervention would provide value for money because it will improve the appropriateness of referrals and clarify participant expectations. This will have a positive effect on participant retention rates. Improved retention will reduce the cost per participant and also improve participant outcomes.
- Regular follow-up sessions should be offered to all service users and training should be made available to encourage peer leadership of the groups. The continued support provided by these follow-up sessions appears to improve the sustainability of participants' improved outcomes. This service, particularly if peer-led, does not require large investment and it offers very good value for money.

- Gains in resilience have been significantly demonstrated in the short-medium term. Further research is required to assess the strength of longer-term effects and develop more comprehensive economic models. There is currently little research into the long-term effects of resilience interventions and the impact of changes in resilience-related outcome measures in the short-medium term on the longer-term prevalence of poor mental health. Systematic collection of service use data would also strengthen the economic modelling. These areas should be a high priority for future research.

Process

- Future programme delivery should extend the resources and time available for programme set-up and partnership building. It should also provide increased resources for programme co-ordination and delivery.
- Recruitment targets need to be moderated for future programme delivery. These should be segmented into priority areas for example, date of diagnosis, gender, mental health experience/diagnosis, ethnicity etc.
- Many of the strengths of Mind's service delivery are based on distinctive local Minds and their initiative, enterprise, and community knowledge. For a nationally funded project, more planning is required to bring national strategic design and local initiatives into closer alignment.
- Future programme development should be based on clearer links between goals, the boundaries for participant inclusion, and evidence requirements. This will improve programme planning, project management, and consistency of delivery.

Introduction

There may be times or situations in our lives that are more difficult than others. The capacity to stay mentally well during those times is what we call 'resilience'.

Resilience is a key part of Mind's strategy, focusing on supporting people who are at risk of developing mental health problems, to stay well.

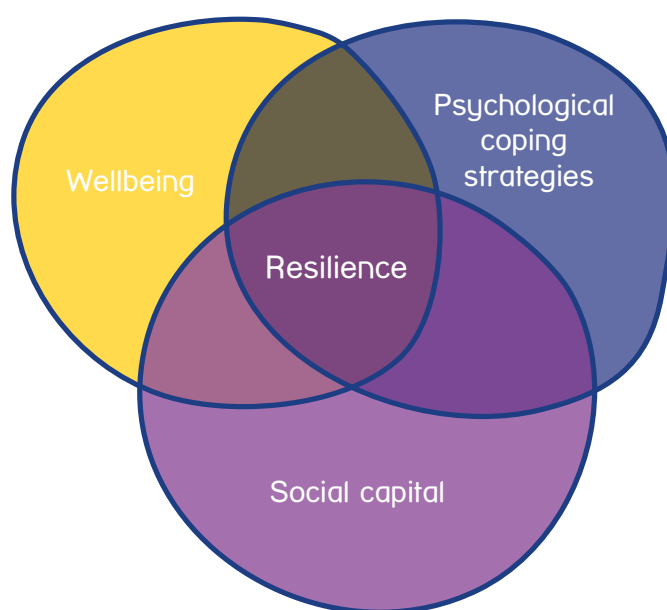
At Mind, we define resilience as an individual's ability to deal with and adapt to challenging circumstances. Resilience is not simply a person's ability to 'bounce back', but their capacity to adapt in the face of challenging circumstances, whilst maintaining a stable mental wellbeing. We believe that resilience is something that can be learned and taught, rather than being something you are either born with or without.

The three parts of resilience

Mind's approach to resilience identifies three key elements, which we believe lie at the heart of staying mentally well: wellbeing, social connections and having ways to cope with difficult events. Our work on resilience is based on helping people to develop all three elements:

- **Wellbeing:** mental wellbeing describes our mental state – how we are feeling and how well we can cope with day-to-day life. Our emotional wellbeing can change, from day-to-day, month-to-month or year-to-year.
- **Social connections:** connecting with other people isn't always easy and many of us can sometimes feel isolated or struggle with relationships. We aim to tackle loneliness and increase resilience by supporting projects that bring isolated individuals and people with similar experiences, together.
- **Ways to cope:** there is growing evidence that psychological treatments, including cognitive behavioural therapy (CBT), can play a key role in preventing, as well as treating, mental health

problems. This part of our work engages with people who are well, and especially with those who we've identified as being at higher risk of developing mental health problems.



What are we doing?

Mind have piloted a number of resilience programmes supporting people to develop these three elements and stay well. Mind's initial scoping report identified people with long-term physical conditions (LTC) as one of the key 'at risk' groups; from this the Building a Healthy Future programme was developed.


Building a Healthy Future is delivered in six week courses and covers a range of CBT and mindfulness techniques. These tools and skills help people to better cope with the stresses, strains and emotions of living with physical conditions, and become more resilient to developing mental health problems.

The programme was delivered by Birmingham Mind and Manchester Mind, who have lots of

experience and success in the delivery of community-based programmes and peer support.

The course was developed by Oxfordshire Mind, who originally delivered it to support people with mental health problems. Working with

Birmingham Mind, Manchester Mind, Arthritis Research UK, British Heart Foundation and Diabetes UK, the course was adapted to focus on building resilience.



I was a little apprehensive about joining the course. Even after the first session I was thinking I wasn't really sure if I was going to benefit from this. But certainly from the second session onwards, it did really trigger something in me. It actually led me to change quite a lot of things in my life straight away.

Methodology

Impact evaluation

Leeds Beckett University's research design included mixed quantitative and qualitative methods to address the evaluation aims:

- A before and after questionnaire survey was administered (on three occasions, including three-month follow-up) to all participants on both projects which aimed to work with a targeted number of 560 people.
- 11 Interviews with nine stakeholders in total (two repeat interviews), at two stages, across the projects, during the course of the programme. These interviews were conducted by telephone.
- Semi-structured interviews during project visits with 24 participants between 12 and 15 months in programme delivery. Members of the evaluation team visited both projects on four occasions each to conduct interviews. The sample was purposive, in order to include female and male participants, and to include those with the main LTC represented on the courses. 18 female participants were interviewed, and six male participants. 13 participants had type 2 diabetes, one had a heart condition and type 2 diabetes, two had heart conditions, six had arthritis, one had arthritis and type 2 diabetes, and one had arthritis with type 2 diabetes and a heart condition.

Prior to collecting data, project leads overseeing data collection were briefed thoroughly about the purpose of questions, and sampling, reiterating guidance about ethics and consistency of approach.

When commissioning the impact evaluation, Mind proposed using three scales to cover wellbeing, self-efficacy, and social capital. These scales have been used in previous evaluations on Mind's resilience interventions and map onto the Mind resilience approach. The Warwick Edinburgh Mental Wellbeing Scale was included. Through consultation with Mind, some adaptations were

made to the Schwarzer-Jerusalem General Self-Efficacy Scale. Concerning the third area, social support, the Lubben Social Network Scale was deemed not fully fit for purpose. Some bespoke items were constructed, modelled on but not identical to the 'Multidimensional Scale of Perceived Social Support' (Zimet et al., 1988). Further individual items were constructed after consultation between the evaluation team and Mind, to capture changes in confidence to manage LTC.

The draft evaluation tools went out for full consultation to projects and to stakeholders, including Diabetes UK and British Heart Foundation. Amendments were made following their feedback. A further amendment to the questionnaire (demographic section) was made with the inclusion of people with arthritis in programme delivery. This followed consultation with Arthritis Research UK in September 2015. Project leads were coached to administer the questionnaires during a meeting with one of the evaluation team. The questionnaire is shown in Appendix 7.

A case study template (Appendix 8) was sent to eight participants who volunteered to keep an anonymous brief narrative record of their progress in the three months following the course. Four brief case studies were constructed from narratives of eight participants to provide evidence of their progress during and after the course. No further interpretative analysis was conducted on the case studies, which add the voice of people with experience to the report.

Data analysis

All questionnaire responses were numerically entered and analysed using a statistical software package, SPSS. Descriptive analysis of the data was carried out and tests performed to examine the relationships between variables. Results were analysed to examine, among other factors, the role of age and gender and condition.

Three sets of analyses were conducted for Manchester Mind and Birmingham Mind separately, and then for both areas combined:

- the first assessed change between baseline and the end of the course (post-stage) only
- the second assessed change between baseline and follow-up (three-month follow-up)
- a repeated measures analysis was then conducted to provide a comparison of change over the three time points (baseline, post course, and three-month follow-up).

The questionnaire comprised four sections each made up of a series of related statements:

- Section One had seven questions related to wellbeing
- Section Two had eight questions related to how positive participants felt and about solving problems and achieving goals
- Section Three had eight questions related to levels of social support
- Section Four had six questions related to the management of LTC.

Responses to each statement were assigned a value from 1 to 5 (in Sections One and Three) and from 1 to 4 (in Section Two). Section Four comprised three statements with assigned values of 1 to 5, and three other statements, which were scored 1 to 4. For all statements the least positive option scored the lowest and the most positive the highest. For each participant the response scores were added together to give a total for each section. A 'combined overall score' was also calculated by adding together the totals from the four sections.

- The maximum possible score in Section One was 35 and the minimum was 7.
- The maximum possible score in Section Two was 32 and the minimum was 8.
- The maximum possible score in Section Three was 40 and the minimum was 8.
- The maximum possible score in Section Four was 27 and the minimum was 6.
- The maximum possible overall combined score was 134 and the minimum was 28.

95% confidence intervals of the mean change in the scores from baseline to post-stage were calculated. Paired (related samples) t-tests were

also used to assess whether there was a statistically significant difference in the mean scale scores from baseline to end of course stage. Repeated measures ANOVA was used to assess change between baseline, end of course, and three-month follow-up.

A confidence interval provides an indication of the range within which the true effect is likely to be. The width of a confidence interval is affected by the size of the sample, with smaller samples tending to have larger confidence intervals than bigger ones. A confidence interval of a mean difference that does not pass through 0 is indicative of a statistically significant change. For all inferential tests a p-value of 0.05 or less was taken to be statistically significant.

It is important to consider the effect size as well as statistical significance (d). This is presented as the number of standard deviations between two groups (e.g. baseline and post). Cohen suggested that $d=0.2$ represents a 'small' effect size, 0.5 represents a 'medium' effect size, and 0.8 a 'large' effect size. Changes of less than 0.2 standard deviations should be considered trivial, even if they are statistically significant. For clarity, the number of responses on which analyses were calculated is provided (n).

Using the formula detailed by Evans et al (1998), the reliable change index (RCI) for change between baseline and post-stage and between baseline and follow-up was calculated. This shows whether a change in an individual's score (e.g. baseline to post) is statistically significant or not (based on how reliable the measure is). It is defined as the change in a service user's score divided by the standard error of the difference for the test being used.

It is worth noting that the formula recommended by Evans et al (1998) is based solely on baseline values, and reliability, but there will be variation in reliability between time points. In this analysis, reliability of the measures was determined using Cronbach's Alpha and the responses of all participants who provided some baseline data (not all of these individuals also provided data at post and/or follow-up).

Semi-structured interviews

Interviews (11 in total) were held by telephone with eight stakeholders (including two repeat

interviews), and in person with one stakeholder, all with particular expertise and involvement in the local projects. Interviews were held with 24 participants (12 in Manchester and 12 in Birmingham). Local Mind coordinators and the research team identified key stakeholders who were involved in the project at the two regions. The stakeholders included: two project coordinators (one repeat interview); one coordinator's line manager; two facilitators who delivered courses and helped with recruitment; one stakeholder from a community organisation who provided venues and assisted with recruitment, one stakeholder from a General Practice (repeat interview) and one from a pharmacy which provided a venue and assisted with recruitment; one national partner stakeholder with an organisation concerning one LTC. Participants were recruited with the assistance of course coordinators.

The interviews with participating individuals were conducted using a semi-structured schedule (Appendix 5). This asked individuals about how they became involved; their experience of the course; what they felt they gained from involvement; their views on the peer support and the coping strategies which they had learned; any thoughts on making sure gains could be maintained; and on improvements for the future of such courses. The interviews with stakeholders explored: expectations for the project; learning about promotion and recruitment; views on how far the course was achieving objectives; factors enabling and constraining success; views on ensuring gains; maintaining gains; and on sustainability.

All interviews were recorded. These were then transcribed and analysed by the research team. The evaluation team conducted thematic analysis of interviews within and across phases, supported by NVivo software. Findings were synthesised from the different components of data analysis to inform conclusions and recommendations.

Ethical considerations

All interview participants received an information sheet detailing the following aspects; what the evaluation was about, why it was being conducted; what would be done with the information; their contribution, the fact that

participation was voluntary and that they could withdraw at any time; confidentiality and anonymity. Consent was taken prior to all interviews. Ethical approval was applied for and attained via the Leeds Beckett University Local Research Ethics Coordinator. All interview participants who attended the course received a £20 high street voucher to thank them for their time.

Economic evaluation

The economic evaluation included a literature review, semi-structured interviews, and modelling cost increases/savings based on case studies and process feedback. The methods used are outlined in more detail below.

Literature review

Due to restrictions on resources, a systematic review of the literature on the management and impact of co-morbid mental and physical health was not undertaken. However, published and grey literature was reviewed to identify existing calculations of the direct and indirect costs of individual physical health conditions, and co-morbid physical and mental health problems (including the combinations with greatest resource burden). The current literature on the prevalence of co-morbid physical and mental health problems was also identified. This information has been used to inform the economic modelling.

In order to provide context to assess the relative performance of the Building a Healthy Future programme, literature was also identified that assesses the effectiveness of existing interventions to address co-morbid physical and mental health problems. Particular effort was made to identify literature that assesses the economic impact of these interventions.

A limited structured search for key terms was undertaken using Google Scholar; reviewing the websites of key government departments, agencies (such as the Big Lottery Fund), and relevant voluntary sector organisations; and also looking at citations in papers that meet the inclusion criteria.

Semi-structured interviews

In order to explore the programme's impact on health and non-health service use, 16 semi-structured interviews were conducted with programme participants (six in Birmingham and 10 in Manchester).

A semi-structured interview approach was chosen because it allowed the research team to probe participants' experience in depth – responding to differences in individuals' responses whilst identifying common themes.

The semi-structured interviews were conducted using a consistent discussion guide that was developed by Mind's research team (Appendix 9). It was designed in consultation with programme staff and in reference to published evaluations of other interventions of this type. The interviews took around an hour. Seven were conducted face-to-face and nine were conducted by telephone.

Interviews were audio recorded (with participants' consent) and professionally verbatim transcribed. One participant declined to have their interview audio recorded and the researcher took handwritten notes. These notes and transcripts were analysed using the framework approach, developed by the National Centre for Social Research (Furber, 2010).

Participant recruitment

Maximum variation sampling was used to ensure the diversity of interview participants. The research team developed a sampling guide to inform participant recruitment. This guide specified age, gender, ethnicity, location, length of time since the course, physical health condition, and mental health status. Participant outcome data was not available at the time of fieldwork to inform the sampling guide.

None of the service users who were interviewed for this economic evaluation had taken part in the qualitative research being conducted by Leeds Beckett University as part of their impact evaluation. However, this was not an exclusion factor.

Participant recruitment was carried out by the two local Minds who delivered the intervention (Birmingham Mind and Manchester Mind). Participation was incentivised with a £20 voucher

and travel expenses were also reimbursed. The local Minds used a standard invitation text and poster developed by the Mind research team. All participants were provided with a participant information sheet and given the opportunity to ask questions prior to the interview.

A diverse range of participants were recruited for the case study interviews:

- 60% of those interviewed were male and 40% were female
- 75% of participants identified as White British and the rest were from a BME background
- 40% of participants were aged 50–59, and 50% were aged over 60. Of the remaining two participants, one was aged 18–24 and the other was aged 40–49
- 70% of participants had type 2 diabetes, 25% had arthritis, 20% had type 1 diabetes, and 10% had heart disease. The percentages do not add up to 100% because over half of participants had multiple physical health issues
- Some of the other health issues experienced included back pain, memory loss, paralysis, prostate cancer, bowel cancer, and asthma.

Case studies

The economic analysis is based on qualitative interviews and case studies because the outcomes tools selected for the impact evaluation cannot be directly converted into economic measures and there has not been any systematic collection of service use data. Therefore, this research design does not provide a comprehensive account of the programme's economic impact.

Seven detailed case studies have been developed to outline participants' experiences of the programme and model its potential economic impact. The case studies represent the experiences of a single service user and have been selected to represent a range of experiences of the programme, different diagnoses, mental health status, location, age, gender, and ethnicity. All 16 interviews were used to analyse the enablers of and barriers to impact.

Research participants were recruited using maximum variation sampling and are not necessarily representative of all those who took

part in the programme. The names of the case studies have been changed and some details (e.g. names of GP surgeries) have been omitted in order to protect the anonymity of the research participants.

Our analysis of the case studies explores emergent themes but not at the exclusion of differences. Understanding the divergence of participants' experiences (and the economic implications of these) will help to inform the future development of interventions and research in this area.

Cost of delivery

The cost of delivering the intervention was calculated using the programme budget for the Building a Healthy Future programme. The project managers in each local Mind were also asked to report how much time they were spending on particular activities (e.g. recruitment, assessments, training delivery, etc.). Costs incurred by service users were calculated using reported experiences from the case study interviews.

Economic modelling

The economic analysis has been conducted from three perspectives. Firstly, a health and social care perspective that takes account of changes in participant outcomes and reported changes in

service use. Secondly, a broader public purse perspective, looking at additional impacts such as welfare benefits. Thirdly, a societal perspective was adopted, including the costs of lost productivity due to time out of work (or other normal role) for both the participant and any family members who provide unpaid care or support. The analysis looks at both cashable savings (reduced/more efficient use of services and other resources) and non-cashable (prevention/avoided costs) savings.

Costs of services have been estimated from the quantities of each type of resource used multiplied by unit costs. Unit costs of resources have been taken from the PSSRU annual Unit Costs of Health and Social Care volume (Curtis and Burns, 2015). All costs and savings have been standardised to a single price year. The total cost of delivering the intervention has been used to calculate the average cost per participant.

The economic impact of quality of life improvements (QALYs) have not been calculated for the impacts of this intervention due to the lack of directly convertible outcomes data (e.g. EQ5D). This is likely to lead to a considerable underestimate of the full impact of the intervention. However, a more conservative approach has been adopted in the absence of further outcomes data. The inclusion of these economically quantifiable outcome measures is a key recommendation for future research in this area.

Literature review

There have been a number of excellent reviews of the literature relating to co-morbid physical and mental health. In particular, this review section draws heavily on Molosankwe et al. (2012), Naylor et al. (2012), and Knapp et al. (2011).

Prevalence of co-morbid physical and mental health problems

More than 15 million people in England – 30% of the population – have one or more LTC (Department of Health, 2011). Those experiencing long-term physical health conditions – the most frequent users of health care services – also commonly experience mental health problems such as depression and anxiety.

Data from the World Health Surveys indicate that people with two or more LTC are seven times more likely to have depression than people without a long-term condition (Moussavi et al., 2007). NICE has estimated that 20% of individuals with a chronic physical problem are likely to have depression (NICE, 2009).

This risk spans across physical health diagnoses. People with diabetes are more likely to experience depression compared to those without – there is a 24% increased risk of depression in people with type 2 diabetes (Nouwen et al., 2010). Depression is two to three times more common in a range of cardiovascular diseases (Fenton and Stover 2006). Up to 33% of women and more than 20% of men with all types of arthritis may have co-morbid depression (Theis et al., 2007). There is some evidence that the diagnosis of co-morbid mental health problems is also higher among women (Thomas et al., 2003; Vamos et al., 2009; Theis et al., 2007).

Co-morbid physical and mental health problems present significant social challenges, as well as

health impacts. People experiencing LTC and co-morbid mental health problems disproportionately live in deprived areas and have access to fewer resources. The interaction between co-morbidities and deprivation is a significant factor in generating and maintaining inequalities (Naylor et al., 2012).

Impact of mental health on physical health

In those with LTC, mental health problems can exacerbate illnesses and inhibit rehabilitation and recovery (Arthritis Research UK, 2012). Cardiovascular patients with depression experience 50% more acute incidents per year (Whooley et al., 2008) and have higher mortality rates (Katon, 2003). Co-morbid depression increases the risk of complications and adverse consequences of diabetes, partly due to worse self-management (Lloyd, 2010).

Self-management is at the core of effective treatment for LTC – but this is significantly limited by poor mental health, which can reduce the motivation and energy needed to comply with treatment plans (DiMatteo et al., 2000). Co-morbidity has a particularly negative impact on self-care practices, such as maintenance of diet, regular physical activity, and use of medications (Ismail et al., 2004). In the UK, compared to people with diabetes alone, individuals with co-morbid depression and diabetes are four times more likely to have difficulties in self-managing their health (Das Munshi et al., 2007).

Cost of co-morbid physical and mental health conditions

Between 12% and 18% 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 (Naylor et al., 2012). Poor mental health increases the average cost of NHS service use by each person with a LTC from approximately £3,910 to £5,670 a year (Naylor et al., 2012).

Nearly all co-morbid physical and mental health problems are associated with significantly higher healthcare costs (Welch et al., 2009). 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 (Naylor et al., 2012). This is higher for some conditions – particularly diabetes where self-management is vital. Healthcare costs for those experiencing depression and diabetes are almost double those with diabetes alone (Simon et al., 2007).

Co-morbid physical and mental health problems have large effects on individual health and wellbeing but they also have a substantial impact on the wider economy (Egede, 2007). Productivity is lower due to reduced work performance, increased absenteeism, and early retirement from the labour force (Von Korff et al., 2005). In the UK, compared to people with diabetes alone, individuals with co-morbid depression and diabetes are seven times more likely to have days off work (Das Munshi et al., 2007). Co-morbidity also hampers the ability to do household tasks or voluntary work, all of which contribute to economic output. Relatives may also need to cut back on paid and unpaid activities to provide informal care (Jonkers et al., 2009).

Existing interventions

There is very little research that examines the effectiveness of interventions to build resilience and reduce mental health problems for people with LTC. Most literature focuses on models of integrated care for treating existing co-morbidity

(e.g. King et al., 2011; Williams et al., 2004; Unutzer et al., 2002; Chiles et al., 1999). Most of the literature is significantly limited by a focus on costs from a health system perspective alone (Molosankwe et al., 2012). This ignores wider economic costs, such as the effect on employment and workplace productivity (Centre for Mental Health, 2010), or the substantial costs of informal care from family members and others (McCrone et al., 2008).

Care for people with LTC could be improved by better integrating mental health support with primary care (Naylor et al., 2012). People with co-morbid mental health problems can gain particularly large benefits from inclusion in self-management support programmes (Harrison et al 2011). Importantly, treating a mental health problem by itself does not always translate into improved physical symptoms or lower mortality from physical illness (Cimpean and Drake, 2011).

A meta-analysis found that psychological interventions in hospitals reduced length of stay by 2.5 days and overall health care costs per patient by about 20 per cent (Chiles et al., 1999). However, these forms of interventions are still not common. For example, 42% of cardiac patients are currently provided with rehabilitation, and only 16% of these programmes have a psychological component, despite 31% of patients experiencing significant anxiety problems and 19% experiencing depression (British Heart Foundation 2011).

Achieving meaningful impact can be hard due to the complexity of co-morbid physical and mental health problems. Jonkers et al. (2009) studied a low-level psychological intervention for people with LTC. Participants received a combination of home-based cognitive behavioural therapy and self-management therapy, in addition to usual care for three months. Patient diaries captured costs beyond the health care system, such as informal care, domestic help and work absenteeism. No significant improvements in mental health or costs were reported.

Impact evaluation

This section presents the results for the two projects combined. Further detail on data analysis (e.g. breakdown by gender) is presented in Appendix 4.

Baseline to end of course

Table 1 presents the average change in scores from baseline to post-stage. It can be seen that there was a statistically significant improvement

over this period for all sections and ‘overall combined score’. The size of the improvement was large for ‘wellbeing’, ‘problem solving/ achieving goals’ and ‘overall combined score’ ($d \geq 0.8$). Improvements were medium sized for ‘management of long-term conditions’ and ‘social support’ ($d = 0.7$).

Table 2 shows the number of programme participants who had increases, decreases,

Table 1: Mean scores from baseline to post-stage

	Mean score at baseline (SD)	Mean score at post-stage (SD)	Mean change (SD)	95% confidence interval	Statistically significant change	
Wellbeing (n=160)	21.03 (4.76)	24.74 (3.80)	3.71 (4.56)	3.0-4.430	✓	t=10.32, df=159, p<0.001
Problem solving and achieving goals (n=153)	19.09 (5.10)	22.88 (4.87)	3.79 (4.95)	3.0-4.582	✓	t=9.47, df=152, p<0.001
Social support (n=157)	26.52 (6.51)	29.78 (5.97)	3.26 (5.44)	2.404-4.118	✓	t=7.52, df=156, p<0.001
Management of long-term conditions (n=155)	16.39 (4.19)	19.44 (4.10)	3.05 (4.30)	2.359-3.734	✓	t=8.84, df=154, p<0.001
Overall combined score (n=126)	83.01 (16.80)	97.60 (16.02)	14.59 (14.97)	11.955-17.236	✓	t=10.94, df=125, p<0.001

Table 2: Number of participants with increases, decreases, or no change in scores baseline to post

	Number of clients with an improved rating at post	Number of clients with no change in rating at post	Number of clients with a lower rating at post
Wellbeing (n=160)	120/160	15/160	25/160
Problem solving and achieving goals (n=153)	114/153	8/153	31/153
Social support (n=157)	112/157	16/157	29/157
Management of long-term conditions (n=155)	118/155	13/155	24/155
Overall combined score (n=126)	108/126	1/126	17/126

or no change in scores baseline to post. Three quarters had higher scores at post-stage than at baseline for 'wellbeing' (75%), 'problem solving/achieving goals' (75%) and 'management of long-term conditions' (75%). In addition, 71% had higher post-stage score for 'social support' and 86% had a higher 'overall combined score'.

Using the formula detailed by Evans et al (1998), the reliable change index (RCI) for change between baseline and post-stage and between baseline and follow-up was calculated. This shows whether a change in an individual's score (e.g. baseline to post) is statistically significant or not (based on how reliable the measure is). It is defined as the change in a service user's score divided by the standard error of the difference for the test being used.

It is worth noting that the formula recommended by Evans et al (1998) is based solely on baseline values, and reliability, but there will be variation in reliability between time points. In this analysis, reliability of the measures was determined using Cronbach's Alpha and the responses of all participants who provided some baseline data (not all of these individuals also provided data at post and/or follow-up).

Tables 3 and 4 present the proportion of service users who reliably improved/deteriorated between baseline and post. They show that a high proportion of service users reliably improved as a result of the intervention and only a small proportion reliably deteriorated. The smallest proportion of service users reliably improved on the social support scale.

Table 3: Proportion of clients with 'reliable' improvement from baseline to post-stage

	Clients with some improvement	Clients with reliable improvement	Proportion of all LTC clients with reliable improvement
Wellbeing (n=160)	120	64/120 (53%)	64/160 (40%)
Problem solving and achieving goals (n=153)	114	70/114 (61%)	70/153 (46%)
Social support (n=155)	112	34/112 (30%)	34/155 (22%)
Management of long-term conditions (n=155)	118	46/118 (39%)	46/155 (30%)
Overall combined score (n=126)	108	73/108 (68%)	73/126 (58%)

Table 4: Proportion of clients with 'reliable' deterioration from baseline to post-stage

	Clients with some deterioration	Clients with reliable deterioration	Proportion of all LTC participants with reliable deterioration
Wellbeing (n=160)	25	5/25 (20%)	5/160 (3%)
Problem solving and achieving goals (n=153)	31	3/31 (10%)	3/153 (2%)
Social support (n=155)	29	4/29 (14%)	4/155 (3%)
Management of long-term conditions (n=126)	24	8/24 (33%)	8/126 (6%)
Overall combined score (n=126)	17	4/17 (24%)	4/126 (3%)

Baseline to three-month follow-up

Table 5 shows the average change in scores from baseline to three-month follow-up. There was statistically significant improvement for all four sections and the 'overall combined score'. Large improvements were identified for 'problem solving/achieving goals'; 'management of long-term conditions' and 'overall combined score' ($d > 0.8$). Improvements for 'wellbeing' and 'social support' were medium sized ($d = 0.7$).

Improvement in 'social support' was found in two thirds of individuals (67%) and three quarters had higher scores at follow-up than at baseline for 'wellbeing' (74%) and 'problem solving/achieving goals' (76%). A larger proportion (80%) showed improvement for 'management of long-term conditions' and a similar proportion (81%) had a higher 'overall combined score' (see Table 5).

Table 5: Mean scores from baseline to three-month follow-up

	Mean score at baseline (SD)	Mean score at post-stage (SD)	Mean change (SD)	95% confidence interval	Statistically significant change	
Wellbeing (n=92)	21.85 (5.27)	25.37 (5.48)	3.52 (5.77)	2.328-4.716	✓	t=5.85 df=91 p<0.001
Problem solving and achieving goals (n=89)	19.63 (5.63)	24.13 (5.85)	4.50 (5.78)	3.288-5.722	✓	t=7.36 df=88 p<0.001
Social support (n=91)	26.98 (6.29)	30.71 (6.46)	3.73 (5.37)	2.617-4.856	✓	t=6.63 df=90 p<0.001
Management of long-term conditions (n=86)	17.01 (4.35)	20.71 (4.48)	3.70 (3.90)	2.850-4.534	✓	t=8.78 df=85 p<0.001
Overall combined score (n=69)	84.82 (18.51)	101.32 (18.82)	16.50 (16.36)	12.578-20.437	✓	t=8.38 df=68 p<0.001

Table 6: Number of participants with increases, decreases, or no change in scores baseline to three-month follow-up

	Number of clients with an improved score at follow-up	Number of clients with no change in score at follow-up	Number of clients with a lower score at follow-up
Wellbeing (n=92)	68/92	3/92	21/92
Problem solving and achieving goals (n=89)	68/89	3/89	18/89
Social support (n=91)	62/91	9/91	20/91
Management of long-term conditions (n=86)	69/86	5/86	12/86
Overall combined score (n=69)	56/69	2/69	11/69

Tables 7 and 8 present the proportion of service users who reliably improved/deteriorated between baseline and follow-up. They show that a high proportion of service users reliably

retained improvements as a result of the intervention and only a small proportion reliably deteriorated over time.

Table 7: Proportion of clients with ‘reliable’ improvement from baseline to follow-up stage

	Clients with some improvement	Clients with reliable improvement	Proportion of all LTC participants with reliable improvement
Wellbeing (n=92)	68	33/68 (49%)	33/92 (36%)
Problem solving and achieving goals (n=89)	68	49/60 (82%)	49/89 (55%)
Social support (n=91)	62	25/62 (40%)	25/91 (27%)
Management of long-term conditions (n=86)	69	37/69 (54%)	37/86 (43%)
Overall combined score (n=69)	56	46/56 (82%)	46/69 (67%)

Table 8: Proportion of clients with ‘reliable’ deterioration from baseline to follow-up stage

	Clients with some deterioration	Clients with reliable deterioration	Proportion of all LTC participants with reliable deterioration
Wellbeing (n=92)	21	4/21 (19%)	4/92 (4%)
Problem solving and achieving goals (n=89)	18	7/18 (39%)	7/89 (8%)
Social support (n=91)	20	1/20 (5%)	1/91 (1%)
Management of long-term conditions (n=86)	12	2/12 (17%)	2/86 (2%)
Overall combined score (n=69)	11	2/11 (18%)	2/69 (3%)

Analysis by gender

When comparing change from baseline to post-stage and baseline to follow-up stage for males and females separately, a statistically significant improvement was found in all four sections and ‘overall combined score’ for both sexes. Further analysis revealed there was no significant difference in the mean levels of change between males and females for any score at baseline to post-stage or baseline to three-month follow-up stage (see Tables 22–25 in Appendix 4 for full results).

Analysis by health condition

Separate analyses were conducted to examine change in individuals with a) diabetes (type 1 or type 2) and b) arthritis (inflammatory and/or osteoarthritis). Change in individuals with diabetes was assessed at both baseline to post-stage and baseline to three-month follow-up stage. Owing to the small number of people with arthritis completing the three-month follow-up questionnaire (due to their late inclusion in the programme), assessment of change for this condition was conducted for baseline to post-stage only. The sample size was too small to include individuals with heart disease.

Diabetes

Table 9 shows mean change in scores for individuals with diabetes at baseline to post-stage and baseline to follow-up stage. It can be seen that there was statistically significant improvement for all scores at both stages.

Arthritis

Table 10, at the bottom of the page, shows the mean change in scores for individuals with arthritis at baseline to post-stage. Once again it can be seen that there was statistically significant improvement in all scores.

Table 9: Mean change in scores for individuals with diabetes from baseline to post-stage and baseline to three-month follow-up

	Individuals with diabetes baseline-post		Individuals with diabetes Baseline-3m follow-up	
	Mean change in score baseline-post	Statistically significant change	Mean change in score baseline-3m follow-up	Statistically significant change
Wellbeing	4.03 (SD=4.38) (n=80)	✓ P<0.001	3.54 (SD=5.68) (n=56)	✓ P<0.001
Problem solving and achieving goals	4 (SD=4.19) n=72)	✓ P<0.001	4.98 (SD=5.87) (n=53)	✓ P<0.001
Social support	3.62 (SD=5.77) (n=79)	✓ P<0.001	4.09 (SD=5.69) (n=56)	✓ P<0.001
Management of long-term conditions	3.44 (SD=4.06) (n=79)	✓ P<0.001	4.33 (SD=3.22) (n=51)	✓ P<0.001
Overall combined score	16.13 (SD=14.15) (n=61)	✓ P<0.001	17.57 (SD=15.68) (n=42)	✓ P<0.001

Table 10: Mean change in scores for individuals with arthritis from baseline to post-stage

	Individuals with arthritis	
	Mean change in score baseline-post	Statistically significant change
Wellbeing (n=30)	3.70 (SD=3.73)	✓ P=<0.001
Problem solving and achieving goals (n=31)	4.68 (SD=4.22)	✓ P=<0.001
Social support (n=32)	3.19 (SD=3.91)	✓ P=<0.001
Management of long-term conditions (n=28)	2.36 (SD=3.79)	✓ P=0.003
Overall combined score (n=25)	13.04 (SD=10.86)	✓ P=<0.001

Repeated measures analysis

When the same data are collected from the same individuals at three or more time points, it is often more appropriate to examine change in a single analysis. In this case, complete data from baseline, post-stage, and three-month follow-up were only available for a small number of participants in each site. This increases the likelihood that the analyses would be underpowered to detect a difference. For this reason the primary analysis focused on examining changes from baseline to post-stage and baseline to follow-up separately. However, a comparison of change over the three time points for participants in both sites combined was conducted and the results provided below.

There was a significant improvement in scores over the three time points for:

- ‘Wellbeing’ ($F=28.16$, $df=1.75$, $p<0.001$)
- ‘Problem solving and achieving goals’ ($F=31.73$, $df=1.81$, $p<0.001$)
- ‘Social support’ ($F=21.56$, $df=2$, $p<0.001$)
- ‘Management of long-term condition’ ($F=35.96$, $df=2$, $P<0.001$)
- ‘Overall combined scores’ ($F=35.13$, $df=2$, $p<0.001$).

Wellbeing (n=74)

Post hoc tests revealed scores at both post-stage and three-month follow-up were significantly higher than at baseline (baseline vs. post-stage, mean improvement = 3.84, $p<0.001$; and baseline versus three-month follow-up, mean improvement = 3.54, $p=0.001$). There was no significant change between post-stage and three-month follow-up ($p=0.513$).

Problem solving and achieving goals (n=70)

Scores at both post-stage and three-month follow-up were significantly higher than at baseline (baseline vs. post-stage, mean improvement = 3.74, $p<0.001$; and baseline versus three-month follow-up, mean improvement = 4.53, $p<0.001$). There was no significant change between post-stage and three-month follow-up ($p=0.53$).

Social support (n=74)

Scores at both post-stage and three-month follow-up were significantly higher than at baseline (baseline vs. post-stage, mean improvement = 3.59, $p<0.001$; baseline versus three-month follow-up, mean improvement = 3.73, $p<0.001$). There was no significant change between post-stage and three-month follow-up ($p=1.0$).

Management of long-term condition (n=73)

Scores at both post-stage and three-month follow-up were significantly higher than at baseline (baseline vs. post-stage, mean improvement = 3.10, $p<0.001$; and baseline versus three-month follow-up, mean improvement = 3.59 $p<0.001$). There was no significant change between post-stage and three-month follow-up ($p=0.64$).

Overall combined score (n=53)

Scores at both post-stage and three-month follow-up were significantly higher than at baseline (baseline vs. post-stage, mean improvement = 15.08, $p<0.001$; and baseline versus three-month follow-up, mean improvement = 16.45 $p<0.001$). There was no significant change between post-stage and three-month follow-up ($p=1.0$).

Wellbeing outcomes

The previous analysis has concentrated on the significance and effect sizes of changes in outcomes. However, it is also important to meaningfully interpret these findings to understand what they represent in terms of service user experiences. It is possible to analyse changes in wellbeing to investigate whether they represent shifts from ‘poor’ to ‘good’ wellbeing and how the average service user wellbeing scores compare to population averages at baseline, post, and three-months.

Taggart & Steward-Brown (2016) emphasise that the WEMWBS scale was not developed in order to categorise individuals according to wellbeing. It was suggested that, if it is necessary to present data on wellbeing in a categorical way, the best approach is to group individuals on the basis of standard deviation from the mean. Consistent with the approach recommended by Taggart & Steward-Brown, participants in this study were divided into three groups based on their wellbeing score at baseline:

1. those with relatively “poor mental wellbeing” (Wellbeing score of more than 1 standard deviation below the mean)
2. those with “average” mental wellbeing (Wellbeing scores within 1 standard deviation of the mean)
3. those with relatively “good mental wellbeing” (Wellbeing score of more than 1 standard deviation above the mean).

Analyses were then performed to examine change in each of the three wellbeing groups between baseline to post-stage, and baseline to

follow-up stage for all participants combined, and the results are shown in Tables 11 and 12.

Table 11: Change in scores from baseline to post-stage, by wellbeing of participants at baseline

Baseline	Poor mental wellbeing		Average mental wellbeing		Good mental wellbeing	
	Mean change in score baseline-post	Statistically significant change	Mean change in score baseline-post	Statistically significant change	Mean change in score baseline-post	Statistically significant change
Wellbeing	8.89 (SD=4.27) (n=27)	✓ p=<0.001	3.17 (SD=3.74) (n=117)	✓ p=<0.001	-1.0 (2.53) (n=16)	✗ p=0.14
Problem solving and achieving goals	5.74 (SD=5.33) (n=23)	✓ p=<0.001	3.95 (SD=4.86) (n=110)	✓ p=<0.001	-0.025 (SD=2.86) (n=16)	✗ p=0.73
Social support	5.6 (SD=6.38) (n=25)	✓ p=<0.001	3.23 (SD=5.08) (n=112)	✓ p=<0.001	1.13 (SD=5.25) (n=16)	✗ p=0.41
Management of long-term conditions	5.33 (SD=4.62) (n=24)	✓ p=<0.001	3.01 (SD=4.14) (n=112)	✓ p=<0.001	0.92 (SD=3.04) (n=13)	✗ p=0.30
Overall combined score	26.35 (SD=16.56) (n=20)	✓ p=<0.001	13.47 (SD=13.89) (n=94)	✓ p=<0.001	3.83 (SD=7.36) (n=12)	✗ p=0.99

Table 12: Change in scores from baseline to follow-up stage, by wellbeing of participants at baseline

Baseline	Poor mental wellbeing		Average mental wellbeing		Good mental wellbeing	
	Mean change in score baseline-follow-up	Statistically significant change	Mean change in score baseline-follow-up	Statistically significant change	Mean change in score baseline-follow-up	Statistically significant change
Wellbeing	7.77 (SD=8.20) (n=13)	✓ p=0.005	3.49 (SD=4.70) (n=67)	✓ p=<0.001	-0.92 (SD=5.14) (n=12)	✗ p=0.55
Problem solving and achieving goals	6.62 (SD=7.23) (n=13)	✓ p=0.006	4.95 (SD=5.58) (n=62)	✓ p=<0.001	0.42 (SD=3.29) (n=12)	✗ p=0.67
Social support	5.75 (SD=8.31) (n=12)	✓ p=0.035	3.68 (SD=4.98) (n=65)	✓ p=<0.001	2.50 (SD=3.92) (n=12)	✗ p=0.05
Management of long-term conditions	4.58 (SD=7.76) (n=12)	✓ p=0.007	4.12 (SD=3.50) (n=60)	✓ p=<0.001	0.90 (SD=2.28) (n=10)	✗ p=0.244
Overall combined score	27.75 (SD=23.55) (n=8)	✓ p=0.013	17.12 (SD=14.95) (n=51)	✓ p=<0.001	4.40 (SD=8.41) (n=10)	✗ p=0.13

These analyses raise a number of issues and interpretation of the results should be done with a high degree of caution, and especially in relation to change in wellbeing score. Clearly, those who score low for wellbeing at baseline have greater scope for improvement than those who score highly. Furthermore, the statistical phenomenon of regression to the mean may influence the results. Those who score low at baseline (lower than 1 SD) are not likely to be exactly the same individuals who will score low at post-stage. If just a few score higher at post-stage, (e.g. within 1 SD), the group mean will move closer to the overall post-stage population mean than to the baseline value.

Data on wellbeing were collected using SWEMWBS, a shortened version of WEMWBS, which relates more to functioning than to feeling. Taggart & Steward-Brown (2016) reported SWEMWBS population norms for adults collected from the Health Survey for England (2011). To allow comparison with these reported population norms, it was necessary to transform total score of participants using a conversion table. Comparison of scores for participants who provided data on at least one time point to population norms is provided in Table 13 (below). Restricting the analyses to individuals who completed baseline-post-stage data, and baseline-follow-up data would decrease SWEMWBS scores slightly. However scores still remain within the 95% confidence interval range reported in the tables. It is also worth noting again that the width of a confidence interval is affected by the size of the sample, with smaller samples tending to have larger confidence intervals than bigger ones.

These data show that service users had worse wellbeing than the general population when they began the course, improved by the end, and maintained this improvement in the three months following the course. Whilst the sample size for the post and follow-up measures is too small to draw absolute conclusions, it appears that service users' wellbeing became broadly representative of the general population by three-month follow-up. It is important to note that the sample size for follow-up measures was small and service users who had the most positive experience were most likely to be motivated to participate.

Additional comments

Participants were given the option of providing additional comments about their experience of the Mind project. Out of the 324 participants who provided some baseline data, 110 commented at the post-stage and 61 did so at the three-month follow-up. Nobody at the end of the course commented negatively.

Comments ranged from individuals simply expressing that the course was "very good" and "excellent" to others who indicated that they had found it interesting, useful, enjoyable and beneficial. Some also detailed what they had learnt from attending such as coping skills and increased confidence. A number of individuals found the group format helpful. There were also a considerable number of participants who praised the skills and abilities of the group facilitators.

Table 13: Comparison with population norms

	UK population norms mean score (95% CI)	Baseline SWEMWBS SWEMWBS mean score (95% CI)	Post SWEMWBS mean score (95% CI)	Follow-up SWEMWBS mean score (95% CI)
All participants	23.6 (23.5-23.7)	20.45 (19.96-20.95)	22.58 (22.06-23.09)	23.51 (22.53-24.49)
Men	23.7 (23.6-23.8)	21.64 (20.60-22.68)	22.73 (21.68-23.78)	23.80 (22.18-25.42)
Women	23.5 (23.4-23.7)	19.91 (19.39-20.44)	22.51 (21.91-23.11)	23.34 (22.08-24.61)

Few suggestions were given on how the courses could be improved, but several people indicated that they would have liked the course to be longer, and a couple of individuals indicated they would like some form of follow-up sessions. One suggested the use of a group Facebook page or something similar to run alongside the project. Comments at three-month follow-up stage were

similar to those at the end of the course, with individuals viewing the course, and what they had learned, in positive terms. However a couple of people indicated that they were still having difficulty coping. Several individuals expressed the wish that the course could continue in the future so others could benefit from it.

You realise you aren't the only person – there are other people going through what you are going through and you may learn something useful from their coping mechanisms.



Economic evaluation

In order to inform our assessment of economic impact, we have calculated the total cost of the intervention. This includes the cost of direct delivery (e.g. venue hire, staff costs, recruitment, etc) but also the cost to participants (e.g. travel, childcare, lost wages, etc). The direct costs have been calculated using the Building a Healthy Future programme budget and the cost to participants has been calculated based on the case study interviews. The cashable and non-cashable savings of the intervention are discussed in the following section.

The detailed economic case studies – including outcomes, assumptions, and sources for costs/benefits – are presented in Appendix 3.

Excluded costs

As the Building a Healthy Future programme has been delivered as a pilot, there have been some costs incurred that would not apply to future service delivery. These have been excluded from our model of costs.

A significant additional cost incurred during the pilot is the evaluations. Expert research partners (Leeds Beckett University and Mind) have been commissioned to conduct in-depth evaluations to build the evidence base for the intervention and develop insights to inform future service development. This has involved the cost of commissioning the research partners, the cost to project staff of supporting the evaluation (e.g. co-ordinating the completion of evaluation materials), and the cost to project participants (e.g. time taken to complete questionnaires, attend interviews etc). This additional cost has been excluded from the cost model in order to more fairly represent the true cost of delivering the intervention in future. However, project staff time to conduct routine monitoring has been factored into the costing.

One of the other significant additional costs has been Mind's resources to centrally co-ordinate the programme. During this pilot, these costs have included developing the intervention protocol, securing programme funding, recruiting programme partners (British Heart Foundation, Diabetes UK, Arthritis Research UK), appointing local Mind delivery partners, commissioning and supporting the evaluations, project reporting etc. The cost of Mind's central role in the intervention has been excluded from our model of costs. However, an estimate of increased project management resource has been included in order to reflect the shift of some functions that would transfer to local Minds in future delivery (e.g. monitoring, funder reporting, etc).

The two local Minds delivering the intervention also spent a large proportion of their time on participant recruitment. It is harder to calculate the suitable level of exclusion for this additional cost. The local Minds have spent time building relationships with local delivery partners and then liaising with potential service users directly. A significant proportion of this cost would still be incurred in future delivery. However, project staff felt there was scope for considerable efficiencies. In particular, if the same two local Minds continued with delivery, they would not need to invest the same level of time and resource to building relationships with local delivery partners. They would also be able to benefit from other efficiencies (e.g. training facilitators). However, if other local Minds were to begin delivering the intervention in new areas, it is likely that they would have to incur these costs in the initial phases. On this basis, we have taken a conservative approach and no compensation for future efficiencies has been made in the cost model.

Delivery costs

Using the programme budget and quarterly financial returns, we have estimated the following costs for each local Mind for one year of delivery:

Table 14: Estimated costs per local Mind per year

Expenditure type	Mean annual cost
Staff salaries (0.5 FTE)	£18,491.20
Additional trainer costs	£7,599.00
Clinical supervision	£1,000.00
Training for staff/trainer	£447.00
Overhead/management fee	£3,326.70
Venue hire/premises	£2,238.60
Project comms	£447.20
Travel and subsistence	£546.00
Total	£34,095.70

These are the costs after factoring in additional project management time and making the exclusions discussed. The figures are based on full cost recovery.

The total costs for both local Minds, over the two years of delivery are: £136,382.88.

Delivery time

Local Mind project staff were asked to report on the proportion of their time spent delivering different elements of the project delivery. Their activity breaks down into four main areas: recruitment (45% of time); course prep and delivery (30%); project admin and reporting (15%); and facilitating follow-up sessions (10%).

The time reported for each of these areas of activity differed between the two local Minds. This reflects local conditions (e.g. the level of engagement of referral partners) but it also reflects the level of resource available in each local Mind. The main differences were the availability of volunteers and the amount of senior staff time committed to the project. The proportions of time presented above are rounded averages.

Participant costs

The resources required for local Minds to deliver the intervention do not reflect the true cost of delivery. We must also factor in the cost to participants of their involvement. There are three principal costs associated with course participation: travel; missed work; and childcare. These were discussed with interviewees during the case study interviews in order to estimate participant costs.

Travel was the largest cost for service users. Travel expenses were not covered by local Minds delivering the intervention. In a few cases, the referral organisation covered service user expenses (e.g. a housing association provided taxis for residents with limited mobility who wanted to attend the course) but this was not systemic. Interview participants who needed to travel to attend the course typically spent no more than a few pounds each time. The majority who travelled drove themselves and the fuel cost for these trips was usually less than £5 for the entire course.

The majority of case study participants were over 60 and this broadly reflects the profile of the intervention's service users. A number of younger participants had also taken early retirement or were unemployed due to their physical health. This meant that only 20% case study participants were currently in work. None of these participants had to miss work to attend the course. Some participants were working part-time or on zero-hours contracts and managed to structure their hours to ensure they could attend the sessions. However, no participants reported that this led to a reduction in their overall hours.

None of the interviewees for this project had childcare requirements. Given the older demographic of participants, they had adult children (if any at all). This reflects the profile of service users more generally. A number of interviewees were carers for their partners or other family members. However, none of these participants had to arrange for care whilst they were attending the course.

Cost per participant

248 participants completed all six sessions of the course and a further 220 attended at least one assessment/session but did not complete the whole course. One local Mind recruited almost double the number of participants of the other (340 and 128 respectively). However, a lower proportion of participants completed the course in that local Mind (45%) than the other (72%).

The cost per participant has been calculated by dividing the delivery costs (see Table 14) by the number of participants who completed the intervention. This is likely to be an overestimate of costs because a number of participants will have benefited from the course but not completed the whole intervention. In the absence of data about these dropouts, we have made a conservative assumption about impact and excluded these participants. The final cost per (completed) participant is: £549.93.

However, many of the 220 service users who did not complete the course still attended multiple sessions. Improving the targeting of participant recruitment and improving retention could significantly improve this cost per participant.

Savings

A summary of the savings calculated for each case study is presented in Tables 15–20. The detailed case studies and calculation of each costing is provided in Appendix 3.

Table 15: Case study 1 (Jasmine)

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Improved self-management of physical health (avoided cost of diabetes complications)	- £1,430.00
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Job retention and improved career prospects (avoided employer productivity losses and increased national insurance contributions)	- £10,885.00
Total	- £14,160.07

Table 16: Case study 2 (Kevin)

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Better pain management (avoided cost of secondary mental health care)	- £9,945.00
Reduced isolation (avoided health and social care costs)	- £45.00
Total	- £11,835.07

Table 17: Case study 3 (Tariq)

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Better self-management of physical health (avoided cost of diabetes complications)	- £1,430.00
Total	- £3,275.07

Table 18: Case study 4 (Denise)

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Job retention and improved career prospects (Avoided employer productivity losses and retained tax and national insurance contributions)	- £18,657.00
Weight loss (avoided cost of medication and primary care)	- £65.00
Total	- £20,567.07

Table 19: Case study 5 (Karen)

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Improved mental health (avoided cost of secondary mental health care)	- £7,359.00
Better self-management of physical health (avoided cost of diabetes complications)	- £1,430.00
Reduced isolation (avoided health and social care costs)	- £45.00
Weight loss (avoided cost of medication and primary care)	- £65.00
Total	- £8,349.07

Table 20: Case study 6 (George)

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of anxiety treatment)	- £1,268.00
Total	- £718.07

Table 21: Case study 7 (Joan)

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Reduced isolation (avoided health and social care costs)	- £45.00
Total	- £1,890.07

Barriers and enablers

Whilst the programme had a positive impact and was well received by participants, the research identified some key factors that have been barriers or enablers for participant outcomes. This section presents the combined insights from the qualitative research conducted for the impact and economic evaluation. These interviews included service users and stakeholders. Detailed qualitative analysis conducted for the impact evaluation is presented in full in Appendix 1.

Project management

National and local stakeholders commented on the high demands on limited project staff. These pressures were particularly acute during the early stage of the programme – with the combined challenges of building and sustaining local partnerships, publicity, participant screening, delivery, and monitoring. The resource pressure appears to have been driven by delayed staff recruitment rather than lack of available funds. However, the programme's tight delivery timescales and high recruitment targets allowed little contingency to accommodate these kind of delays.

One of the sites invested considerable time attempting to build relationships with local CCGs and clinical networks. This had limited success within the short timescales of the programme. Some local stakeholders were concerned with the amount of work required for referral partners to identify suitable participants and signpost them to the intervention. Future delivery should ensure that roles and expectations are communicated clearly and consistently to potential local partners.

There were significant differences in the level and type of engagement of national, condition-specific stakeholders. This led to further challenges because local referral routes from third sector partners were less effective than anticipated. However, the time invested in building

partnerships has developed strong local relationships in each pilot site, and these need sustaining. This includes communicating the participation and impact of the intervention on an ongoing basis with local stakeholders.

The project management response to these challenges was limited by patchy reporting. There was some confusion and inconsistency in the information reported by each local site. This made it harder to identify issues at an early stage and provide a national response.

Participant recruitment

The two pilot sites approached recruitment in different ways. One site recruited participants via a small number of medical settings, with a focus on engaging people on the basis of their condition. With resource constraints, engaging CCGs and LCNs to reach practices resulted in few practices engaging. The other site primarily used community self-referral routes and was less stringent in applying pre-agreed recruitment criteria. Whilst it improved recruitment rates, this approach made it harder to target the recruitment of service users.

Whilst the Building a Healthy Future course aims to increase the resilience of people who do not have a diagnosed mental health problem, some of the service users were currently experiencing moderate to severe mental health problems when they were recruited. Both of the local Minds delivering the intervention conducted some level of participant screening. However, the criteria used were not always clear or consistent. It appears that as the local Minds came under greater pressure to hit recruitment targets, they were less strict in applying these criteria. A common approach is required to ensure clear, fair, and consistent treatment of people with mental health problems who wish to join the course.

The challenge of recruiting sufficient numbers of participants who are 'mentally well' has been experienced in previous resilience interventions run by Mind. Local Minds are used to working with people who have mental health problems and often find it difficult to deny access to a service for someone they believe is in need. However, the recruitment of people who are actively experiencing mental health problems presents potential issues for the delivery of the intervention. Having a group with a very mixed level of need could make it harder to facilitate and could undermine peer support between service users.

“One [participant] in particular, he was all about the problems in the mind, whether he mentioned suicide, I can't remember, but he was close, you know. He came out and I don't say he got more attention, he probably did, because he was so worried about what he could do and what he couldn't do.”

There were differences in the branding and vocabulary used by the two project sites. This led to some confusion for national stakeholders. Many promotional materials produced by the two project sites downplayed associations with mental health. A number of interviewees said they were attracted by this indirect language and reduced Mind logo because they felt it was more accessible and less stigmatising.

However, more precise promotion would have been helpful. Some participants expected a focus on managing physical symptoms. Some interviewees said that it was hard to assess whether the course would be relevant to their needs and they often did not realise the focus of the course on mental health until they attended the sessions. The majority of the interviews for the economic evaluation were with people who had attended five or six sessions. However, one interviewee had dropped out after realising that the course was not what he anticipated. Helping to clarify the expectations of participants like this during a screening phase may have reduced the dropout rate (and associated disruption) in the sessions themselves.

“Well when they mentioned diabetes, I thought, 'well, that may be interesting, I may learn something.' It wasn't about diabetes at all... just sat there, and okay, I had a few words to say, but nothing really involving my illness if you can call it an illness, the diabetes. That's when I decided

that I wouldn't go again after a few sessions... I suffer with the diabetes type 2, and, you know, it was all to do, obviously with the mind and mental health. It [diabetes] wasn't affecting my mind.... if I had have known the full facts I probably wouldn't have gone to be honest.”

Some local stakeholders were surprised by the lack of diversity of service users, compared to the communities where the programme was taking place. Projects disproportionately recruited participants with certain characteristics. Both sites had greater success in recruiting people with diabetes (particularly type 2) and much lower success in engaging with people with heart disease. There was also a large number of participants aged over 50, a large majority of female participants, and a disproportionately low number of participants from BME communities.

Attendance rates

Recruiting and retaining participants was the biggest obstacle identified by the local Minds staff. They reported that they spent 50% more time on recruitment than they did on course delivery (45% vs. 30%). Both national and local stakeholders agreed that participant recruitment targets need reviewing because they required a large proportion of staff time to be dedicated to recruitment and this detracted from delivery of the intervention.

The dropout rates for courses in both sites were high. One local Mind reported that the majority of dropouts occurred after session one of the course because the content was not what participants expected. They reported that, whilst they had explained the purpose of the course in advance, most dropouts expected the course to be more clinical or condition-specific.

The other Mind kept more detailed records about the exact numbers, timings, and reasons for dropouts. Almost a third of their registered participants were either no-shows or dropped-out early in the course. 13% of registered participants never attended any session and most provided no reason. Where they did provide a reason, these were most commonly: physical health too poor, mental health too poor, or clashes with work. 18% of registered participants attended the first session but dropped out before the end of the course (mostly after first and second session). The main reasons given were:

physical health was a barrier, mental health was a barrier, they misunderstood the purpose of the course, and accessibility issues (i.e. course too far from home).

“I think there were about 15 or so [at the beginning]. Generally I think there were only about four of us who attended every single session.”

Low participant retention presents a number of issues for delivery. Firstly, it makes the intervention less efficient by increasing the cost per participant and increases the proportion of staff time spent on recruitment. Secondly, it disrupts the development of peer relationships, which has been shown to be one of the most valuable elements of the course.

The pressure to achieve large participation targets may have provided a perverse incentive for local Minds to recruit less suitable people for the course or spend less time ensuring the course was a good fit for their needs. Investing more time to better manage participant expectations before they attended the course would have provided good value for money.

These delivery issues are reflected in the feedback from interviewees. By far the most common negative comment about the course related to the drop-off in participant numbers.

“It was a little bit mixed, the group came and went. There were probably, I think, two of us finished that started, and yes, there were only two of us that came to the follow-up group, but they did get apologies from a couple of others. One or two just disappeared off the face of our Earth... So that was a little bit difficult to deal with, the changes in the group.”

“People would come to one and then maybe not come to the next one and then, sort of dropped which was like, disruptive. You know, ‘if you’re going to be here, make an effort.’”

In some courses, the initial recruitment was more of an issue than drop out.

“For the six weeks of the course, there was just myself actually.... It was okay, but being on my own, I suppose in a way I was privileged to have [the trainer] to myself. But I didn’t know what to talk about.”

Many interviewees acknowledged that a high dropout was to be expected on a course with people who have physical health problems.

“I would probably be interested to know, you know, why some of the people who quit the course didn’t carry on with it because, I mean, for me I was getting so much out of it, and I don’t know whether their condition was so debilitating that they just couldn’t make it, or other priorities, I’m not sure.”

“I think that six people were due to come on but I think five did and there was a core group of about four, but one thing you find with any course like that, people with health issues they’re not going to be able to make all of them.”

Some also saw the small group size as positive. However, even in these cases, interviewees were still referring to group sizes of around six people. This is larger than the average group size for this intervention.

“I think the smallness of the group was the best part, because it wasn’t intimidating at all. You know, you felt that you all had a chance to say something, and it wasn’t overwhelming.”

“I think there were only six of us in the Mind group, so that was a much more intimate setting, if you like, and you got to know people slightly better than you would from a bigger course, a bigger group.”

Venue and timing

Hosting courses at a wider range of locations and offering more evening and weekend courses might have helped to attract a more diverse range of participants. Most sessions occurred during the day and this hampered recruitment of working-age people. Where sessions were held in GP surgeries or local Mind offices, these settings may not have been suitable for some communities.

One interviewee mentioned that the (unusual) timing of a course in the evening was the only way it was possible to attend, due to work pressures. The inconvenient daytime scheduling of another course had stopped them participating earlier in the year. Only a small proportion of service users were employed whilst taking part in the course. The fact that most courses took place during working hours on weekdays may have contributed to this participant profile.

“My GP did refer me to some other place but I was waiting for ages... I didn’t engage with that

[psychological support] anyway because it meant taking time out of work and actually physically going there during work's time, whereas the Mind course was in the evening, so that was in my own time... [My boss] wouldn't have wanted me to go in work's time and it would have caused another problem so I didn't even bother to ask."

Many service users had limited mobility and required accessible venues. This was often a deciding factor in whether they would attend or not. The majority of interviewees found the location and timing of sessions suited their needs.

"It was only down the road... It was just at the surgery, our GP's surgery. I knew it very well."

"The location was practical. I find-, because it was at the Diabetes Centre, I found it very, very easy to find, basically, because I knew where the hospitals were. As I go to the Diabetes Centre anyway, so I found it very easy to find."

"The location was quite good. It was very good because I used to be able to drive right up to the course and it was easy."

However, some interviewees did find the location of their course to be a barrier to participation or they needed clearer instructions on how to find the venue. Given that travel was the largest cost for participants, investment in convenient venues or travel subsidies may have improved participant retention and ultimately impact.

"They offered two courses, one that was close to me, only about a mile away, or a mile and a half or something. That one fell through, so I had to go into [name of town] which is about six or maybe eight miles away... It was quite a bit of a walk at the end and if it was raining-, that's the only thing wrong with it.... It was the long walk that my legs didn't like at the far end."

"Then the follow-up session then-, are all held in[name of suburb] which is very hard to get to at, well, the time as well."

"I was given a postcode and it took me right over the other side of town. It took me a good few weeks to actual-, before I knew how to get to the place."

Mixed groups

Almost all of the courses included participants with a mix of physical health conditions – primarily diabetes, arthritis, and heart disease. Many of these were experiencing multiple health issues. This is reflected in the sample of interview participants, over half of whom had multiple physical health issues. However, the majority of all course participants had type 2 diabetes. Many interviewees found this shared experience very helpful. But some participants with other health conditions thought this dominance of people with diabetes presented some difficulties.

"What I would say about the programme is that when you're diabetic, you don't live in constant pain, and when you've got a heart condition, you don't necessarily live in constant pain, but pain is such a physical barrier to things that not all those [course] materials were relevant to me... So I think there was a difference in the three groups that were put together.... diabetes and heart conditions can be fatal, I totally accept that, whereas maybe arthritis isn't. However, arthritis has a daily impact on your life, whereas if you're being treated for heart conditions and you're being treated for diabetes, your life can be normal."

However, other participants without diabetes disagreed and believe that lots of the course content was transferable across conditions. There is no ideal position here but it may be helpful to manage expectations more explicitly at an early stage.

"So the majority [of other course participants] had diabetes, which, I'd say, is something I couldn't really necessarily relate directly to it because it's not something I have. However, it didn't make too much difference, you know, because all the issues that we were talking about, there was nothing that was too specific."

Most participants valued having men and women together but a number of interviewees commented on the dominance of women in the groups. Some interviewees felt that the men in their group talked less fluently about feelings and needed more support to open up. However, developing trusting peer relationships with women who are already comfortable discussing their feelings allowed some of the men to extend their comfort zone and be more expressive.

Whilst most men said less than the women in their group, they were listening and still felt this experience was valuable.

Course content

Almost all interviewees felt that the course was well designed and were very positive about the quality of facilitation. Trainers were felt to be knowledgeable and sensitive to different comfort zones, and how they can be extended over time. This created a safe trusting environment and allowed people to explore lived experiences. Engaging visual materials, relevant case studies and scenarios, and a balance between presentation and participant-controlled discussion were highly valued by participants.

A language of control of thoughts and emotions resonated better than language of clinical diagnosis. Whilst LTC presented significant challenges for service users, other life challenges (e.g. difficulties sustaining a job and family caring responsibilities) presented further stressors. Isolation was a particular challenge for many – often exacerbated by limited mobility. Interviewees were pleased that they could explore these related challenges during the course as well as health-specific issues. However, some participants felt it was essential to start conversations in a cultural comfort zone (e.g. sharing dietary advice or talking about managing pain) before moving to broader discussion of life stressors, emotion, and mental health.

Relaxation techniques were particularly popular with participants and some would have appreciated further resources (e.g. CDs with guided activities) to help them maintain these practices after the end of the course.

Self-management

Participants reported a large number of positive impacts since attending the course. These included gains in confidence, setting clearer boundaries, reframing perspectives, increasing social activity, ability to positively discuss life challenges, and improved motivation. Participants also described improved mood, reduced use of anti-depressants, less anxiety, and better sleep.

However, few participants discussed improvements in their physical health or large changes in their self-management.

One interviewee (who is also a patient representative for their CCG) neatly described the potential benefits that improved self-management can have on the healthcare system.

“If people can manage themselves, or be able to understand what it is all about, what causes it, it will resolve lots. One, they will be able to use less medication because they’re able to identify their condition and regulate or, should I say, manage it by what your teaching is all about, you know. ... Secondly, because the condition is managed, you have less visits to the GP, because of that, there are two, three, four things done and, from the patient’s view, now they’re doing it all themselves... Most of the things which the course teaches, it is without having to use a lot of medication and it’s the self-control and things like that, which, again, reduces the need for more expensive medication.”

This is reflected in the course outcomes. One of the key determinants of the course’s success was a participant’s existing level of self-management before attending the course. Those who were very confident in managing their condition still enjoyed the course and found benefits for their mental health. However, the course had little impact on their physical health. Others who found it harder to control their health experienced more positive effects.

“I’m very lackadaisical, shall I say. I take things for granted as well. I’ve got diabetes. I’ve got to take these tablets. My partner says, ‘have you taken your tablets yet?’ ‘No. I forgot to do them today’... I have learned a lot about diabetes [from the course]. It doesn’t worry me now, and that’s the difference between me and my mother... When I speak to my sisters, diabetes frightened her.”

One of the striking findings from the interviews was that confidence in self-managing physical health had little relationship to length of time since diagnosis. Some participants who had been diagnosed decades ago described poor self-care whilst some newly diagnosed participants felt very confident.

“I knew all about diabetes because my wife has got it for so long, so I know it.”

“All the changes, I adjust them myself. In other words, I go and see the consultant regularly and they keep on changing different insulins, different things.... I've got conditions like blood pressure, arthritis and cholesterol all well-managed now... everything seems to be under control at the moment.”

“Once I was diagnosed, all the science behind it makes sense and I fully understand what my body's doing which is quite nice to be aware of. I suppose that's one of the few pros of having a long-term health problem, you, kind of, do become more in tune with your body.”

Peer support

Participants were very enthusiastic about the peer support provided on the course. Particularly among older groups, for example, with arthritis, the experience of meeting new people and reducing their isolation was motivational. Interviewees identified two principal benefits of peer support: ‘practical tips and advice’ and ‘normalising/de-stigmatising’.

Most interviews mentioned that the advice and information provided by other course participants supplemented and often reinforced the course material itself.

“If somebody comes up and says, ‘I've had this problem, yes, but this is how I managed it’... it's an amazing thing. A lot of people don't know even where to get the help from... I felt that I could help others.”

“People would comment on what I was saying and giving me feedback on that, but then people were sharing their experiences and ideas, and even just things about, you know, how people find it useful to relax. I thought, ‘that sounds interesting’... When I was talking about things that I wanted to do there was the element of getting support from people, which was really good, and I think having the group discussions around the topics on the course kind of helped to actually cement an understanding.”

The normalising and de-stigmatising effect of meeting other people with similar challenges had a profound impact on some interviewees.

“I learned it's not just me with it, which is a big thing. Basically, it's surprising how many people do have it.”

“We would have looked such an odd group, if we had gone to the pub together, or a coffee shop, we just were so different, even on the outside we looked so different, it would have been a really odd mix of people, but it wasn't an odd mix of people, because we found a commonality. We shared something, and we really cared about each other. We got to really care about each other.”

“You can absorb other people's problems and a lot of your own go away then.... You're not the same as other people when you have diabetes, because, you know, you have got to take injections in public, or go to the loo or do what you can. When you talk to other people, you become part of a group, so you know there are people out there, so you don't feel so cut off.”

“What I found out is that most of the people who came there with the same diabetic conditions and so on were suffering from long-term conditions and it was causing them a lot of heartache and depression, can you use the term depression? I don't know, but something like that, you know? It was very useful for everybody to share their pain.”

Where interviewees had negative comments about other course participants, these focused on the difficulty of establishing trusting peer support relationships when there were high dropout rates. The challenge of attendance is discussed in more detail below.

A number of interviewees also commented on the value of sharing common experiences with some of the course trainers/facilitators.

“I really liked [the trainer], she was, like, a person I could relate to... She also had rheumatoid arthritis, which my mum has as well. So kind of things that she would say I could relay to my mum as well, you know, like, swimming's a good idea maybe... I really liked her approach to the way, like, she just really welcoming.”

“[The trainer] was brilliant... we all felt quite secure that we could say anything to her because it was all confidential... She was a brilliant facilitator and wasn't afraid to speak about herself.”

“I liked [the trainer], I mean she obviously has her own health problems and she would say, you know, ‘this is what I've found,’ which I think made it a lot easier for people to say, ‘oh yes’.”

“I think one of the big things, for me, was how good [the trainer] was. Now, I mean, one of the things she always did, which I haven’t really seen before from disability training, is that she was prepared to talk about her own physical condition that she has fibromyalgia/arthritis, and how that affects her. Straight away that was, you know, a really good way of engaging with the group, because we all knew that she experienced and could probably relate to some of the things we could. So it was the fact that it was very honest, you know, for her to open up and talk about her own challenges... I guess that takes from someone who’s quite, maybe, brave or self-confident as a trainer, you know, to actually share that stuff personally, but that was really good.”

Whilst peer support among course participants was very highly valued, there could have been more preparation for participants to become peer supporters after the programme. Reunion gatherings and follow-up events were organised, but not consistently across the two sites. The continued support provided by these follow-up sessions appears to improve the sustainability of participants’ improved outcomes. This service, particularly if peer-led, does not require large investment and it offers very good value for money.

Sustaining behaviour change

One of the hardest challenges of any training intervention is sustaining the impact beyond the time of the course itself. Researchers spoke to people who had completed the course and those who were still taking part. Some participants had completed the course up to 18 months prior to their interview. This provided a useful indication of the differential effects of the course over time.

The majority of interviewees felt that the course was helpful whilst they were taking part but that the lasting effect was much more mixed.

“It’s really difficult coming away, and then transferring it into real life.”

“I suppose during the course, it does reinforce what you should be doing in certain ways, not because they would give you diet tips or anything like that, but because of talking about motivation, and things like that. The trouble is, once the

course finishes, you tend to slip back into your old ways. I can’t say that I carried that motivation forward, no.”

“I’ve been using some of the techniques but the thing is, with the course, yes some of the things are very useful but I don’t think of them that much.”

Unsurprisingly, participants who completed the course more recently were able to recall more detail and were still regularly using the techniques that they had learnt.

“I’m still finding the course useful I think, which is a key thing. There are still things that I’m using so there was some things that I was aware of in terms of the circles of influence, I tend not to get stressed about things I can’t control so we did cover that and I was quite sound with that, I sort of practice that with my life anyway. I think there were other things, the bit about you know, the balancing thoughts and the ‘I’ statements that we covered was quite good.”

Some interviewees were surprised that they had not used the techniques that they had learnt more often.

“I am sort of aware that I’m not using the relaxation ones as much as I thought I would be, because I think when I first went on the course I’d be thinking ‘well, I’ll be using the relaxation techniques’, a lot more than I am.”

Where participants felt the strongest lasting effect, they were regularly consulting the worksheets that were provided during the course.

“I always keep them [worksheets] so we can go through them.... When I get really low I just flick through them.”

“I’ve had it pointed out to me a few times by the ladies that I do things differently... according to the lady, the friend I have, she points out to me sometimes that I am not doing it and she sort of kicks me into it. It makes me start thinking again, in different ways.... I’ve still got them sheets because I can read through it again and it reminds me of things that we did.”

However, not all participants found these sheets helpful.

“I have sadly not used the techniques much. I should have gone back to the worksheets. I appreciate that, you know, but life intervenes

and all that... I did try to plough through them last night, and I was beginning to lose the will to live, to be honest. You know, it's heavy reading, really... I suppose, it's, sort of, in the back of your mind, and it probably does sway you a little bit. I haven't done the breathing exercises or anything."

Local and national stakeholders highlighted a need for more future focus and personalisation in the final weeks to better prepare participants for embedding the learning from the course into their daily lives. This should include more explicit signposting for those who require further support.

Participants who had attended follow-up sessions also showed longer-term impact. However, attendance on these follow-up sessions was much lower than on the course and, amongst our interviewees from some courses, there was only patchy awareness. Indeed, a number of participants suggested that follow-up sessions should be provided, without knowing that they were already on offer.

"When we looked back and I talked to some of the people there, they were hoping that there would be some follow-up. The course that was delivered was only six weeks and, whatever the case, you know, we were expecting to have some sort of follow-up and things to carry on at a later time."

"Maybe, the course needs a follow-up for people to be able to communicate... I think the course does raise some issues so maybe after the six weeks finish have a gap of six weeks or four weeks and then everybody come together again. The danger is, that people would've got other things in their diary and out of the six or four you might just get two, but still might be useful to have that interaction with somebody and the tutor as well, just to see where you are really, and maybe somebody might need to be referred somewhere else [for extra support]."

"If I was to say there was anything wrong with the programme, I would say it didn't carry on, because I could have carried on every week really. I'm sure the material would have run out, and it could just have fizzled out to be just a meet for a coffee somewhere, but it's such a shame to let those people out of your life when you've made such a connection to them."

A number of participants at one of the two regions expressed frustration at the poor organisation and communication about follow-up sessions.

"The follow-up session happened just before Christmas. To be quite honest, and I will say that, we found it all a bit of a muddle, because we kept getting phone calls and letters and things and nothing happened... It seemed to me that they would send you a letter, saying, 'oh, we're going to do this, this, and this,' and it never actually transpired, you know, for months and months afterwards, and you had sort of forgotten about it... I found it all a bit of a muddle, to be quite honest, and it was too long after the event. Yes, too long after the event."

"You probably heard that the turnout of people [at the follow-up session] was very, very small, which indicates, obviously, that perhaps something is not quite right, I don't know. We went anyway. There were only one or two from our group."

"The follow-up was too long after. That was to reinforce the course. We were told it would be about three months, when we did the follow-up thing, but it wasn't. It was a long time after that."

Conclusion and recommendations

This section presents the combined conclusions and recommendations of the impact and economic evaluations.

Impact

This research demonstrates significant improvements in service users' resilience, wellbeing, social support, self-efficacy and problem solving, and confidence to manage LTC. These positive changes were sustained from the beginning (baseline) to the end of the course (post), and from the beginning (baseline) to three months after the course (follow-up). The combined results for the two programmes show no significant change between post-stage and follow-up scores at three months. This is positive because it shows that positive improvements were sustained and there was no significant drop-off in resilience during the three months after the course for those who completed the follow-up questionnaire.

Interview findings highlight the positive experiences of most participants. The course was a very rewarding process for almost all participants, and they reported a range of positive impacts on their wellbeing, management of their LTC, and increased social engagement. Participants benefited from the opportunity to meet with other people with similar experience of managing thoughts and feelings associated with LTC. The skilled facilitation, flexible use of materials and the empathy and reciprocity experienced in peer groups established a safe space, in which participants could receive support and explore coping skills in a comfort zone which might be extended as the programme progresses.

The economic evaluation indicates that the Building a Healthy Future programme has a positive economic impact, in addition to the positive effect on individual's wellbeing and resilience. The case study analysis suggests that the intervention could produce overall savings

between £718.07 and £20,632.07 per participant per year (PPPY). However, most of these savings are non-cashable and distributed across a range of funders, commissioners, and service providers.

The high costs and poor individual outcomes associated with co-morbid physical and mental health problems mean that this intervention will produce considerable non-cashable savings if it can help to prevent the development of mental health problems in the longer term. However, the intervention leads to little change in health service use in the short-medium term.

Benefits are not evenly distributed across different groups of service users. People who are already confident in self-managing their condition may still receive positive mental health benefits from the course. However, the economic impact of their participation will be lower than their peers. There are some positive indications that the intervention can improve the employment prospects of participants – supporting their job retention and career prospects. However, the predominantly older demographic of service users, the majority of whom are retired, limits broader economic impact in this area.

More systematic collection of service use data and long-term monitoring of participant outcomes is required to make more confident conclusions about the impact and value of the intervention.

Referrals and recruitment

The two pilot sites approached recruitment in different ways. One site recruited participants via a small number of medical settings, with a focus on engaging people on the basis of their condition. The other site primarily used community self-referral routes and was less stringent in applying pre-agreed recruitment criteria. Whilst this improved recruitment rates, the approach made it far more likely that participants would have existing mental health problems as well as

physical LTC. A common approach is required to ensure clear, fair, and consistent treatment of people who wish to join the course.

Participant recruitment targets need to be reviewed because they required a large proportion of staff time to be dedicated to recruitment and this detracted from delivery of the intervention.

The programme disproportionately recruited participants with certain characteristics. Both sites had greater success in recruiting people with diabetes (particularly type 2 diabetes) and much lower success in engaging with people with heart disease. There was also a large number of participants aged over 50, a large majority of female participants, and a disproportionately low number of participants from BME communities.

Hosting courses at a wider range of locations and offering more evening and weekend courses may have helped to attract a more diverse range of participants. Most sessions occurred during the day and this hampered recruitment of working-age people. Where sessions were held in GP surgeries or local Mind offices, these settings may not have been suitable for some communities.

Participant retention

Both sites experienced retention problems. This is a common challenge when working with people who experience physical health problems. However, this problem was compounded by inconsistent recruitment approaches, mismatched participant expectations, and limited staffing resources to follow-up with no-shows.

High participant recruitment targets may have provided perverse incentives for local Minds to recruit participants who are less suitable for the course and spend less time on screening and briefing newcomers to improve participant retention. Improving recruitment processes is likely to reduce the cost per participant and also improve participant outcomes.

Programme sustainability

In the early stages of the programme, project staff struggled to cope with the demands of

building and maintaining partnerships, recruitment, delivery, monitoring, and follow-up.

Peer support among course participants was very highly valued on the programme but there was little preparation for participants to become peer supporters after the programme. Reunion gatherings and follow-up events were organised, but not consistently across both programmes. Regular follow-up sessions should be offered to all service users and training should be made available to encourage peer leadership of the groups. The continued support provided by these follow-up sessions appears to improve the sustainability of participants' improved outcomes. This service, particularly if peer led, does not require large investment and it offers very good value for money.

Future research

There would be considerable value in using individual outcome measures that can be directly translated into economic impact (e.g. EQ5D) when conducting future research in this area. Equally, it would be very helpful to systematically collect service use and other relevant economic data from future programme participants. This would help to test the indicative calculations of economic impact made using assumptions from case studies in this evaluation.

Unless otherwise stated, all costs/savings have been calculated on a one-year basis because there is currently no data on the longer-term impact of the programme. However, this is a conservative assumption because it is likely that most outcomes will have longer-term effects.

Further research would be required to assess the strength of longer-term effects and develop more comprehensive economic models (e.g. including monitoring service use and calculating Quality Adjusted Life Years (QALYs), Years of Life Lost (YLL), and/or Years of Life with Disability (YLD)).

There is currently little research into the long-term effects of resilience interventions and the impact of changes in resilience-related outcome measures in the short-medium term on the longer-term prevalence of poor mental health. This should be a high priority for future research.

Recommendations

Impact

- The intervention has been shown to have significantly positive effects on participants' outcomes. It also provides good value for money. With minor revisions, this intervention could have a very positive effect if rolled out more broadly.
- Further development work is required to refine the targeting of the intervention for group(s) or participant characteristics who will benefit most from the intervention. This report provides detailed analysis of the impact of the course on a range of participants – including diverse mental health needs and severity of LTC.
- More careful screening of potential participants in the intervention would provide value for money because it will improve the appropriateness of referrals and clarify participant expectations. This will have a positive effect on participant retention rates. Improved retention will reduce the cost per participant and also improve participant outcomes.
- Regular follow-up sessions should be offered to all service users and training should be made available to encourage peer leadership of the groups. The continued support provided by these follow-up sessions appears to improve the sustainability of participants' improved outcomes. This service, particularly if peer-led, does not require large investment and it offers very good value for money.
- Gains in resilience have been significantly demonstrated in the short-medium term. Further research is required to assess the

strength of longer-term effects and develop more comprehensive economic models. There is currently little research into the long-term effects of resilience interventions and the impact of changes in resilience-related outcome measures in the short-medium term on the longer-term prevalence of poor mental health. Systematic collection of service use data would also strengthen the economic modelling. These areas should be a high priority for future research.

Process

- Future programme delivery should extend the resources and time available for programme set-up and partnership building. It should also provide increased resources for programme co-ordination and delivery.
- Recruitment targets need to be moderated for future programme delivery. These should be segmented into priority areas e.g. date of diagnosis, gender, mental health experience/ diagnosis, ethnicity etc.
- Many of the strengths of Mind's service delivery are based on distinctive local Minds and their initiative, enterprise, and community knowledge. For a nationally funded project, more planning is required to bring national strategic design and local initiatives into closer alignment.
- Future programme development should be based on clearer links between goals, the boundaries for participant inclusion, and evidence requirements. This will improve programme planning, project management, and consistency of delivery.

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Appendix I:

Detailed qualitative analysis

Codes in quotations

Quotations by participants in this section are anonymised. Codes appearing after the quotes identify the programme and the participant's condition.

Quotations by stakeholders have codes including (ST) and those by participants including (P).

For example, (MPD6) indicates the participant (P) took part in a Manchester course (M), and has diabetes (D). (BPDAH8) indicates the participant (P) took part in a Birmingham course (B) and has diabetes, arthritis, and a heart condition (DAH).

Impact of long-term conditions

Physical health

LTC were seen by stakeholders as having tangible impacts on physical health and mental wellbeing. Some conditions had obvious related specifics, for example, diabetes might affect eyesight.

“Ok, I've got diabetes, I'm having to deal with it, what other parts of my body will it affect... so basically if I'm diabetic it's gonna affect my eyesight.” (BST2)

Some participants, attending due to a primary LTC, i.e. diabetes, were often experiencing the impact of a number of physical health issues or co-morbidity.

“I'm diabetic with a whole lot of complications I have fibromyalgia, I have diverticulitis.” (BPD6)

“I've various health issues. I'm diabetic, I've got fibromyalgia, cervical spondylosis, glaucoma, cataracts.” (MPA10)

“The majority in the groups that I've run they've had multiple conditions.” (MST3)

Underlying health issues may therefore have been numerous, some participants identifying

three or more diagnosed conditions, demonstrating the complexity of the LTC which the programme was encountering.

Pain

Pain was another area in which LTC were impacting physically on the participants. This was viewed by some stakeholders including a course coordinator as an area which the programme could address.

“Pain management is talking about the psychological aspect of the pain, not the medical aspect of it... so the hand-out talks about primary and secondary pain; primary pain, that's what you feel, your secondary pain is what you do with what you feel, so it is more about understanding the psychological impact of pain, we don't go much in distraction techniques or medication ...” (MST1)

“Some participants noted that pain was an issue for them: 'I am more or less in pain all the time'.” (BPD6)

This was sometimes related to a multitude of co-existing conditions. While severe pain may accompany all three conditions, it was highlighted how physical pain is very frequent with some people with arthritis.

“Pain is one of the most significant challenges for a lot of people that have an MSK condition.” (NAST1)

Life challenges

For some participants, their LTC had brought about serious challenges in relation to aspects of their lives, such as work, which might become hard to sustain.

“My job was a large part of my life. I've got to the stage where I felt that I couldn't continue in that job because the fibromyalgia and other ailments.” (MPA10)

“I did feel that I had given up work too soon but I don’t think that I could go back into [work] again, I don’t ever want to feel the way I felt then.” (MPA11)

“This bout has resulted in me losing my job. My contract was terminated on health grounds.” (MPD5)

Others reflected that their lives contained challenges not directly related to their condition, but perhaps contributing to lowered resilience. These challenges might include serious family health issues or relationship troubles.

“I lost my husband some years ago to motor neurone disease and I was off with four children. Anyway ... my main focus has been bringing them up, helping out my son that’s got the disabled daughter.” (MPA10)

“The depression. Yeah, I had that when I was at work, so that was in my twenties. But I did recover quite a lot from that and then it really started up again when my husband was first ill.” (BPA13)

“My husband died, my mum died, my poor little dog died. I know, my mum and husband died, but come on my dog? ...Like I say I get angry but my brother is in [X hospital]. He fell down the stairs, fractured his skull. He has been there six months and has had pneumonia. Thought had started to get better, started to speak, but then he’s stopped and he’s being fed into his stomach and he’s such a lovely person... So these things happen but it’s how to deal with it, and I’m not always very good at.” (MPA7)

“My two daughters were bullied at school, the parents ganged up and caused me a bad depression.” (BPDH8)

“My daughter recently, well not, last year got divorced and that’s been an upsetting time.” (BPA14)

“I lost my mum. Just before that, I’d lost my dad. So everything seemed to happen at once....then as I got settled into my job here, and everything had settled down, it was like flum. I just went right down.” (MPD12)

Narratives of unpleasant, traumatic or life changing experiences were therefore brought to the setting of the programme. Others noted the challenge of isolation through ill health or wider life circumstances.

“I live on my own. I love cooking but half the time I can’t be bothered cooking just for myself.” (MPD6)

“I used to go out every week with my friends and I just stopped...I just stay in, it feels like it’s safer.” (MPA7)

Challenges, or further ‘bumps in the road’ can also throw participants off course in their attempts to manage their LTC. For example, a participant with heart disease discussed feeling he was making progress with his health, when a different health dimension emerged.

“I was ill until I had my operation and that’s when the low periods came in.... after the surgery. And then I was getting back on track and then my hip went so I had more stress.” (MPH9)

A number of participants were therefore aware that their resilience had been tested or depleted by wider life challenges, which were important aspects to share as part of their journey. A certain vulnerability persists for a number of participants, reflected by the understanding of one stakeholder, on one programme, about how the course may have drawn in different groups than was initially anticipated, particularly those recruited through community routes.

“People who want to come on the course have experienced some level of mental distress, either in the past or maybe currently to a low level and we are generally not getting a lot of people who are psychologically healthy with no history of any mental health problems from their condition or from their life are going to come on a course like this....Positively, although I know this course isn’t supposed to be aimed at people with mental health problems or a diagnosis, I think it is helping people who’ve had a previous diagnosis, who all currently have low levels of depression or stress or anxiety. And... I know that’s who I’m getting.” (MST1)

Therefore, among those attracted to the course, are people who have faced challenges and have lowered resilience, not all due to their LTC. LTC were seen as complex within the lived experiences of participants, and pain highlighted as of specific resonance for some groups, including those with arthritis.

Condition specific aspects

The broadening of the programme in the second year, with the inclusion of arthritis to sit alongside the other two LTC was viewed positively by stakeholders facilitating the course.

“I thought that’s good, going to reach more people and why not, it wasn’t clear what the reason was for limiting it...I’d say why not help more people if you can, widen it.” (MST2)

Broadening the programme was viewed by one stakeholder as a means of helping people with particular high risks around resilience building. Needs were shared among people with different LTC, concerning stress management and coping.

“Since we’ve expanded the eligibility we’re getting more people because I think people with arthritis and fibromyalgia are more at risk of stress and mental health problems and that there isn’t very much serving them, especially people with fibromyalgia, because there isn’t really a treatment.” (MST1)

“So across the conditions people tend to still want similar things...; help with stress, relaxation and calming down, and with the psychological aspect that nobody else understands, nobody can...” (MST1)

Participants also accepted the ‘fit’ between the three conditions focused on within the resilience programme.

“I mean the diabetes... you know... something you control but arthritis is a bit of a... but then again if you need the relaxation and that... so I suppose really, yeah the three would go together.” (BPD5)

That the programme engaged with a variety of LTC was therefore viewed positively from both participant and stakeholder perspectives specifically due to the shared experiences this could bring.

While the impact of LTC on mental wellbeing was a primary concern, anticipated by the programme design and goals, some participants, particularly recruited by community routes, had long-term mental health experiences which were affecting their physical health.

“I’ve been having some mental health problems for a while. Depression, anxiety. I had quite a lot of past issues and it was affecting my health. I found out twelve months ago that I was diabetic.” (MPD12)

The addition of arthritis as a LTC made a challenging difference to the landscape for recruitment. Lists of people in medical settings were passed to the coordinator and when contacted some people stated that they did not

view themselves as having arthritis – their condition being mild. Conversely, it was pointed out by one stakeholder that many older people have arthritis in addition to other conditions such as diabetes, but that this may not have been flagged up in their records. Course groups consisting mainly of people with arthritis tended to be mostly older people.

“So you know somebody who is reported a little bit of knee pain in the past might have a code of osteoarthritis but doesn’t even think of themselves of having that disease. And so the recruitment of these patients they have been a bit of a mixed reaction.” (BST4)

“The youngest lady was late sixties, the other ladies were in their seventies, and I’m in my eighties, so..” (BPA14)

Recruitment

The high targets for recruitment presented serious challenges to the two programme sites, especially given that resources in the first instance for all-important outreach were less than they were to become later on, by which time tensions between achieving numbers, maintaining consistent boundaries, and achieving diverse and targeted referral routes were all-too-apparent. Recognition of the challenge of high targets soon occurred to a stakeholder at one setting, who highlighted referral criteria and excluding those ‘being treated with mental health conditions’.

“We soon realised how difficult it was to get the referrals, due to the criteria of people could only attend the course if they had a long-term condition but they weren’t being treated for mental health conditions...a massive group of people on the books of the service that I run, hundreds of people with long-term conditions as well but were being treated for them with medication, we couldn’t engage with those people.” (BST3)

Medical-focused recruitment

There was a challenge of how far to prioritise recruiting participants through medical or community pathways. The two different sites for the programme took differing approaches to recruitment, affording a useful insight into how

recruitment pathways may work, and the value of varied approaches in reaching different audiences.

For some, the medical community proved a means to engage with those with LTC. For example, systematic approaches to Clinical Commissioning Groups, Local Commissioning Networks and GPs provided a potential access route, making it possible for one programme to engage a small number of practices in providing referrals to courses held at very few practices (alongside a few others at a pharmacy). The 'medicalised' approach involves recruiting potential participants by suggesting that the course may benefit them due to their physical health status.

"I contacted people that regularly come, especially people that we do medication for that have got diabetes and heart related problems,... the people that were eager to go on the course I put them on first." (BST2)

Whilst the medical setting may offer ease of access to potential participants, challenges concern getting the GPs to prioritise this project with their workloads and competing agendas. So, numbers of practices engaged remained very small, and reliance on one specific centre to host many courses reflected frustrations in diversifying the catchment.

"Because this is a completely new project, it's a pilot, however to engage people in this is proving challenging and we've gone into GPs, I've been to so many LCNs meetings and presented now, GPs getting back to you has been another barrier because their workloads are ridiculous and they have so many things on their agenda...." (BST1)

"It can take a few years sometimes for people to get their confidence, so it's really difficult to get lots of practices on board." (BST3)

Once GP practices were engaged, recruitment still remained a challenge. Participants across both regions who had attended the course following signposting from a medical setting sometimes mentioned the importance of a trusting relationship with a health practitioner. Prior trust mattered because the GP might not be involved in direct recruitment. There could be anxiety concerning why a doctor had passed a name to Mind. Exceptions were described, where for example, a health visitor promoted the course.

"It was just "here's a leaflet", "thought you might be interested in this". My GP's quite good she's very approachable and hands on." (MPD5)

"Whether I'll get anything back from the doctors or find out why they've sent me I don't know." (BPA14)

"The health visitor said this might help, health anxiety and arthritis, would you like to try it, so I said ok." (MPA7)

Recruitment through the medical practice route brought challenges in that when the GP provided unfiltered lists of people with LTC which the local Mind coordinator used to phone all potential participants, a proportion of those contacted did not see the programme as relevant or were confused about its focus. It was said that it would have been helpful if the practice provided information in advance of cold calls.

"It would have been more helpful if it wasn't completely cold calling ...one practice that's really come on board and they sent us hundreds of names, from 100 phone calls we think we've got 10 on board but you have to put a lot of work into making calls to get 10 people." (BST3)

"I don't think the practice has said anything to them, they have literally given us a list of patients...I think people [when cold called] expect you to be talking about blood tests or a course around healthy eating with diabetes or pain management with arthritis." (BST3)

"She will end up maybe phoning more people than she might have done if we had actually filtered the list out there. I think definitely for arthritis because it's such a broad term isn't it really. Looking back we could have probably done a bit of filtering on that." (BST4)

Community-focused recruitment

Community settings offer a different route, sometimes initiating relationships with specific 'target' community organisations such as housing associations, and Asian women's groups, to promote the course to individuals. The more community-focused approach was said to have drawn strongly on 'self-referral'.

"People are largely coming to this course because they're self-referring, so despite ongoing meetings and presentations, meetings with nurses, consultants, physiotherapists, the

recruitment did not come through referrals... ... there doesn't seem to be one route so even with the referrals, there's been three or four from the diabetes centre not many, there's been two or three from doctors across the whole of the city, the housing associations have been the greatest because they've recruited at localities; so where we've been in a community centre or we've been in a housing association, they've publicised it for us and helped us recruit, that's the most successful. So we build relationships with the community centre or with the housing association who have access to people who would benefit from the course and tend to know them personally and that has brought in the largest numbers." (MST1)

For example, a specific women-only course was put on in collaboration with a local Asian women's group. Engaging with a variety of community settings is resource-intensive and not exhaustive in reach, for example, concerning diversity. Certain community organisations were also said to be resistant to new initiatives.

"We haven't had the resources so if we were looking at increasing those numbers it would involve talking to different people, so for example churches and I did try with Afro-Caribbean groups..." (MST1)

"She went into one diabetes, and they didn't really welcome her. It was very much what are they muscling in on our patch kind of thing." (BST3)

"Some community centres can be quite particular about who they're letting in. There are a few support groups through [national charity...] and [national charity...] who have been particular." (BST)

Project participants also suggested both medical and community routes as potential vehicles for recruitment.

"A vast number of people are in the housing association. They are living in the houses, living alone." (BPD3)

Recruitment and referral boundaries

A related issue for the programmes was the inconsistency in setting recruitment boundaries around mental health diagnosis. One stakeholder observed that one regional programme recruited

many people through community routes who may have had previous mental health diagnoses, whereas practice-based recruitment in the other region was based on physical health diagnosis. There had been some screening for mental health 'risk' by a GP early on, but later the course facilitators were provided with lists of those with physical conditions to phone. A stakeholder from a national condition-related partner organisation was unclear exactly how boundaries were to be applied.

"Our understanding, recruiting people that were already getting some help or some form of support for their, I don't know if they had been diagnosed with some sort of mental health condition, we weren't to be recruiting those people... there may have been people that got a diagnosis that weren't necessarily receiving treatment for the diagnosis... Yeah I think people who had received help, they were, from my understanding, ok..." (NAST1)

The use of housing associations resulted in many older people being recruited, inclusive of people with arthritis.

"Through one of the housing associations I think she's [Y] had quite a few referrals coming through that particular route, I think she found that she didn't have that much luck through primary care, whereas the [X] one, I think they focused on CCGs, practices and actually haven't really had much luck." (NAST1)

A few participants noted their recruitment came through pathways related to other aspects of their lives such as work.

"I'm not working and the Government wants you to work, I have been referred to the working well programme and so it was my key worker. I kind of asked her about certain things like this about stress and worry and so she found out about this and referred me." (MPA8)

Some participants also had engaged with other LTC groups, and for some this offered a safe pathway into the resilience programme.

"I go to a heart club on a Tuesday...and it was put forward." (MPH9)

The approaches to recruitment were therefore mixed, with people being drawn through medical routes directly related to their LTC, or through more community-focused avenues. Pathways were more diverse in one region, more medically

oriented in the other, where a small number of specific settings proved fruitful. The diverse routes led to engagement of participants reflecting different life challenges.

Advertising

Community routes into the course were for some stakeholders heavily linked to the way the course was promoted.

“Because it’s the promotion that’s bringing people in, so making sure we get flyers with the new course dates on and posters and putting them up in various places local to the course.” (MST1)

Being able to recruit into courses through advertising was viewed as involving ‘thinking outside the box’, for example, through use of local radio, not always viewed as the mainstream means for services to recruit.

“We put a lot of resources into developing promotional material that we thought people would be attracted by, and I don’t know that other services may think of things in that way.” (MST1)

“I’ve been on local radio stations to promote the course, and I think the community radio enables you to talk in language that people can identify with.” (MST1)

Advertising was also a way in which the focus of the course could be conveyed to potential participants.

“You need to explain to them what the course is actually about.” (BST2)

Although advertising was more prevalent within the more community-focused programme, participants across both programmes noted that more informative advertising would be beneficial.

“I would advertise it a bit more and say exactly what it’s for.” (BPD8)

“I didn’t know what the course was about or anything till I go there.” (MPD2)

In medical settings there was a view that the use of video/TV media for example, in the GP surgery had been minimal and could be used to interest participants in what the programme has to offer.

“The GP surgery puts leaflets in but I’ve never really looked at them and they have videos going all the time about diabetes but there is very little

about to do with mental health issues or long-term illnesses.” (MPA10)

“If there was something on the TV screen would be the most ideal. Because when you are sitting in the waiting room you would look at the screen absolutely and if you have got a visual example of what a group looks like and may be a testimonial or two from patients, then I do think that would have a significant effect.” (BST4PM)

Also, it was said to be important to tailor advertising for particular cultural groups, including language translations.

“I think it could’ve been good if it was translated in different languages...” (BST2)

A national LTC organisation stakeholder considered that the use of websites, and newsletters has shown good results, yet still more media coverage was needed, from early on.

“I’m not entirely sure that enough people knew about the programme to begin with... I think there could’ve potentially been more communications around it, local media, local newspapers ...” (NAST1)

Mind branding

The Mind brand has been seen as a potential challenge in terms of the recruitment process. On one programme the use of individual branding for the project, reducing the Mind logo, and including a bespoke logo was viewed as successful within recruitment.

“We haven’t used Mind’s branding on our materials very prominently, we’ve not used Mind’s colouring; we had a bespoke logo which has been very successful, our materials don’t look like Mind’s materials.” (MST1)

Some participants noted that the LTC focus and the less obvious mental health branding was appealing to them and potentially to others on the course.

“Making it not scary because it’s about long-term health conditions and mental health issues a lot of people do find it scary.” (MPA10)

“You don’t feel you are being institutionalised or labelled with mental health.” (MPD5)

Some participants overtly attributed the linkage to Mind as off-putting, mirroring wider stigma.

“I mean the name, I think that’s what puts a lot of people off, Mind, the word ‘mind’... I think it probably did, because it’s associating Mind as a mental illness.” (BPD8)

Some participants stated that the word ‘resilience’ was not used. Stakeholders also noted that the word resilience can be challenging at first. Plain familiar language is important at the recruitment stage.

“Things like this is a course to help you deal with your feelings and emotions and often when we’ve got conditions like this we can worry about how it’s affecting our life. Really plain speaking.” (BST3)

“I think the word resilience is not always that common when someone’s faced with a health problem but the subtext around aims was quite clear on confidence building, adapting your lifestyle.” (MST2)

For some participants, the word ‘stress’ was to provide a ‘hook’ for them into their participation. ‘Coping’ was an alternative, linked to daily life. An adaptive approach to make the mental health aspect accessible was used, and participants responded well to this accessibility in the first instance.

A challenge was that the two different regional programmes were using different branding and names for the course, as well as different recruitment channels. This raised issues about consistency for providing evidence to commissioners that the programme is working, and on what basis. National stakeholders also believed that the inconsistencies in branding could be confusing. One programme (community-directed) used the Mind logo less prominently than the other (more practice-based). One programme avoided resilience in its promotional materials, the other was thought to have included it in non-prominent positions. This was challenging for national partners to work with.

“So we had one in Y that called the programme something completely different to the one in X, and the one in Y was getting referrals or promoting the programme through channels that the one in X has said we’re not supposed to be getting referrals from.” (NAST1)

“They are both calling it ‘Building a Healthy Future’, one is a course to help strengthen emotional resilience whilst living with... and the

other one is a wellbeing course for people with...” (NAST1)

“On the X one, I think the Mind logo was quite prevalent, but on the Y one it was more subtle, and the ‘Building a Healthy Future’ was the main logo that people would see, I think that one worked better...” (NAST1)

Discussion of how the brand impacts on the recruitment process therefore relates to the language used, including whether this is the language of ‘mental health’. The term resilience might not be understood at this stage, whereas during the course, explained and explored, it could have resonance.

Location and timing

Relevant timings were important in terms of recruitment. One stakeholder at a pharmacy was able to offer a location for evening courses, ideal for including those who work. Many courses were run in daytime hours, perceived to have led to more older people and fewer working people attending.

“[Evening class – rare] Most of the people who are in work, the age demographic is younger” (MST3)

“We can always run courses in the evening when people are coming back from work.” (BST2)

“We’ve missed out a lot of people by not putting on more evening courses, people in work who could benefit from the course... Daytime courses we are getting a lot of retired people, older people.” (MST1)

“I couldn’t have done if I’d have been working.” (BPDH11)

The location of the course, near where participants live, or very accessible by transport, was viewed as very important for participants to be able to attend.

“The course was run at [venue name] which is very near [town] precinct so it was good for buses.” (MPA10)

“I said to [coordinator] ‘where will it be?’ and she said ‘at the surgery’, I thought ‘lovely’ (laughs).” (BPDH11)

The space available at some larger medical practices was also an advantage in that the

participants were regularly able to access a bookable meeting room in a discrete location.

“Space, I know that’s an issue for some practices.” (BST4)

Recruitment summary

Recruitment was therefore a challenge for the programme. Medical approaches kept the focus tightly aligned to the key LTC, and retained some focus on early intervention, whereas community approaches created greater opportunities for self-referral and immediate self-identification with the programme. Advertising was a key means for generating community routes; how the courses were ‘sold’ to participants remained important. Low-key, reduced inclusion of Mind branding or other mental health related language was viewed as important.

Programme expectations

Participant expectations

Expectations for the programme were mixed among participants. A number were unsure of what to expect; and many comments were linked to the recruitment process and advertising.

“I had no idea (MP3), I came here very blindly I didn’t know what I was expecting.” (BPD1)

Some participants suggested they would have preferred to have had a clearer idea of what the course involved before it started. Some participants took the advice of others and this framed their expectations.

“My coach was saying to me that it was obvious that I needed to get some distance on what was wrong with me and what I felt the future was.” (MPA10)

Others expected the course would offer practical ways to deal with physical or emotional challenges concerning their LTC, and, for some, interactions between physical symptoms and anxieties around coping.

“Well to start with actually, I thought it would be all about the arthritis and the medical side of it.” (BPA13)

“I knew there would be discussions on stress and finding solutions, or looking at solutions.” (MPA11)

“Manage the diabetes and anxiety. To stop other health issues, migraines, aches and pains.” (MPD12)

Some participants hoped to gain shared experiences with others who would ‘get it’ in terms of the thoughts and feelings associated with having a LTC. However, some participants expressed anxieties about engaging with others on the course, an aspect of low self-esteem.

“They might think I’m stupid, other people’s opinions... part of my issues was lack of self-esteem and things that had happened in the past making me feel a bit worthless so I didn’t want to go in front of everybody else and start talking about my problems.” (MPD12)

“Whichever illness it is they will be going through similar feelings, I thought it would be good to attend.” (BPD6)

“Just meeting other people that were in the same situation and understood.” (MPD12)

Some participants, recruited by telephone from a medical route, expected the course to focus substantially on their physical condition. One participant however said their expectations were far exceeded by the reality.

“We expect something before attending but we have seen probably triple what we expected.” (BPD9)

Stakeholder expectations

Stakeholders facilitating courses understandably had clearer expectations for the courses than participants, involving helping people to increase emotional intelligence and emotional management in relation to their conditions. One stakeholder also expected peer support groups might be set up, but this was not clear to all.

“So from the beginning my expectations are that they’ll be able to have tools and techniques to better manage their condition and keep their emotional wellbeing healthy.” (BST1)

“Improving people’s confidence and ability to self-manage their conditions and have a better understanding of their own emotions and thought patterns and ideas of how to better handle those.” (MST1)

“They would build up some peer friendship or peer support and some people would continue

with that and we could have some peer groups set up, or even people swapping numbers.” (BST3)

Stakeholders delivering the course were aware that participants may attend with preconceptions. It was important that the course focus was explained during recruitment and reaffirmed during the initial session.

“There’s always at least one person will say that they’ve come thinking that they’re going to get some advice on what to eat and what not to eat.” (MST3)

“The letter emphasises this is not a course about your medical condition; I made it clear to referrers.” (MST1)

Partner stakeholders facilitating recruitment or providing locations held expectations about wider goals for the community rather than only individual participants.

“[We] think it will be good for the local community. Especially in the [ethnic minority] community... other things are linked with it as well, depression, healthy eating, and sharing the experiences.” (BST2)

National stakeholder expectations around LTC and the programme highlighted taking a holistic view, considering interactions between pain, mental health challenges, and giving people confidence, understandings, and skills to cope better with stressful situations and difficult days, for example, where pain keeps them house-bound.

“It’s important to look at the condition of the person and the treatment in a holistic way as opposed to looking at all these different treatments separately.” (NAST1)

“People with arthritis being able to take part in a programme that provides them with the skills and the knowledge and the confidence to be able to deal with stressful situations or days where they are in a lot of pain.” (NAST1)

There was a clear view of one stakeholder at a participating medical practice that this programme was primarily preventative in intention, in relation to mental health problems. Inconsistencies of expectation arise in relation to the medical and community routes, concerning how to interpret ‘preventative’ in relation to mental health problems which can persist undiagnosed, or have been diagnosed at a past time.

“We don’t just want to react to patient’s illnesses we want to try and prevent things from happening and try to think about their wellbeing as well as physical ailments so that’s obviously a very good fit for us and we are very pleased to have the space to be able to offer the service.” (BST4)

Expectations for participants therefore, although not always clear, focused around making changes in some way, and gaining support from the experiences of others. Stakeholders often played a key role in adjusting expectations in order that the participants understood the course was not about managing physical ill-health but about managing thoughts and emotions that may sit alongside the diagnosis and the lived experience of having a LTC.

Mixed groups

A key aspect of mix in terms of recruitment concerns ensuring that people with different LTC were catered for. In practice, the proportion with heart conditions remained low.

“There has been a lot more diabetic patients coming on board than heart conditions and I don’t know what the reason is.... From my research it shows that it is prominent for both conditions to be honest in the city.” (BST1)

There was a consensus across the stakeholders and the participants that groups of mixed physical LTC were working well within the courses. Participants often found the experience of sharing the course, and working with others with different health issues and conditions, revealing and informative.

“I think everybody respected that everybody had a health issue it wasn’t seen as oh, you’ve got heart, you’ve got diabetes.” (MPH4)

“Even if you’ve only got the one condition, like I had really, the arthritis, you still listen and learn from other people that have got different problems.” (BPA13)

“It was a nice way of being introduced to a subject and also to meet other people. That had something, you know, different wrong with them to what you’ve got.” (BPA14)

“That mix lets people move away from talking about their condition...it’s about your approach to having a condition that people can’t always see

that you manage everyday that's causing you pain that's impacting your life." (MST3)

"People are bonding quite well regardless of their diagnosis." (MST1)

"Looking at things in a different way. Giving real examples, talking about each other's experiences." (MPD5)

It was noted that there was a mixture of people with recent LTC diagnoses and those who had been living with a condition for a longer period of time. This increased the variety of experiences within the programme. Being able to understand other people's realities provided a way of contextualising experiences which may have cross-cut conditions. It was also a way of gaining perspective in relation to their own challenging individual situation, and not being isolated with such challenges. The mixed group, regardless of condition (heart disease, diabetes or arthritis) offered a more collectively situated experience. Participants learned from one another, demonstrating the importance of both peers and lived experience as a tool for building resilience.

"You realise you aren't the only person, alright there are other people going through what you are going through and you may learn something useful from their coping mechanisms." (BPD6)

For a few participants the mix of conditions in the group had problematic elements, for example, one participant said of their course that "the diabetes took over in that group." (MPD1). This reflects an imbalance in numbers. A very few noted a challenge for the group that heart problems were more immediately frightening than diabetes.

"I found it awkward to associate with heart problems, because with diabetes you've got to take tablets and inject yourself but with heart problems it's completely different." (MPD2)

The view of one stakeholder from a national LTC organisation was that mixing people with different LTC together can be successful, as they share experiences and provide support and reassurance.

"It's also probably quite reassuring to think that there's other people around the table struggling not necessarily with the same condition so yeah." (NAST1)

Diverse recruitment routes led to other aspects of diversity within the groups. Stakeholders

particularly identified disparate age or cultural backgrounds. Too much age/diversity could be viewed as challenging for participants.

"[Discussion of varied cultural/ethnic origins of group]...so really different cultural backgrounds and I thought 'wow' how am I going to make a group dynamic from this lot, then with the very much older guy...but it did work, once they started to chat about their problems they found common ground." (MST2)

"I think as you get older you perhaps want people your age to talk about." (BPD14)

Bringing together such complex dimensions of diversity, there are challenges, but the mutual experience of having a LTC was viewed as underpinning the potential of groups to establish common ground.

Gender and participation

There was a view from one coordinator that some male participants came due to the influence of their partners.

"People have told me that men tend not to come on courses like this, so the men who have come have been open. A proportion have been persuaded to come by their partners or wife, and some have come with their wives." (MST1CO)

"Yes and my wife was sort of pushing me to it." (MPH9 – male)

A male facilitator phoning male patients from a GP-provided list proved important for recruitment.

"We did have success with recruiting male patients because of the male voice on the phone." (BST4)

There was also a view that recruitment and retention of men is more challenging. Holding courses in the evening might encourage greater attendance but was not sufficient to ensure retention of men.

"He [man who dropped out] thought it was going to be more of a course about the medicinal side, the arthritis and how to cope, and I don't think he was that interested in the mind side of it." (BP13A)

"There were men and women. I wish we had been able to keep the men more (MST1)

Men tend to drop out don't they? Though they are included and were quite confident at the beginning." (MPA11 – female)

The mindfulness aspect of the programme, with its 'awareness' focus, chimed with some women in particular.

"Definitely, I'm big on the mindfulness I'm just on, I've done, mindful eater." (MPD1 – female)

On the whole, participants found it interesting to have men and women together on the course, as it was valuable to meet people with different perspectives and lived experiences of LTC.

"Oh yes that wasn't a problem. Sometimes it was nice to hear a male perspective." (MPA11 – female)

"I thought that was nice you know, sometimes exclusively female groups get a bit more [makes a laughter sound indicating women may be more intense]." (BPD5 – male)

"I think a mix... we've all got different approaches and...you could get it from both sexes." (BPD5 – male)

Trust and extending comfort zones

The process of developing trust with people, including some women, allowed some men to extend their comfort zone in terms of ways of talking.

"You could get them talking about their feelings and you suddenly realise you're that odd-bod, so you start to open up...It's like the ones who are willing to help – male or female or whether they're willing to open up what they feel. You suddenly feel, 'oh I'm not the only one that feels whatever', and then you do start to talk... There's times when you think, 'I must be the only person here that's got this problem'..." (BPD5 – male)

Possible differences in interaction styles were pointed out. Talking about emotions fluently came quite easily to some female participants – and there was some evidence that this was embedded in experiences of care.

"I felt very guilty, very angry, very worried cause I've got my 11 year old son, I've got a much older daughter.... and most of my life I have suffered with either stress or depression. ...Really isolated, as I didn't know anybody that had diabetes. I am also very controlling. I am in

charge of everything and they know that and so that's just the norm.... I've got no filters." (MPD1 – female)

"Yeah I don't feel like I'm strong I don't think I've ever been confident or strong." (BPD1 – female)

By contrast some male participants tended, at least initially to talk less fluently about their own feelings in isolation, while expressing interest in their condition and in understanding techniques for coping. Men were more likely to initially frame talk about emotions in language emphasising degrees of distance and control ('one', 'you', 'normal').

"I don't have any other sort of condition like depression or anything, so I thought, 'I might learn something from this'. I might teach somebody else when I have experience in that you know, that's what I thought." (BPD2 – male)

"Obviously the relaxation techniques can help you to relax. I don't think I'm basically an anxious person, I'm pretty level-headed so I don't suffer from stress and anxiety usually." (BPD4 – male)

"Obviously I lost my mother a few years, about 10 years ago, and one would have probably had a minor reactive depression to that with bereavement, that's pretty normal." (BPD4 – male)

Despite these differences, overall, many of the men may have said less than some women but proved to have been listening and absorbing interactions.

"I think ladies find it easier to discuss things. A couple of the men, at the end of the course, I was shocked that they'd taken so much in. They weren't saying much, but they'd obviously benefited from it. I was surprised how they'd listened to what other people had to say. That was a real confidence-booster for me." (MPD12 – female)

Delivery mechanisms

The quality of facilitation by the course lead is vital for delivery. Participants commented that the course was well planned, and above all participative. Ground rules were set by the group and the combination of boundaries, structure and participatory approach helped to build trust. The facilitation was designed to ensure that safe

spaces for group discussion were created through variety of activities.

“I thought it was very, very well planned.” (MPD3)

“Interactive, participative...and I think it was very engaging because people were happy to share and people opened up very quickly ...there was a good element of trust there because we set ground rules initially.” (MPH4)

Flexibility

Learning on the programme has involved moving away from over-strict adherence to the written materials, which were found to be too rigid, and not easy for some participants to read.

Developing a larger bank of case studies helped make sessions more interactive and imaginative.

It was considered important that facilitators provide time for participants to exchange experiences, around their lives, their conditions, and their thoughts and emotions, so written materials should not be too wordy. The importance of visual materials was highlighted.

“We’ve got more cases studies, a bigger bank which is more useful for people...” (MST1)

“There was a certain balance I think once I started delivering it with letting people share and learn from each other and also covering the material, because I found people actually really did want to chat and find that solidarity with someone else with that condition.” (MST2)

“Didn’t focus on reading things a lot, we had papers and she picked out bits of them that she wanted to highlight and then we would do one of the trials or circles on the flip chart together and then we’d have a look at an exercise to do together. She would read through that with us and then we’d do the practice session with her as a group and then go and do it in twos or threes.” (MPD5)

The flexibility involved the facilitator making time for participants to take control. This meant developing a topic in unpredicted directions, e.g. around specific episodes, conditions, and mental health problems.

“It felt safe and I think the person that leads it makes a big difference. I know you are going through a programme but it didn’t feel like you were being herded through this gate.” (MPD5)

In effective delivery, the skills of an experienced facilitator, concerning pacing, were combined with well-structured, varied, materials to create a safe imaginative environment where participants could explore ideas and ‘embodied’ emotional experiences with each other and themselves. Participants welcomed being able sometimes to take a listening role, at other times reflect on memories or situations.

“The whole thing was planned out properly so you went from one phase to the next. Led it nicely.” (BPD5)

“It was a good pace because we were always given the option of saying was there anything we wanted to talk about from last week...It’s quite fluid and moveable ... you never felt you were going through the mill.” (MPD5)

It was emphasised that different participants feel safe at their own pace. Some have to stretch their comfort zone before they can speak; they may not be used to speaking about thoughts and feelings around conditions. Some may mainly listen for the first weeks. A skilled facilitator is sensitive to this process.

“In this group session you could say as much as you want or as little as you want. And it’s left entirely up to you ... that’s good because not everybody is the same...three weeks down the line before she was comfortable enough to say anything and that’s when she started, saying what her situation was and everybody giving her kudos and advice and she took it on board and after that she was able to do something about it.” (BPD6)

Language

There were challenges concerning the language used for course delivery. One programme had been delivered giving reduced prominence to Mind’s branded colouring. ‘Mental health’ was not much used; words such as ‘stress’, ‘wellbeing’, ‘emotional’, ‘negative thoughts’ were used. This has the initial advantage of fitting to participants’ lived experience, and avoids potentially stigmatising or frightening language.

“The language we’ve used, we’ve talked about wellbeing, emotional wellbeing, stress management, relaxation techniques, difficult thoughts and emotions or negative thoughts and emotions so we haven’t really talked about mental health.” (MST1)

The extent to which the language of resilience was used in delivery was discussed. The course was called 'Building a Healthy Future', yet there was a view that the focus of the course materials is not on resilience. If course materials crowd out the possibility of exploring at a later stage what resilience means, that is possibly a problem. The complex interactions between life challenges, LTC, pain, and thoughts and feelings challenges people's ability to adapt and change in a forward looking way. This future focus is at the heart of 'resilience'.

"I think the course is a resilience course but I think it doesn't teach about resilience so it doesn't make me feel comfortable. I tend to mention it in the three-month follow-up because then we'd be able to see that's resilience, you've dealt with that stress in a way you wouldn't have been able to deal with it before, and I do occasionally mention, I guess it depends on the group but I don't specifically mention it. The space is about teaching them techniques which will increase their resilience but I don't have the space to teach them why the techniques are about resilience if you see what I mean." (MST1)

It was also strongly argued by a coordinator that talking about being in control of thoughts and emotions resonates better with participants than the language of clinical diagnosis. This is important since the course aimed to include people without a clinical mental health diagnosis, and might also be empowering for those who have a diagnosis.

"People who've come on with a diagnosis of depression, they feel a bit refreshed that it's not that kind of language and the biggest emotional journey is around understanding that their thoughts and emotions don't need to control them." (MST1)

The language and materials of the course needed to be appropriate for community groups, including many who may be older. This means adapting age-inappropriate materials.

"A 25 year old woman who's worried about going to a party and drinking, the older male people don't get it; some of the older women didn't get it." (MST1)

A strength in specific groups, for example, one Asian women's group, has been the use of an interpreter. In a different south Asian group some people had problems understanding English.

A peer had translated some materials for a person. There was wider need for interpreting or translated materials.

"Having a translator there would be good." (BPD3)

"Out of seven, about three people could not understand properly." (BPD2)

The language of a resilience programme needs to cater for participants' readiness to engage with vocabularies of mental health and emotions. This can be affected by personal histories, gender and culture, for example. One Asian participant stated that speaking about mental distress was difficult in her community. The strength of the course partly rested in supporting people in groups to move from sharing dietary advice "in their comfort zone" to talking about coping with thoughts and emotions in that context.

"I think it is very difficult for Asian people to talk about anxiety and depression.... Once they feel comfortable talking about something that's in their comfort zone something that is a necessity of everyday, food and drink, then they might feel comfortable open up about the mind side of it. 'Oh I was trying this, it didn't help they put me on injections, I felt terrible I felt so alone, how did you cope?'" (BP1CO)

The course materials and language needed to support participants to share information advice and support within their comfort zone, and then extend that comfort zone to include (further) consideration of managing thoughts and emotions. Individuals' comfort zones will differ, condition histories affect this, and there may be gender difference. The course needed to move at the pace of the participants to extend their comfort zone for emotional insight. If the language and materials are too remote, difficult or depersonalised this is less easily achieved. Yet, the value of the resilience model should be seen. This could involve exploring possible meanings of resilience and other key terms, perhaps by the middle of the course, once a shared comfort zone has been established.

Effective components

What makes a course effective includes a combination of factors that makes people feel they are in a safe, engaging space, and helps

them think they are benefitting. One stakeholder – a course facilitator – summarised some factors: highlighting environment, structure, variety, and resources.

“I think the relaxation helped. There’s quite a bit of variety in the content, which helped. I think it’s helped giving people a plan at the beginning of what they’re doing each week so they know. I think it’s helped have kitchens and tea and coffee and that as well, on-site. I think it helped having the office support for things like attendance, especially with the large course that’s been really helpful.” (MAST2)

Mixing CBT and mindfulness

An aspect of the variety which has kept participants interested was the mix of Cognitive Behavioural Therapy (CBT) and aspects of mindfulness. From CBT, a core aspect, came techniques promoting reflectiveness and re-conceptualisation, while mindfulness techniques promoted reduction of symptoms and holistic healing. The emphasis was on a flexible balance between aspects that help people cope with life stresses. Specifically, coordinators asserted the value of activities that promote a range of coping skills e.g. confidence building, taking care of self, wellbeing, relaxation. Resilience-building components highlighted in the Mind approach include: activities that contribute to a sense of wellbeing; developing coping strategies; and peer support, perhaps leading people to greater social engagement. All these elements were experienced by participants, for example, relaxation activities, perspective-changing coping strategies and peer support were valued. However, there was perhaps less of a clear sense of future focus, and planning for sustaining wellbeing in the future, though the course was called ‘Building a Healthy Future’.

“Learning how to relax properly, also how to turn things on their head somebody’s running me down, I find a good point and turn it back again.” (BPD5)

“I think it is a flexible balance, it isn’t a mindfulness course.... The elements that have worked have always been there, the relaxations, and most people benefit from them.” (MAST1)

“So the CBT, biggest element is that people can change their minds, change their perspectives.” (MAST1)

Among the participants, some had previous experience of mindfulness or of CBT-based courses. Many participants welcomed a structured mix of approaches on this course (which had strong CBT components). The mix probably also reflects the broad recruitment range, and diversity of needs and experiences. There is some suggestion that participants welcomed not being controlled by a rigid single approach.

“Think there was a good mix of things. It wasn’t just focused on doing the relaxation or doing the exercises, she split it out between classes and then at the end we would do the relaxation.” (BPD6)

“Have tried CBT twice and it doesn’t work for me talking and then all of a sudden write down what you feel.” (BPH10)

Tools and techniques

The importance of balance and variety in materials was emphasised. The practical aspects of the course were appreciated, so that people could apply techniques to daily life.

“I think it’s a brilliant course... everything was, it was nice and practical because you could use it in everyday life, this is all designed I think for everyday living.” (BPD5)

Materials which supported people to have a shared object for discussion and reflection such as scenarios were clearly useful, and also techniques which could be applied after the course, such as relaxation techniques, and thought charts. There were immediate gains of shared experience within the group, which reduces isolation, and longer term benefits if a technique could be applied without anyone else present.

“The activities, the relaxation in particular a really good one for me was just sitting quietly with no noise around me, doing just the breathing.” (MPA10)

“The thing that I’ve found helpful are the thought charts. You can think about things but your thoughts can fly about all over the place. But to write it down and have to think about it and then I can go back and oh yeah I’ve written that down, because especially with fibromyalgia’s when you’ve got brain fog, what did I just think of, so to write it down is very helpful for me.” (MPA8A)

“There was one thing, the calming and the breathing. I was shocked that that would make a difference when you feel tense... she taught us how to breathe through, and I do that...” (BPDAH8)

Among the valued elements of the course were specific tools and techniques for providing insight into emotions such as comfort zone exercises, circles of influence, and thought records. Participants valued techniques where they could gain awareness of how they could control their mood and behaviour.

“There’s a circle where there is things we can control and another circle where we have no control. And that happened because I thought, there are certain situations, when the boys are constantly kicking their ball against my window, the theory is the window is gonna break and it’s the fear, and I’m not in control of that, ...now I ring the police and say I’m not going to deal with them you come and deal with them and I’m not an assertive person but I think I’ve passed the responsibility.” (BPD1)

The value of take-away material was said to lie in approaches which increase control beyond the course e.g. over deciding to be more active, or to achieve more social engagement. Take-way materials also helped participants to remember more, especially as many participants were older.

“She said it’s homework... we all went ‘homework!’ She said, ‘I want you to decide that you are going to do something and what you have not done for a while or before’ so I hadn’t been walking for a few weeks, so I put that down and then I said I am going to make an appointment for some reflexology, so I did that. I couldn’t get in until I think it was the Wednesday last week. And then I did that so...” (BPA7)

“I do listen but I don’t always take it all in, but then I do read all the literature when I get home.” (BPD14)

A valuable take-away was considered to be techniques to cope mentally with crisis periods. Participants valued being able to link managing physical symptoms, managing pain, and managing stress and mental health symptoms, understanding connections between these.

“Like the diabetes when you go out, and I’m on insulin and you are worried about having an episode which has happened loads of times and

it does restrict you from going anywhere because it’s embarrassing and she used to talk about what to do and how to manage it, ...” (BPDAH8)

“The cycle of emotional, physical, aspects – the actual real illness and how it can affect you emotionally, physically, in your daily life. And not putting too much pressure on yourself.” (MPD12)

Personal time

The importance of building in personal time for input, discussion and individual reflection was emphasised. A group of around 6-12 people gave space for reflection. The course should not to be too crowded with material.

“Hearing other people and their situation they’re still able to get something out of it, in that they can still go away and say that person said they did this and that and the other when they felt this way and that way, alright and so they’re able to get something from it.” (BPD6)

It was important within carefully designed activities covering the planned topics to have time for personal reflection and for peer support and discussion. One coordinator said that people feel less valued when they are just given course printouts. Among participants a participative approach and variety of tasks including scenarios was welcome.

“It was so participative and it was very engaging because people were happy to share.” (MPD3)

“There are a number of scenarios given and people have been putting their views forward how they have got the parallels of it in their life because if they can identify it they can resolve it. I found it was useful.” (BPDH3)

It was also emphasised that the course had to be comfortable i.e. with opportunities to break for refreshments.

“We did have a break in between and they have tea and refreshments all the time.” (MPH9)

Challenges

The two projects achieved a substantial number of successful courses. Nevertheless, there were considerable challenges. Among these were: resources (the coordinator needing support); use

of time; among some participants an expectation that the course would be focused more on physical than mental health (e.g. pain management); managing group size; language needs and the perceived excessive focus on written materials; course length.

Resources and support

It is very important that the course is properly resourced. Coordinators with lived experience are resourceful, and potentially vulnerable, but they were making exceptional efforts to build partnerships, recruit, deliver and sustain projects in relation to rigorous targets. It seems clear that support was scaled up half way through the course rather than at the start, when it would have been most useful. With larger groups it was felt to be valuable to have a second person to support people's personalised needs. There was also a view from one national stakeholder that only one of the three national LTC charities had been able to support the programme around referrals.

“Really she [coordinator] was lone working... and she had to keep going on with it and it was a bit disheartening when you've done loads of promotion and then start a course and only two people turn up.” (BST3)

“Their capacity has definitely been an issue and according to them we're the only charity that have supported this that have actually made headway with referrals.” (NAST1)

Expectations

Some participants expected that the course would be focused on physical condition management and pain management. It is clearly very important to have thorough, culture-sensitive preparation in advance around expectations, with partners, and with participants.

“I think with the Asian community that age group it's very much how can you stop this rather than managing it, or it's yes we know I've got it, I've got to learn to deal with it.” (BST2)

There were ongoing challenges concerning retention and management of very small groups after attrition.

“The other challenge was not having a very big group. It started with the four and then it was

three and two. It's quite hard because a lot of the course is built around discussion and exercises.” (MST2)

Written material

There was the challenge of ensuring that the language of materials and the communication was suitable for all. The course was perceived by some to be 'print-heavy', 'incredibly wordy', and not written in everyday language. This problem was not overcome, and may have reduced diversity on the course. Some participants did not like to write too much.

“We had our own in-house translator to translate for X Mind as well. Sikh community, yeah. And we did that free of charge. No, not for long I'll be honest. It was a one-off because when I tried to do a group, second, third time it was difficult yeah.” (BST2PH)

“Other challenges, things like people's specific needs, not just mobility but also some people with English as a second language found it daunting, and people with learning disabilities, he really struggled and I had to have the lady from housing association sit to help him for writing, there's a lot of writing in the course.” (MST2)

“Too many hand-outs, and incredibly wordy... in the middle of the physical triangle on the first week it says physical in one hand-out and somatic in another...people want... real words for real things... there isn't enough for visual learners... simplifying the materials to give a bit more space for people.” (MST3)

“Yeah, very print-heavy, some of the language was not necessarily the kind of language that your everyday person would understand and particularly people that have additional needs.” (NAST1)

Overall, there was a prevailing view that the weekly sessions and the six-week structure encouraged people to join and stay on the course, and gave enough time for delivery but perhaps not for ideal levels of personalisation. One coordinator found herself adding up to 30 minutes extra at the end of each session for one-to-one contact.

“If it had been 8 or 12 [weeks], from my experience it's hard to keep people engaged.” (BST3MA)

“What I ask for is to have 20 minutes to half an hour after in case anyone wants to ask me any questions.” (BS1CO)

Participants’ views about the six-week length of the course varied. Many felt that this was sufficient. Others said that eight weeks would allow people to become more confident.

“After six weeks I just thought ‘oh is that it?’, and I panicked slightly.” (MPD1)

Future focus

Coupled with unresolved debate about the course length, is consideration that the programme should include a more future-focused and personalised element, especially in the final week. This would, in one coordinator’s view, support more ‘goal-setting’, and focus on ‘resilience’ in people’s complex lives going forward, as well as, possibly, on ‘acceptance’. Recruitment strategies have only increased the diversity of participants, and their challenges. So a six week course needs to be very well designed and may not be enough to prepare people to face the future.

“I think that although it’s not long enough I think our last session doesn’t use the time very well at all and we could do more in that session that would be worthwhile for people....that would probably be the session that I actually get a bit more goal-setting going.” (MST1)

“If you are billing something as a resilience course then teaching people a bit about what resilience means and giving them some expectations of what it means for them in their lives is really important and this doesn’t quite do that, but I think I would like to see more on the course about the future, there isn’t anything specifically about what to do, in the last session it asks what will you do if you have a setback, but there isn’t a build-up strategy, a plan or goal-setting and sometimes I know that people are really worried for their futures and the acceptance stuff still is missing.” (MST1)

“I think I could have done with another couple of weeks.” (MPA10)

“Another two weeks would have been better perhaps.” (MPA11)

Coordinator as resource

The course was delivered by the lead coordinator, and also by other facilitators when there was more than one course running concurrently. Having more than one person trained to deliver seems very important, given the multi-tasking required of coordinators who recruit participants, deliver courses, and sustain engagement with partners. It was seen as important that the training engages with the methodology, the resilience model, techniques, and knowledge about both physical conditions and their mental health implications. Facilitators who had been trained saw this as essential.

“Mind employed me to deliver the course whenever [Z] couldn’t. I think her targets were quite high over the years and of course she had to deliver and then she was only on part time hours.” (MST2)

“There was a lady at the training from the British Heart Foundation. That was helpful because she explained different heart conditions to us and how people might be, in reaction to any anxiety they may have. But I might have felt a bit more confident if we had a bit more of that for diabetes.” (MST2)

It seems important that course facilitators should receive similar training, while lived experience (around life challenges, and especially LTC or mental health) was a great asset. It was pointed out that extensive experience working with people with mental health problems can equip people with appropriate skills and insight. However, programme sustainability also depends on high quality resources, support, and trained facilitators.

“Well [lived experience] gains you more trust and respect with the participants, you can relate to things a lot more. You can share personal examples as well, tips and so on, yeah and I think people were just more open and more willing to share if you’re sharing... it puts you on a level with people and I think that’s really important, but I suppose if you have facilitators who work with people with mental health problems.” (MST2)

“That’s [lived experience] really useful and important, but not essential, I know [Q] doesn’t.” (MST1)

Qualities

The main qualities praised by participants included understanding of LTC and pain, empathy, topic knowledge, communication skills, and not seeming opinionated. Participants valued that the facilitator speaks as an equal, as well as being organised and skilled. It was important that the facilitator engage with them in a personal way that, it was perceived, some health professionals lacked time to do. These qualities helped participants to feel safe.

“Yes she’s been very good. Just the little things that she would say. You know ‘it’s not homework, I’m not going to be asking for it ...’ it stops you from worrying.” (MPA8)

“Because she wasn’t opinionated on anything. You could say anything.” (MPD12)

“Completely different illness but the feelings and the thoughts, which was what this course was more about... really hit home that other people go through the same.” (MPD6)

“They allowed you to talk and then they would tell you some of their experiences sometimes so that you realised that they had never always been as confident as they seemed.” (BPA13)

“She listened, that’s the main, she listened to what you were saying and she answered.” (BPADH8)

“She seemed to be really interested in what she was doing.” (BPDH11)

“She was very good at it. She wasn’t speaking down to you; she was speaking at the same level.” (MPD2)

Support for facilitators

It was very important for coordinators to have sufficient back-up resources to develop materials and engage with participants effectively. It was suggested that further support (e.g. a second role) is needed to assist the coordinator.

“When you’re carrying out a difficult role [coordinator] that you don’t know if people are going to turn up. I think when you’re working with a peer and something is challenging, there is a way that they work together and how they were supporting each other and it worked really well.” (BST3)

“At the moment we are running five courses at the same time, that’s not physically possible for me, so we’ve had two people trained up assisting with delivery since September when we started to really ramp up the number of courses, and I have an admin assistant here, doing pre-course phone calls and reminders.” (MST1)

“We’ve had some extra money off national Mind so were able to recruit a part time engagement worker for 15 hours a week from November. It’s worked really well we’ve got 10 people on this next course.” (BST3)

In building relationships with potential partners in medical practices it was important that the lead person showed efficiency, and flexibility to understand their priorities. Both coordinators brought valuable experience to the tasks of building partnerships.

“She has been very key to it being successful she just comes, she gets on with it.” (BST2)

Both programme coordinators found the role highly demanding with challenges out-reaching their allocated paid time. There were advantages in having a second person to ring potential participants at the recruitment stage (e.g. a male to ring men), and assist with delivery, but this was only facilitated at a later stage of the programme. The work of ensuring participation and pursuing high targets involves resource-intensive phone calls, letters, texts, and repeat calls.

“The person who’s running the course, who we engaged with initially, was key to getting us on board.” (BST2)

“What I’m trying now is have three days where I’m doing two courses per day. If I’ve got eight people that I’m trying to address issues with after, I can’t... no way that I can be stretched.” (BST1)

Peer support

Participants were very supportive of the experience of peer support within the course, for overcoming isolation, and normalising their experience. An important aspect was the recognition of difference and possibility. Peers were able to reframe a participants’ understandings of situations as well as normalising and reinforcing their experiences, to be non-judgemental, to offer

an example, and to support a participant to come out of an isolated mindset. Participants could enjoy reciprocity, and exercise practical empathy.

“It was helpful to meet people who were like-minded. Sometimes you become insulated and you feel that no one has a problem and no one understands and then you realise that (laughs) it’s very egotistic that you are thinking of yourself all the time.” (MPA11)

Participants welcomed having peers who understood how their LTC affected their wider life circumstances, for example taking account of perceived and in some cases internalised stigma over LTC, and supporting them to engage with those challenges. At the end of some courses, participants were invited to write a message to others, and these showed the value of reciprocal support.

“Some of the comments came like ‘thank you for saying certain things, because I wanted to say it, and found that I couldn’t say it. It helped me you saying it.’ And one of the gentlemen had put in ‘you faced your fears by telling your work colleagues – well done, and good luck in the future.’ And you thought ‘ooh, they’ve genuinely listened.’” (MPD12)

Trust and challenge

Gentle challenge predicated on trust was important. The peer support could push participants outside a very isolated comfort zone, and perhaps support them to question habits of mind. Extending the comfort zone was possible because participants were in a safe space with a skilled facilitator and group-set ground rules e.g. non-judgemental comments, with flexible materials allowing supportive discussion.

“We set the ground rules, in saying look whatever we say nobody to judge.” (MPA8)

“Both of us have got different ideas...in a way you’ve got a different way of looking at something.” (BPD5)

“A guy said ‘excuse me...I think you cope really well, you might not think you do, but I look at you and see someone who copes really well.’” (MST1)

“It helped from the point of view of the discussions, because one person was coping with their problems one way and another one will use another mechanism for coping with pain or

problems and having the discussion ok, actually helped us all out I think because... you take little bits and pieces of information from everybody. And you can apply it to yourself to see which one works best for you.” (BPD6)

Some participants were further along a road of resilience, others less far, and this difference was felt to be positive in offering participants perspective and challenge.

“You could, looking on the other side say how good or bad they are and think, well... I was like that before or I’ll end up to that standard, so you, you got double feedback with those people.” (BPD5)

The process which supports extending the comfort zone was at times strengthened by the facilitator mixing up groups. That the group had people with different conditions did not generally harm this process and may have added to it.

“She said ‘I can’t have you sitting with the same people and doing the same things, so you’ll all have to inter mingle’, which I found very good, because then you are not just talking to one person.” (MPH9)

“It was a group and it was like-minded people. I wasn’t quite sure as it’s headlined people with diabetes, heart disease, long-term chronic conditions, but I think we have all been down that same road.” (MPD5)

Activities and talk about life challenges

Supportive talk was triggered through activities such as comfort zone and thought circles, in relation to discussion of life struggles (e.g. caring), and to emotions arising from fluctuations in condition management. Some participants contrasted this group experience with individual CBT counselling. Perceived advantages were that they were not alone, and the approach was felt to be flexible. This flexibility was strengthened by coordinators adapting a CBT-based course.

“What I had was better than sitting one-to-one saying ‘I feel like this, I feel like that.’” (MPD12)

“I have had some CBT before and didn’t really feel like it did anything. Now this setting is much much better. A class setting and listening to other people. They might say something that you are a bit reluctant to say.” (MPA8)

“I’m not knocking CBT...but I don’t think it’s a one size fits all because you are talking to other people and they are sort of saying all the things you have gone through, you don’t feel like it’s just you.” (MPD5)

Participants were able to talk about life challenges and not just their specific condition. In some cases discovering a bit more about somebody resulted in mutual choice to keep in touch after the course.

“We meet each other here and we become good friends outside. They feel there is somebody that take care about me and she asked about my health,...if we visit each other I think it will be good.” (BPD9)

Several participants said they had difficulties in daily life discussing their condition, pain, challenging life events, and their impact on emotional wellbeing. The group discussion enlightened participants about these complex relations.

“It was the work stress and I couldn’t get out if it because the manager was being awful not just to me to a lot of us and that’s why I couldn’t understand I was being really strict with my diet but why was the sugars going up high to like 14/15. But what didn’t help is I didn’t know the two things were related. Now I know better... And now if I hear anybody say ‘oh I’m going through so much stress, my blood pressure is really high’ I’ll say to everybody, ‘please if you can get out of it, you know even if it means going for a walk at lunch time, take yourself out 20min fresh air, calm your mind down.’” (BPD1)

A stakeholder for a national LTC voluntary organisation supporting the programme stated that peer support was likely to benefit participants with arthritis, particularly older age groups who may be isolated.

“I think people with arthritis that would access the course would benefit from definitely the social interaction particularly some of the older ages groups who possibly don’t get out as much.” (NAST1)

“People talk about feeling isolated, they really value being around other people who understand.” (MST1)

After the course

Concerning whether the participants maintained peer support and developed friendships after the six week course, the key element seems to be choice. Some participants clearly did not want follow-up contact. The group allowed people to talk about conditions away from their daily life rather than within their daily round. Others were very happy with phone numbers and the option of contact, which some took up enthusiastically.

“There didn’t seem much camaraderie after. Although there was a lot of empathy during the group.” (MPA10)

“We’re meeting next week, so that’s a fortnight from that, and I think a fortnight will be enough for us.” (BPA13)

“Just swapping numbers and two or three of them meeting up for a coffee or just swapping emails. So they are in control and it’s informal, just natural involvement really and friendships made.” (BST3)

One programme offered monthly drop-in sessions as well as a three month follow-up. The drop-ins were popular for a geographically limited number of self-selecting people. The other programme organised a celebration event for participants to catch up, eat, make contacts with each other and mental health staff, with an offer of massage. Such follow-up events offer further opportunity to meet different people with LTC.

“We have the monthly drop-ins and a core group of people coming since the course was here.” (MST1)

“You’re not within that same group. It’s different people who are all saying the same things.” (MPD5)

“If the people that run it would like to meet us in three or four months’ time, I myself would like that.” (PBA14)

Some participants welcomed the three-month follow-up as a one-off event to maintain contact and check on each others’ progress and wellbeing. There was a wish to get on with life and reduce dependence, consistent with resilience.

“I don’t think anybody would want [three-month follow-up] to be a regular thing but it was nice timing.” (MPD5)

It was recognised by some participants after the course that they had missed a support group. Many participants would welcome staying connected with others with a similar condition to provide peer support around managing their condition and emotional resilience. Some participants formed informal peer activity and friendship groups. An example was described as a walk-and-talk group.

“There’s two of the group started an informal walk-and-talk...which I think is brilliant...so we went over to the pub and had coffee. God I was thinking [sigh of relief] and we sat just nattering for about two and a half hours...some of it was about this and what it had done for each of us.” (MPD5)

“Is there a possibility we could set up a support group for people with diabetes or heart conditions on a regular basis...for volunteers to set up even for ongoing... I personally and from what I’ve heard from other people in the group rather than have a mind group, nutrition or you know diabetes people want to amalgamate the two, they go hand-in-hand.” (BPD1)

Peer experts

Some, not all, participants, suggested that they would like to play a role as people with experience to support others. While some participants wished to informally help friends and colleagues, others were interested in a more formal role perhaps in community self-help groups or condition-related local groups. At one drop-in session, peer support training was provided (from Oxfordshire Mind) over half a day.

“Course helped me in a lot, I can take more care about my health and I can teach my friends if they have beginning like me diabetes, I can help and tell my experience.” (BP9D)

“They are talking about doing peer support groups. I went to the training session for that. I am assuming there is going to be some more, I don’t really know, but it just makes it feels a bit real, a bit more attainable.” (MP5D)

One course participant suggested that it could be valuable in future courses to have a previous participant along as a peer supporter every two or three weeks: this might help reduce attrition. Some participants had already taken on an

‘expert’ role; there was potential for that role to be extended to include linking physical and mental health experiences.

“Bring people along who were on a previous course... to talk to people on the course to enable them to gel as a group ...just say, you came on this course, what you did, how you did it and how you’ve moved on.” (MPH4)

“Yeah, I went and did the expert patient course... I chair patient support group in my surgery so I will make sure they know about this group... a lot of people do not understand or are not aware that there are a lot of people in the same boat. Sharing their experiences and hearing that somebody else is diabetic, the psychological effects it has on them, are the same as their suffering.” (BPDH3)

However, it was said by facilitators that the programme development, course structure and materials did not include preparation of peer experts by experience, and therefore this training aspect was not really developed.

“I think if people want a project like this to be doing more of that then actually you would have some material about peer support on the course...if that’s what the outcomes are for the people who come on the course to be able to support other people.” (MST1)

Outcomes

Participants have reported life-changing impacts of the course in areas which included: accepting limits; developing and implementing new coping mechanisms; reduced anxiety; being more relaxed and more resilient; taking a greater interest in life; finding that reducing stress also has an impact on physical conditions; and healthier lifestyle. These impacts will be discussed under headings of: confidence; mood, relaxation, perceptions and perspective, social engagement, activities, and physical health.

Confidence

An aspect of gains in confidence attributed to the course consisted in being able to set boundaries and say no to excessive demands. Some individuals were said to be poor at putting themselves first and finding ‘me time’.

“Looking at why we feel that we should be like super person and having the confidence to say to like family that ‘alright I can’t do this today or maybe not this week, but maybe next week.’” (MPD10)

“It got her thinking more about that and once or twice she actually put herself first.” (BPD5)

Another aspect of confidence was not to feel unworthy in social contexts because of health issues. Tied to this was greater confidence to step out into social situations.

“It did boost my confidence, to realise that people weren’t going to just dismiss me just because I had health issues.” (MP10A)

“More confidence in talking to people. Some years ago, this would be my worst nightmare...” (BPDH8)

Greater confidence was evidenced for some participants in being less liable to panic or get very anxious. This was tied to an ability to dismiss negatives and push positives forward. Confidence was evinced in being able to pursue a goal such as routine exercise.

“I’ve been going to that now moving on to referral to the gym... it’s made me like I have to keep doing it.” (MPD6)

“It’s made me more confident in some of the things that I’m doing, rather than getting panicky.” (MPD6)

“Like if I want to go swimming, I’ll go swimming. Not be so worried of what other people think.” (MPD12)

The course gave people more confidence to talk about connections between life stresses, LTC and coping. Some participants expressed confidence they could manage their LTC better.

“Overall summary is they give you confidence how to explain yourself. Open up more. Some people don’t want to disclose it they don’t want to talk to other people, okay if I talk to them he will find out, oh he is suffering from blood pressure, diabetes, heart disease.” (BPD2)

“But it started from the outer circumstances, work stress affected my diabetes going out of control then affected my mind in that order which I wasn’t aware of. I would love to run this course. We need to educate people who may be suffering with the mind issue of it...and if that’s sorted, if

you calm that down, your health surely has to start getting better and touch wood, my diabetes is getting better.” (BPD1)

Mood

Participants described impacts of the course on their mood which included: feeling calmer; lighter mood; less anxiety; and better sleep patterns. Improvements in symptoms such as headaches were described.

“My sleep improved, my breathing. Improved headaches, improved social life.” (MPA11)

“My mood has definitely lightened.” (MPA8)

Improved or ‘lightened’ mood was associated with reduction in use of anti-depressants, and coping with anxiety-provoking events such as a flood in a flat without getting too stressed.

“Yes and I have reduced my anti-depressants. I’m coming off them.” (MPA11)

Relaxation

Participants described relaxation techniques they had taken from the course. Achieving relaxation was seen as a meditative labour involving practice.

“I do the relaxation stuff and the breathing exercises. I do some things in my head without realising that am going through that kind of process. Coming home we were sat in traffic and I could tell my mum was getting a bit irritated and I was like ‘right come on we’re going to do some belly breathing’, I’d been teaching them what we’ve done, so we did it. I said ‘mum do you feel better’ she said ‘I do actually.’” (MPD5)

There was realisation that gains were provisional, that life could always kick back.

“Life is life is life. I do feel better with the anxiety but it depends what’s going on with your life and how you can cope with it, and putting it into practice, which sometimes I’m not doing.” (MPA7)

Therefore, participants recognised space has to be made in life’s routines for coping strategies.

“Relaxation therapies...you have to make the time to do it because it’s not always possible...” (BPD6)

For some participants, activities which they liked doing could be focused on as therapeutic, such

as music, puzzles, and walking. Sometimes these activities could be social, bringing additional relief. Many people with LTC may want to relax at times when physical pain and anxiety makes this challenging; the activity may bring benefits.

“We’ve always loved music anyway... just cannot get to sleep...And what I’ve found recently is puzzles... I have an iPad and every night before I go to bed I have to do at least two puzzles....” (BPD6)

Perceptions and perspective

In the view of one course facilitator, the main advantage of the CBT course elements consisted in supporting people to realise they can change their perspectives. Participants reported that they could interpret other people’s behaviour differently, set boundaries to avoid punishing themselves for failure, and reframe negative thoughts more often.

“So the CBT, biggest element is that people can change their minds, change their perspectives.” (MST1)

“Because I have fibromyalgia I feel that any stress seems to make it worse because of the flare-up so I was looking for anything that can be useful in stopping me thinking negative thoughts, and bad memories. And it has helped me, given me tools so that I can challenge the negative thoughts.” (MPA7)

Participants were able to better accept what they could not change. This includes setting boundaries to expectations in caring roles, making time for themselves, and having social strategies for this.

“Things like coping strategies, and I’ve actually got out of it that it’s ok not to be alright, which is something I have never got before. Logical side of my head will tell me all these things, but the emotional me... that’s different. And more about learning to live with it and cope than trying to cure it because I’m 57... It’s not to go away is it, you know.” (MPD5)

“My health issues are compound, I’m a carer as well... one thing that I take away is I write things down now. I’ve got appointments with specialists, and I tend to go with her but I’m not going to get up there if I’m stressed by doing that. I’ll use the relaxation techniques, reference back to the strategies.” (MPH4)

“She was always the one everyone looked at to support them never thinking she has her own problems and also needed breaks away from everything and I think then she sort of realised, hey I can take time for me without failing and letting everybody else down.” (BPD6)

The course had clearly been valuable in letting participants accept boundaries, and have a toolkit to reconsider their perspective in order to live with the adage ‘what you can change, do, what you can’t, let go’.

“The old saying what you can change will be wonderful and what you can’t change just let go.” (BPD6)

Participants also stated that their ability to take a more understanding perspective of social adversity was enhanced. They were able to reframe social situations, not to overreact to perceived slights or unpleasant behaviour. This could include routine work situations that seem unavoidable.

“I’m in charge of membership and we had a comedian... one committee member decides to start, not exactly running me down, but saying ‘look we could do with doing this with the new members’ and that was what I already do... and instead of – I’d have flared at him at one stage – I just sat back ... How to relax at every opportunity that’s a healthy thing and also this turning a negative to a positive.” (BPD5)

“Because in here, it can be very confrontational with patients – I decided in my head ‘just don’t take anything personally. It’s not you, you could be anybody.’” (MPD12)

Occurrences of negative thoughts might happen in fraught situations such as when not being able to sleep, or in a family crisis. The learning from the course would be tested in moments of crisis.

“If I couldn’t get to sleep at night with all those thoughts would go through my head and make me feel worse, so I want to be able to sort those out. I know I can’t change anything and I probably will still remember things but I don’t want it to be the real bad negative thing anymore, I want to think about the nice things.” (MPA8)

So participants acknowledged that the course had helped them get a perspective on their problems but that in really challenging situations they remained vulnerable to oscillating between more and less positive patterns of thought. There

was recognition of the vicious circle of stress and physical ill-health flare-ups, and the vital role of cognition in affecting this.

“Managing the thoughts, that never stops (laughs). I’ve got a worry going round in my head all the time (laughs). I think it [course] did help yes.” (BPDH11)

“It’s like a big circle... you get stressed, so your blood sugar level goes up then you, so you’re getting more stressed so that puts it up even higher... you just get into a... spiral then. So as soon as you see something going wrong... put yourself somewhere quiet or get yourself out the way of everybody... and almost look inside yourself and sort it...” (BPD5)

Social engagement

An impact reported by several participants was overcoming isolation and improved social life. Making new friends from the course for mutual support and social activities was a very positive outcome for some participants. Others spoke of this as an aspiration. The course gave them confidence and some choice over keeping in touch.

“The niceness of it is because it’s informal. ... in the summer there is places we could meet up.” (MPD5)

A few participants reported becoming more open to social engagement even if they had not kept in touch with people from the course. Some aspired to find a condition-related support group after their course experience.

“So you tend not to panic at social events. You see them coming up and you think ‘oh, I’m running to the other side of the park’... but you suddenly think ‘no I can’t I’ve got a job to do...’ and so you sort of go with up a big sort of smile on your face and... y’know start to talk to them...” (BPDH8)

“I’m looking for a support group that’s open for diabetes which is good.” (MPD2)

Activities

One course coordinator believed that the participants were taking more exercise and pushing themselves more as a result of the course.

“They are looking after themselves more and doing things for themselves that they may not have been doing before, whether that’s relaxation or exercise or getting out of the house or pushing themselves a bit more...” (MST1)

It was reported that some participants have included exercises in their daily routines and as ways of responding to life stressors. The range of activities which participants reported taking up since the course included: volunteering at a community centre; crochet work; taking a holiday; and a variety of physical exercise activities. While activities are often social, some participants welcomed creative or constructive time reserved for themselves.

“I’ve started volunteering with a group with people whose first language isn’t English.” (MPA10)

“I’m going to knit one little square by New Year ... so I’ve actually started doing it. And it’s ok to have that time to myself rather than sharing it with everybody.” (MPD5)

The group had encouraged some participants to resolve to persevere with exercise, e.g. gym, jogging, walking, rather than be sporadic. Greater confidence and self-esteem made it easier to engage in physical activities in public places.

“At first I was like really hobbling along, so it’s nice cos everyone gives each other a boost and has a laugh and a joke. It’s made me like I have to keep doing it, it’s something that’s important.” (MP6D)

“I didn’t want to put a costume on, being a big girl. People looking at you. ‘Is that your interpretation of what people are going to – ?’ Anyway, I went away for the weekend with one of my friends, and we went swimming, and it’s like nobody’s bothered!” (MP12D)

Physical health

Evidence of improved physical health from the course was mostly indirect (e.g. reports of increased exercise). However, one course facilitator believed that some participants were taking better care of themselves so that their health was improving.

“Some people are reporting better physical health as a result of being able to take care of themselves better, you can see it in their body

language often they are coming in, not looking at the floor.” (MST1)

Some participants believed they were now taking better care of themselves, through understanding better the interactions between physical health and mental wellbeing. For example, one participant made connections between course participation, regular exercise, improved diet, and lower blood pressure.

“Start with exercise everyday every morning at 2km I jog on the treadmill every day and sometimes I go up out with my husband walk around the lake and I watch my food and I think exercise is very important and I left everything in and I start with green tea, my blood pressure become low.” (BPD9)

Wider social returns

Coordinators and participants referred to impacts which they expected and had begun to observe in terms of the wider social value of the course. Coordinators observed that the GPs were looking for fewer patient appointments, and evidence of improved emotional wellbeing, management of medication and health condition. However, the course could at times lead to increased engagement with the health service as people want to understand their condition more.

“Here are a lot of people who are very ignorant about their medication or their conditionwho wanted to be referred to the diabetes centrethere could be an increase of NHS services because people want more information and to understand their condition more.” (MST2)

Among the impacts reported by participants, some mentioned sharing what they had learned more widely. Carers mentioned being more effective in caring work, so having a positive impact within their family.

“I’m looking now for something to help X....In my role as caring for people to pass it on.” (MPD3)

“I think it’s good because then you can promote the course to other people can’t you?” (MPH4)

Sustainability

Maintaining gains

Course facilitators believed that if an aim was to develop ongoing peer support as a means of maintaining gains after the course, then some peer support training elements should be built into the course specifically, as an extra week at the end, or in reunion sessions. The focus on both acceptance and goal setting could be strengthened during the final session to prepare participants for maintaining gains after the course.

“Another idea of mine was to get people back together and just go through a couple of hours. I don’t know whether to call it peer support training but for people equipped about how to set their own support group up. If you did another session on what’s next, how can we peer support each other, even if it’s to talk about how could you meet up as a group if you wanted to continue to do that.” (BST3)

It was also emphasised by stakeholders, including facilitators and national LTC partner, that follow-up sessions after, for example, three months, offer a means of setting goals, and encouraging participants to return to materials and to maintain new routines. The drop-in sessions which had been held in one programme were also considered very useful for connecting people to each other, as people came to drop-ins off different courses, so offering social opportunity and challenge in a safe space with a familiar facilitator.

“The follow-ups would be good to...see if people have returned to the material.” (MST2)

“We do a goal setting exercise in the three-month follow-up and I think it’s quite useful.” (MST1)

“It’s really important to do an icebreaker and remind people of the rules, confidentiality.” (MST1)

“Not everybody is going to be happy with a six week course and never see those people again.” (BST4)

“Keeping regular contact with those people maybe for the first six months, maybe every three months just bringing people back together again and helping them to develop and build relationships with one another because it’s quite hard to do that in the course.” (NAST1)

Participants' views

Participants own reflections on ways of ensuring gains are maintained included joining: a LTC support group; a healthy lifestyle group; follow-up sessions; peer support groups following training; informal walk-and-talk groups.

One theme from different participants was that it would be useful to bring together support over managing the LTC with support over emotional wellbeing. This reflects the connections participants perceived between their moods, pain management and their physical conditions. So one participant had joined a LTC (fibromyalgia) support group. The participant believed they would not have done this previously due to lack of confidence and fear of encountering their own future.

“As a follow on from that I found out about the fibromyalgia group, that meets once a month. I don't think I would have gone [before the course] because I've always felt a mixture of fear and lack of confidence. Fear of what I am going to encounter... people worse than me, and what that bodes for my future, rather than looking at it positively. Alright these people are worse than I am but that doesn't mean to say that I'm going to get to that.” (MPA10)

“This one involves changes in life skills. So it includes diet, exercise, relaxation things as well.” (MPA11)

Participants were generally enthusiastic about a three-month follow-up session and where they had participated found this valuable. The facilitation of these sessions was very important to allow participants to bring up any new challenges in applying their learning in practice. It was very important to ensure that participants did not fall back on habits that reflected their vulnerability, and this was the opportunity to strengthen resilience.

“Because there was a follow-up that made a huge difference for me ...It was three months after the course. Most of the people that were in the group that were there just sort of went over what happened in the group and how we felt about things now and whether it done us any good....if it raised anymore issues.” (MPD5)

“One thing when we finished I was like ‘is that it? Are we just left now?’ It was quite a nice group but then (facilitator) said we do get back together

in three months to re-visit it, which is good.” (MPD6)

Some participants, welcoming the three-month follow-up also said the option of further follow-ups would be useful. Some had valued the monthly drop-in sessions which were offered in one locality of one region. Others had participated in a celebration event in the other region. This was valued in that it offered food, meeting others, signposting to other therapy and counselling opportunities, and a massage offer.

“It was a lovely, lovely spread, a lovely buffet and massage...” (BPDH8)

“On that day, we brought signposting information.” (BST3)

Overall, participants stressed that while the choice of continued engagement should be theirs, it was very important after six weeks not to feel abandoned, because the challenge of implementing what had been learned had not even started. Some participants were in a vulnerable state before the course, for example, lacking confidence or motivation to leave their house. The risk of relapse is real, especially if participants are recruited who have some history of long-term mental health problems. Some participants felt anxiety and impending loss as the course ended. If the six week course still left some participants feeling their individual needs had not been fully voiced, follow-up sessions and optional signposting to one-to-one support or continued group interaction, would enable this to happen.

“If there is another group session that I could join...if there is a one-to-one session because I just don't feel like I'm ready yet I've got this social phobia and I don't even know how to get out of that I don't even know how to get out of my comfort zone.” (BPD1)

“We didn't have really time to speak as individuals... but on this course there was no follow- up.” (BP6D)

“You've done six weeks so you then have double that to go away and practice the things and see how you're feeling. It gives you a good time to see if it's made a difference, so I think that's a good timing, and I think maybe three/six months ones after that... not necessarily with the people you were on that with but with the wider community that have been on that course. But I

think it needs to be organised rather than you can just come into the centre.” (MPD6)

Sustaining the programme

The programme delivery was heavily shaped by the national numerical targets, which turned out to be demanding. In the regional setting which followed a medical and primarily ‘preventative’ route, while the targets were not attained, participants’ satisfaction was positive and lessons learned. Taking a broader community ‘self-referral’ route, as in the other region, opened the programme to people who are more likely to already have more extensive mental health experience, so easing recruitment. The debate concerns whether criteria should be opened up in this way.

“I don’t think the project has achieved the objectives with the numbers of people but I think it’s achieved its objectives with participants’ experiences, the positive outcomes from it and the feedback that we’ve got from people.” (BST3)

With this duality, there is a likelihood that people with LTC would be referred by GPs, while from community settings some people might attend who already have long-standing conditions, including possibly experience of mental health conditions. A stated purpose of the course was preventative, to engage with people with LTC in order to encourage them to develop resilience strategies to prevent mental health conditions from becoming serious or long-standing. The width of recruitment makes it necessary also to consider whether the programme helps people who may already have mental health experience, which may be contributing to their LTC.

Preventative focus, referrals, and evidence

Concerning sustaining the programme with a preventative focus: a stakeholder from a pharmacy which provided assistance with venue and recruitment wanted a well-structured system of GP referrals, and for the programme to connect with working environments, including for example, call centres which are stressful work environments, and through job centres where people with LTC may be obliged to attend.

The pharmacy stakeholder suggested GPs could contact employers/job centres recommending attendance. Later out-of-work hours for the course would be good for attendance of working people.

“Things like this needs to be advertised in the working environment allowing employees the opportunity to go out to these courses...I’d use the Job Centre as well. I have already done that as well, because I found it a bit challenging at the [Z faith centre] so I linked up with the Job Centre, and I said loads of people are on sickness and benefits and there must be a reason, let’s target the people that have got these diabetes...the big call centres as well. The last thing that any employer wants is their staff to be off sick.” (BST2)

A stakeholder also believed sustainability would be facilitated through gathering evidence of how effective attendance was for newly diagnosed people attending the course in relation to those not attending who had been living with the condition for a long time. It was felt to be imperative to run these courses through effective partnerships with GPs and perhaps employers, to ensure sustained recruitment and feedback of evidence within health and work sectors.

“The doctor’s just diagnosed you with diabetes, by you going on the course, on the very outset managing your lifestyle, has it reduced your medication? Has it, how you manage your stress levels, comparison to somebody that’s already dealing with that?...It’s only worth running these courses if we work together in partnership with other organisations, like the GPs and employers...” (BST2)

In medical settings there was a view that evidence of outcomes is needed that fits with CQC. In the first instance, if a GP provides a list of patients who might attend a Mind course, it was suggested by a practice manager that the GP should be made aware who might have attended the course, and is provided with follow-up information concerning the patient’s progress.

“Some evidence that helps to facilitate a dialogue between the patient and the GP next time then if the doctor feels that they have improved we can document that we can you know recode any information which is searchable we can provide our evidence ourselves.” (BST4)

“We know as practices we are going to get the best possible outcomes from the CQC if we can offer the service and show that it has got the evidence we think it has and so it’s getting that evidence really I think is the key to it. It isn’t easy is it?” (BST4)

Concerning recruitment through the statutory health system, general practices are linked vertically to Local Commissioning Networks and Clinical Commissioning Groups. It was argued, early, that evidence of success in particular practices should be disseminated through these channels and used to encourage other practices to participate. If a course was run effectively and easily at a practice, without much inconvenience, and with good fit with CCG assessment criteria around enhanced services, that encourages a practice to repeat the offer.

“We are actually looking at other avenues of care, different services that we can provide and so from our point of view, it fits that criteria as well that we can show, we’re providing extra services.” (BST2)

To sustain engagement, outreach, considered as relationship management, needs to be ongoing. Delivery and evidence collection needs to fit with GP criteria which concern patient time, and evidencing emotional wellbeing. It was considered important to evidence gains in Local Commissioning Network meetings.

“The outreach is going to have to be a constant; to make sure it’s constantly on a GP’s radar or a healthcare professional’s radar, you have to maintain that essence of relationship management.” (BST1)

“But I have got there with two LCNs now....So let’s say X has 12 practices; those 12 practices will actively recruit for those two courses... I think it will sustain because as I’ve said I’ve managed to establish these networks. Where I’ve delivered, they kept me on because they see that it works and patients are benefiting from this.” (BST1)

The reality was that at one pilot programme, these aspirations were not fully met. Resource constraints and priorities both within Mind and within the medical practices and CCGs meant that delivery remained largely constrained within one practice. At the other programme, prioritisation of community routes leaves begging the question of whether primary care GP and CCG routes would have been effective.

Delivery

Concerning delivery, to support retention, some additional support for individuals in larger groups and fewer writing demands were suggested by stakeholders. It might also be a good idea to formally integrate the three-month follow-up within the course structure and plan from the start, it was said.

“With larger groups it’s quite useful to have someone else on support sometimes when people can’t write very well, or if they have a special need.” (MST2)

The efficient and warm communication between the coordinators and partner stakeholders e.g. in medical practices was a very important ingredient in the success of the courses. This efficiency included minimising workload for the partner stakeholders e.g. practices. However, this efficiency is threatened if the coordinators are overstretched or cannot cope with all the demands.

“It has been easy for me in that the people who have been providing the service have been very approachable even when they are not on site I have been able to contact them very easily via email or telephone and they have always been very responsive.” (BST4)

Capacity

Capacity was a serious issue. In the early phase of the programme, the lead coordinators were overstretched. While resources were increased at half way point, by then there were serious challenges of achieving a balance between networking to recruit, maintaining partnerships, delivering courses, administration and follow-up. In the end, the range of partnerships used for recruitment at one programme and the overall balance between prevention and recovery at the other was probably affected to some extent by planning issues and scarcity of resources in the earlier phases. Coordinators with experience need peer support.

“As a learning if we could do it differently we would straight away have two people. I know that money can be difficult but even if it’s a part-time recruited volunteer, or another part-time post to co-deliver courses and help with engagement from day one really. For peer support for the coordinator and support with facilitating and

support with engagement.... It's been allocated at a later date we've got a part-time post so I think that could have been done at the beginning." (BST3)

"I was initially employed on 17.5 [hours] and that went up to 19 and then with the assistance of the two freelancers and the admin worker." (MAST1)

"You need enough resource in terms of staffing, so I think you need somebody on the ground scoping out potential referrals, building the relationships with people, you need somebody who is going to actually run the course, collect the data on the course etc." (NAST1)

Partnerships

Partnerships with organisations supporting people with LTC were expected to bear fruit in terms of recruitment and sustainability. Of the three such national organisations involved, one very actively recommended routes to referral but these routes may not have been consistently followed by the programmes, and feedback was not received on this. On the one hand, coordinators may have developed their own community routes in a self-determining way. On the other hand, programmes may have exhausted their resources for outreach before some of the new opportunities arose. More early contacts were perhaps needed at a local practical, not just national level. In any case partnerships still have unrealised potential, if carefully coordinated, both centrally and locally.

"[A need for] engaging with these organisations at more of a local level really. Getting in there from the beginning because we had the contacts of people at more of a national or strategic level." (BST3)

"I haven't had any information from the [X] course where the referrals have come from." (NAST1)

In terms of community routes, one participant highlighted the potential for using the support networks which participants engaged in. One suggestion was promoting the course through carers' networks.

"They could tap into places like carers' forums, there's a lot of older carers looking after their own that would benefit from that kind of thing." (MPD3)

Boundaries

There was discussion about the range of conditions to include, and where boundaries should fall. One coordinator believed that potentially terminal conditions (cancer) should not be included, but otherwise a wide range of LTC could be included. People with COPD had been included, and those with chronic fatigue, in this view, could well be included. This would be further to continuing to work with those with fibromyalgia who had been included within the broad definition of 'arthritis-related' conditions. With this breadth extending to non-structural conditions where medical diagnosis can be challenging, issues are raised concerning the interplay of physical and emotional LTC. Another stakeholder (a manager in a medical setting) believed that cancer should be included due to the unnoticed mental health challenges accompanying diagnosis.

"Cancer probably isn't one that I would include. Because I think there are different issues around death which we don't cover and obviously someone who is terminal, also is different, I think we have people with COPD on the course, it has been useful for them, I've been hearing a lot from nurse practitioners – will you be expanding to include COPD and also chronic fatigue which isn't on the list, I think that is applicable to people with fibromyalgia, they have similar symptoms, so generally the invisible illnesses that people experience." (MAST1)

"If you get a cancer diagnosis that's a shock to people. Then they realise they are going to lose time from work they will have to pay extra for prescriptions until they can get the certificate which says they don't need to pay." (BST4)

Course participants also reflected on how the course might be made to attract more people and enhance its sustainability. Many had felt very satisfied with the programme.

"I can't think of anything. I think the course was very good. I can't fault it." (MPH9)

"I think don't, don't tamper with it, it ain't broke so don't fix it." (BPD5)

"You know you don't feel like you are being institutionalised or labelled with mental health." (MPD5)

Concern over stigma prompted participants to praise the discreet locations for some courses. There was a view that self-referral could be difficult for people at work, due to stigma in the workplace. This could skew the background of participants towards those not working and available in the daytime, either because of age or health – with possible gender implications.

“Because it was in a setting where lots of things go on, you could be walking in that building to come and get your feet done ...who knows.” (MPD5)

“When one of the ladies said she’s come from work, she’s told her boss but she’s not told others. And I thought ‘well she’s ashamed because it’s about mental health.’” (MPA7)

It was suggested that long-term sustainability might involve combining face-to-face course delivery with peer support and online platforms. Combining physical and virtual resources was, it was argued by a stakeholder for a national LTC organisation, a way of furthering sustainability and cost-effectiveness. Online support could not take the place of face-to-face work, but could complement it.

“Perhaps we could develop some kind of package that people can access online through online support forums... you’re just not going to get the same kind of outcomes as you would from a face-to-face, so I know the face-to-face is the kind of ideal...” (NAST1)

Wider potential

Concerning the wider potential of the programme, it was pointed out by one stakeholder, within a national organisation, that partnerships between organisations focused on LTC and on mental health were relatively new, and this programme had great learning value and potential as a pilot for possible future collaborations. Conversations need to be sustained, and learning at organisational and partner level built on. Some participants also voiced the potential for greater integration of work done within local support groups working with physical conditions and local Minds.

“We as a charity haven’t historically had partnerships like this before and this is a really new and different way of working for us as an organisation so I think it’s been a really positive move for us... thinking about this resilience programme and the potential for where it might go next, I think we just need to be responsible for keeping the conversations going really, we will.” (NAST1)

“And from them [support group for physical condition] doing something about it, we will be able to have the newcomers understand that sharing a problem is halving the problem and that probably they should be part of the group who shares theirs.” (BPDH3)

Appendix 2:

Impact evaluation case studies

The four cases within this report are based on case study diaries kept by participants who attended the resilience programmes in either Birmingham or Manchester. The participants were asked to think about their expectations of the course, how they felt before, during and after the course and changes they had noted in their lives and wellbeing as a result of attending the course.

The case studies provide further illumination of the types of changes and improvements that participants felt from their engagement with the Mind resilience programme. The names used in the cases are not participants' real names; these have been changed to protect the identity of participants.

Case study 1: Lucy

"I feel that I'm in more control over my mental and physical health – that feels so good to say."

Lucy is a female with type 2 diabetes. When Lucy joined the resilience programme in Birmingham she felt her diabetes was poorly managed, and this was impacting on how she felt in terms of her mental wellbeing. She described herself as feeling 'panicky' and 'anxious' as a result of fluctuating blood sugar levels, and her diagnosis had also led her to withdraw socially.

Lucy hoped that the course would help her to meet other people who had diabetes so they could share coping strategies. She also hoped the course would enable her to manage her stress levels generally and help to be able to relax more.

Lucy felt that the course was useful to her, and particularly valued the peer support which she gained from it. The experience of attending the course was seen to be 'educational and enjoyable'. One month after her participation in the course, Lucy felt that she was better able to control her feelings of negativity and panic when

they arose. She felt the techniques she learnt have helped her feel calmer, and hopes to continue to practice these to further improve her abilities to relax and manage her stress levels.

After three months, Lucy felt her confidence levels had increased, and had been practising the relaxation regularly and was noticing further improvements in how calm she felt. As a result of these changes, Lucy identified that she was now finding it easier to participate in social activities and overall attributed her improved wellbeing to having been on the resilience programme. The course enabled Lucy to move beyond feeling 'stuck' and gave her guidance and support which she believed had enabled her to ultimately improve her sense of happiness.

Case study 2: Austin

"It has allowed me to look forward and really plan what I want for my future and not to feel as if I'm limited because of my health."

Austin has a heart condition, and had previously suffered a heart attack. When he joined the resilience programme, Austin described his mental wellbeing as 'ok', although acknowledged he could have some 'low days' which he wanted to manage better. His primary motivation for participating in the programme was around learning new information about LTC, and particularly to learn from and share with others with ongoing health conditions.

For Austin the course opened his eyes to the negative thought patterns he was actually engaging with each day. The course enabled him to gain awareness around his thinking, and to try and challenge his negativity and find new perspectives on things.

One month on from the course Austin felt his health had improved, and he was surprised by this as he didn't think he would gain direct health improvements from the course. He felt he was

more motivated to exercise as a result of the course and had begun walking with two other participants from the course on a regular basis. He describes feeling more in control about his health now.

For Austin, the health improvements from the course continued, and three months after he had completed the course he had lost over a stone in weight and increased his fitness levels. As a result, this helped him feel more confident. His exercising had progressed to gym attendance with his peers from the course, and they now go to the gym three times a week, and he 'see[s] this as a social outing too'. Austin attributes his improved confidence, greater willingness to socialise, increased fitness and weight loss to the attendance on the course; "I'm in much more control of my health, I feel proud of myself."

Case study 3: Gerald

"I was not depressed but I was unhappy as each chronic complaint made my life more difficult and I wanted to do something positive to help myself."

Gerald has a number of LTC, including diabetes and heart issues. Gerald joined the course in Manchester after his wife heard about the programme and encouraged him to attend. He suggests that he had a low level feeling of 'life closing in' despite his attempts to keep an active social life. He thought the course might offer him something positive around his health and was particularly looking for strategies around dealing with his low level feelings of anxiety.

For Gerald, the course facilitator was a highlight of the programme, and he enjoyed the sympathetic and understanding manner of the facilitator. He felt trust built within the group quickly even though the participants had different backgrounds and abilities. He found he knew about many of the things on the course, but it was an important reminder to him about practicing those things.

A month after finishing the course Gerald described feeling more in control. He felt this sense of control had enabled him to make decisions more calmly, and manage busy family situations, and he had given a public presentation which had been an aspiration for him. Gerald felt he had been pacing himself better since the course, and he was admitting when he was tired

more readily than before, which was positive for him. He also felt he had been more active since the course, including going bike riding.

Three months beyond the course he described feeling 'in control more often', although was still prone to worries at times, though felt he was more likely to challenge those thoughts since the course and to try and counter them with rationality. Gerald described having been more physically active and was feeling more energetic and enthused as a result. He had tapped into support from his spouse and extended family, and had talked with his spouse about decisions he needed or wanted to make.

Case study 4: Misha

"Thoughts are not facts – that's a powerful tool in my life tool box."

Misha attended a resilience course in Manchester; she has arthritis. At the time she attended the course she had what she described as a very 'frustrating' time with her health over the previous 18 months. She felt her health was interfering with her ability to be independent and said she "felt very vulnerable". For Misha the aims of attending the course were twofold, firstly to learn to cope with the future, and secondly to learn some relaxation techniques.

She describes the course's focus on the link between thoughts, emotions and behaviour as particularly valuable to her, as well as the ideas around how to challenge thoughts and moving out of the comfort zone. Misha also enjoyed the relaxation aspects of the course.

As a result of the course, she described feeling more confident and in control, and was able to realise the impact negative feelings could have on her wellbeing now. A month on from the course Misha had begun volunteering one day a week, enrolled on a computer course to learn IT and had found a Tai Chi class online with her new found IT skills, and was attending Tai Chi once a week which she found calming and relaxing.

Three months after participating in the resilience programme, she believed she was 'calmer and more accepting of arthritis', although she identified that pacing herself and not getting frustrated by her physical limitations was still difficult at times. Misha felt that she had made

positive changes around healthy eating and exercise as a result of the course, and three months on she was still using the relaxation techniques learnt on the course if she was unable to sleep. For her the 'realisation that feelings can

be modified by challenging thought patterns' was seen to be the most important aspect she had gained from the course, and she believes this would not have happened if she had not participated in the resilience programme.

Appendix 3:

Economic case studies

Case study 1: Jasmine

Participant experience

Jasmine is a young woman in her early twenties.¹ She was diagnosed with type 1 diabetes at 16 and struggled to manage her condition. She was frustrated by the lack of support on offer from health professionals, who she felt were often condescending or dismissive.

“Doctors, they don’t really tell you much... I don’t want to be babied, because I know it’s something that I’m going to have to go out and do myself anyway, but I was still really young so it would’ve been nice to, kind of, get a bit more support or reassurance. I felt, just like, thrown out, you know, with this insulin pen.”

In particular, she found it hard being different from the ‘typical diabetic’.

“I don’t think I’ve ever seen a young person in the diabetic centre apart from myself and maybe somebody’s, like, child that they’ve brought with them. I never see, like, young people, in there and it would be nice so I could, you know, talk with somebody who’s going through the same.”

Her condition began having a negative impact on her mental health and eventually the pressure forced her to drop out of college.

“It’s hard being somebody not of routine, and having diabetes, because diabetes is such a routinized thing... I found it so hard to integrate diabetes into my life and manage, like, a job and education as well at the same time... The first year, I got on with it, type thing, but then, like, the second year and the third year, they really knocked me. It was just the grind of it... I was having, a lot of, like, I don’t know whether you’d call them like breakdowns, but I’d get like upset and then not be able to like, shake it off. I’d stay,

either hysterically crying or, you know, really down.”

After being referred by her GP, Jasmine began attending the Building a Healthy Future course run by Manchester Mind.

“I was so low and I was just, you know, just about making it to these sessions. That might have been the only place I went all week. So it had, like, a big impact on me... I was like, ‘Right I need to pull it together, you know, accept it and embrace it and manage it the best way I can to have a good quality of life,’ and get out of this place where I was just feeling really, like, low... I never felt, like, criticized in there or talked down on, like maybe a doctor would talk down on me.... I looked forward to them each week.”

The course began to have a positive effect on her mental health.

“I did the course which really helped me with, kind of, definitely how I think about things... Sometimes your thoughts are so like jumbled when you’re at a low stage like that, and you need to just get them on paper. So that has really helped... It does work and, I’ve gone and used what I’ve learned there and read up on other, like, relatable things. I feel like that was the biggest key in kind of getting myself, kind of repairing myself, that was the first step in getting there.”

Jasmine found the peer support from other people on the course particularly valuable.

“Talking to other diabetics, that was probably the most helpful, I believe. I don’t know, I always feel like I learn so much more and we have so much more to relate-, so, it makes more sense to me... There are some really good characters that you meet [on the course] and you’re like, ‘wow, they’ve lived all these years with what I’ve got now,’ and, like, ‘look at them still, you know, still joking, and laughing, and they’ve got somebody that loves them as well’... That’s always the thing, when you’re young and you’ve got a health condition, you’re like, ‘who’s going to want me?’”

1. The names of the case studies have been changed and some details have been omitted in order to protect the anonymity of the research participants.

The course also had a significant impact on Jasmine's physical health.

"I'd never properly realised the health benefits... [the course] made me realise that I need to get my physical body-, like my actual me in a good place along with my mind... At the time I was, like, avoiding the diabetic centre, wasn't going to any of my appointments. It was just like, my sugars were, you know, not very well."

After attending the course, Jasmine referred herself for counselling and began to take more control of her physical health. She has experienced some difficult events since completing the course in summer 2015, including her family being evicted. However, she feels that the course and subsequent counselling made her more resilient and better able to cope with the challenges.

"I've had evictions and all sorts... which has been... something hard to get through. I feel like all this [the course] has really supported me on my way. I've got all my sheets, we used to get like hand-outs and stuff, and stuff to read, especially about meditations because you can forget about those within an instant... I've still got all my sheets to hand... They're not far, even with moving and everything I've done since then."

Jasmine has maintained her part-time retail job and also found a new paid placement in an art gallery. This is a role that is closer to her desired career path.

"It's a zero hour contract which is pretty horrible. That's why I hate this retail scene. The hours and stuff just don't suit my, kind of, health. It's really physical. I need something that's a little more laid back because I often have low sugar at work because I am rushing around. It's quite an intense job, to be honest. It's busy in there all the time... Recently I've got a paid placement at [the art gallery]. I mean, it's only added to my CV in, like, the best way possible, especially seeing as though it's something on the kind of route that I want to go down... I'm quite excited to see where that takes me this year... I hope that they'll want me to work for them or work on the gallery floor because I know that pays well."

She is now feeling very confident about the future and is sharing what she has learnt with other people.

"You know, like, there's so much I've learnt from these things that I've been able to share and that

are relevant to other people... Once I got out there a bit again and I did this Manchester Mind... thing, I just felt like I got back to my confident, outgoing, like, adventurous self. It is hard to be adventurous with a health condition, but I'm getting there."

Outcomes

Based on the interview with Jasmine, we conclude that attending the course has had a number of positive outcomes. We have estimated some of the costs/savings associated with these outcomes in order to model the economic impact of the course. These have been calculated on a one-year basis, because there is limited data on the longer-term impact of the course. However, for some outcomes it is very likely that the benefits will have long-term positive effects.

Better self-management of physical health

Jasmine feels more confident to manage her condition and has begun regularly attending her scheduled appointments with primary care staff. This reduces the chances of diabetes-related complications (e.g. damage to eyesight and poor circulation). As she has been diagnosed as a teenager, if Jasmine continues with this positive behaviour, she will improve her health and quality of life for decades to come.

The cost of prescribing medication for diabetes complications is around three to four times the cost of prescribing diabetes medication (Kanavos, Aardweg, and Schurer, 2012). Clare et al. (2003) calculated the direct healthcare costs of different diabetes-related complications, resulting from poor self-management. These ranged from £1,212.00 to £11,750.00 at current prices. Annual inpatient care costs, to treat short and long-term complications of diabetes, are estimated at between £1,800 and £2,500 per patient per year (PPPY). This compares to annual outpatient costs, which includes the cost of medications and monitoring supplies, estimated at between £300 and £370 per patient (Diabetes UK, 2014). Therefore, a conservative estimate of the saving produced by Jasmine's improved self-management is £1,430 (PPPY).

Early intervention for poor mental health

Jasmine's mental health was quite poor before she attended the Building a Healthy Future course. This had resulted in her dropping out of college and becoming increasingly isolated. The course had a positive impact on her mental health and encouraged her to seek further mental health support. Since completing the course and receiving counselling, she believes that her mental health has substantially improved.

This early intervention to tackle her poor mental health reduces the need for more intensive mental health interventions and medication. The average service costs for those with depression in contact with services is £2,395 (PPPY) at current prices (McCrone et al., 2007). This does not include lost employment and productivity, which is outlined below.

If the positive effect is sustained, it also prevents the compounded costs of co-morbid physical and mental health problems. Poor mental health is associated with a 103% increase in total annual medical costs for people with diabetes (Thomas et al., 2005). These costs are primarily caused by poorer glycaemic control, more diabetic complications, and lower medication adherence (Das-Munshi et al., 2007).

The prevention of this co-morbid cost-burden may lead to significant cost savings. However, there is currently no data about to demonstrate a prevention effect for this intervention, beyond the improved self-management savings discussed on the previous page. Therefore, we made a more conservative assumption and not factored in further savings for Jasmine.

Job retention and improved career prospects

Since attending the course, Jasmine has maintained her part-time retail job and secured a new paid placement at an art gallery. This new role is closer to her preferred career and she is hopeful that it might lead to a full-time position. It is also more suited to her physical health needs. These improved job prospects and higher wages have very positive economic impacts.

There are a number of economic benefits of Jasmine maintaining her employment and increasing her hours. The average productivity cost of sickness/lost employment due to depression is £10,690 (PPPY) at current prices (McCrone et

al., 2007). Jasmine is currently working part time and earning the 18-20 youth minimum wage (£5.30 per hour). Therefore, she is not currently subject to tax or national insurance contributions. However, with her increased hours and new paid placement, Jasmine will contribute £195 in national insurance contributions in the coming year². The combined saving and contribution is £10,885 (PPPY). This would increase if her new placement leads to a better paying job.

Jasmine's increased hours and new placement also avoid state responsibility for Job Seekers Allowance (JSA) and other benefits. However, as Jasmine is not currently claiming JSA, Disability Living Allowance (DLA), or other benefits, we have made a conservative assumption not to factor in these potential savings.

Costs/savings

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Improved self-management of physical health (avoided cost of diabetes complications)	- £1,430.00
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Job retention and improved career prospects (avoided employer productivity losses and increased national insurance contributions)	- £10,885.00
Total	- £14,160.07

Case study 2: Kevin

Participant experience

Kevin is a middle-aged man who has experienced chronic and debilitating back pain for ten years. He has undergone operations, injections, and physiotherapy but there is irreparable nerve damage.

"The discs are still crumbling. It's a degenerative condition.... If I have a bad flare-up I'm crying in pain, the worst pain I've ever experienced. I've never been stabbed or shot but I imagine that's the kind of feeling it would be."

2. <http://www.thesalarycalculator.co.uk/hourly.php>

His pain levels and mobility fluctuate. However, even on his best days, he is only capable of two to three hours of activity. His deteriorating physical health had a large impact on his working life. He had to take time off work for his operation and then took a career break with the intention of completing a Master's degree in Business. However, he had to quit the Masters, as well as freelance work, due to the pain.

"I really struggled for a very long time to come to terms with the fact that I couldn't work anymore. I used to work as an accountant so I was well paid, it was a job that had some prestige attached to it, and also I had lots of colleagues and business acquaintances who I would socialise with. There was a very good social life attached to it... I had the intention of returning when I got better, because at that stage I thought I was going to get better, but it never happened."

Kevin felt that losing his job had a much more negative effect on his mental health than the constant pain. He began experiencing severe depression and anxiety.

"The pain wasn't good but it was just pain. The mental health problems were more about coming to terms with the fact that I can't do that work anymore. Whenever you meet someone new the first thing they say is, 'what do you do for a job?' You're defined by your job to a certain degree, or it's a big part of you. That was suddenly gone, that was all missing... I felt a bit pointless. I had no reason to live I suppose you could say. Take your family out of the equation. That kept me going. I think if I had been a single person I might have done something drastic."

Kevin had been prescribed medication to manage his mood in the past but never received any psychological support. He heard about the Building a Healthy Future course from a relative and reluctantly agreed to attend.

"I was a little apprehensive about joining the course. Even after the first session I was thinking I wasn't really sure if I was going to benefit from this.... but certainly from the second session onwards it did really trigger something in me. It actually led me to change quite a lot of things in my life straight away."

Kevin used the techniques he had learnt to challenge his negative patterns of thinking and saw a marked improvement in his mental health. He decided that he was spending too much time

on "pointless" arguments online and he quit social media. He also signed up for a year of evening classes and regained a lot of his lost confidence.

"I have to say this course helped a lot with my mental health... I suppose I had a bit of a 'eureka' moment of thinking more about what I can do than what I can't do... So if I've got three hours a day that are available to me, I could actually achieve a lot of things that I would find satisfying and enjoy doing in that period of time... For some reason it's taken the course and talking about it to actually eventually reach that realisation."

He has also applied these lessons to managing his physical health.

"I can't do anything about the back issues, I don't know how to. What I do know is that I'm overweight. I can do something about that. So I've now started to do something about that as well... I've put on an awful lot of weight over the last, about ten years, without keeping it in check at all, but now... I've got a much clearer idea of where I'm going."

"I'm feeling better now, I think I have really come to terms with my condition and accept what's done is done, can't change it, this is how it is and then see about making the most of it in future. It's taken a long time to get to that point of acceptance. A long time... What is the point in worrying about stuff that you can't control? I was, and I feel that I've just dropped all of that now.... I feel liberated from it."

This confidence has also helped him to increase his independence.

"One of the things that I did as a result of course-, I used to really enjoy going to concerts, and I would still go occasionally, but I'd always go with somebody. I had a ticket booked to go and see a concert that was on, with a friend, and he bailed on me, and it was a band that no-one else was particularly interested to go and see, so I thought, 'That's it, I can't go anymore.' Then I actually used a coping strategy, you know, 'But why can't I go on my own?' and what could happen, and so I rationalised it and I went ahead... I attended a concert on my own for the first time and I had a fantastic time, I really enjoyed it. So now that doesn't hold a fear for me anymore... as a practical experience that shows something that I can do, and since then I've been to a couple of concerts by myself."

Outcomes

Based on the interview with Kevin, we conclude that attending the course has had a number of positive outcomes. We have estimated some of the costs/savings associated with these outcomes in order to model the economic impact of the course. These have been calculated on a one-year basis, because there is limited data on the longer-term impact of the course. However, for some outcomes it is very likely that the benefits will have long-term positive effects.

Early intervention for poor mental health

Kevin's mental health was quite poor before he attended the Building a Healthy Future course. This had resulted in him feeling increasingly isolated and hopeless. The course had a positive impact on his mental health and boosted his self-esteem. Since completing the course and regaining some of his independence, Kevin believes that his mental health has substantially improved.

This early intervention to tackle his poor mental health reduces the need for more intensive mental health interventions and medication. The average service costs for those with depression in contact with services is £2,395 (PPPY) at current prices (McCrone et al., 2007).

If the positive effect is sustained, it also prevents the compounded costs of co-morbid physical and mental health problems. Poor mental health is associated with a 103% increase in total annual medical costs for people with diabetes (Thomas et al., 2006). These costs are primarily caused by poorer glycaemic control, more diabetic complications, and lower medication adherence (Das-Munshi et al., 2007).

The prevention of this co-morbid cost-burden may lead to significant cost savings. However, there is currently no data about to demonstrate a prevention effect for this intervention, beyond the improved self-management savings discussed further on. Therefore, we made a more conservative assumption and not factored in further savings for Kevin.

Better pain management

Kevin feels better able to manage his activity levels without resulting in severe flare-ups. This reduces his dependence on opiate painkillers and

his dependence on primary and secondary care. The reduced opiate usage is also positive for his mental health because he had previously experienced an episode of drug-induced psychosis. His improved pain management (with reduced dependence on opiates) also prevents his need for secondary psychiatric care.

The annual direct cost per patient of Early Intervention for Psychosis, plus associated community psychiatric services and inpatient care, has been estimated at £12,340 (PPPY) at current prices (Knapp et al., 2011). We have made a conservative assumption to deduct the saving of avoided depression treatment costs from this saving because we do not wish to double count savings on avoided psychiatric services. This brings Kevin's avoided costs to £9,945 (PPPY).

We have also made a conservative assumption not to include further savings for reduced primary and secondary care use for managing his pain condition because Kevin did not report changes in his use of these services since attending the course. However, this may be an underestimate because the interview was conducted shortly after he completed the course and his service use may reduce subsequently.

Reduced isolation

Kevin's limited mobility and chronic pain had led him to feel increasingly isolated. He must spend most of the day lying down to minimise his back pain. He has struggled to come to terms with his condition and resisted the use of a wheelchair because it symbolised resignation to his illness. However, since the course he has become much more positive and is embracing the potential of what he can achieve rather than focusing on limitations. He has also used the coping strategies that he learnt on the course to increase his independence and begun attending events on his own.

Reducing isolation can have positive impacts on physical and mental health. Bauer et al. (2012) calculate that the combined public purse and quality of life saving from reducing isolation is £2,900 (PPPY). It is important to note that this figure includes relatively small cashable savings for the public purse (£45 (PPPY)) because the majority of economic benefits come from quality of life improvements. Quality of life savings have not been calculated for other intervention impacts

due to the lack of directly convertible outcomes data. We have extended this decision to savings relating to reduced isolation and will only credit the public purse savings calculated by Bauer et al (2012). This is likely to be a considerable underestimate of the full impact of the intervention. However, we have opted for a more conservative approach in the absence of further outcomes data.

Weight loss

Kevin was previously focused on the limitations imposed by his physical health condition. However, using the circles of influence technique that he learnt on the course, he is now embracing the potential of what he can achieve rather than focusing on limitations. He accepts that there is little he can do to improve his back pain but he can reduce his weight. He now has a plan for improving his fitness and is committed to losing a couple of stone this year.

This weight loss will have a positive effect on his physical health and will help to prevent the development of further health complications (including diabetes). However, the interview was conducted with Kevin shortly after attending the course and so there is no available evidence on the impact of the course on his weight – beyond his renewed motivation. Therefore, we have made a conservative assumption and not included any cost savings for this behaviour change.

Costs/savings

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Better pain management (avoided cost of secondary mental health care)	- £9,945.00
Reduced isolation (avoided health and social care costs)	- £45.00
Total	- £11,835.07

Case study 3: Tariq

Participant experience

Tariq was diagnosed with bowel cancer around six years ago and is currently in remission. About a year after his cancer treatment, he was diagnosed with type 2 diabetes.

“I’m a foster carer so when you’re training to be one, you go through a medical and that’s when it was flagged up that I’m diabetic... I feel that the bowel cancer may have had an impact on the diabetes because after surgery, there was... about a month or six weeks to build up your body fat so you could start another round of chemotherapy... I was on about 8,000 calories a day, because you lose all that weight through treatment. They bump it up with-, I don’t know what was in the protein drinks but I don’t think it would have helped the future diabetes. As I say, if you had propensity, they definitely pushed it on. Pre-cancer, I’d led a fairly healthy lifestyle.”

Whilst Tariq is currently in remission, the cancer treatment has had a significant effect on his physical health. He has a permanent stoma fitted and has experienced trouble with his memory and concentration since receiving chemotherapy. This has made it more difficult to manage his diabetes.

“I don’t do the kind of exercises that I used to be able to do, like badminton or squash because, you know, the stoma. I’ve tried loads of protection but it just rubs against anything you’re wearing and there’s a lot of bleeding and granulation and pain and things... Some of the foods which are really good for diabetes, like broccoli and cabbage, those kinds of food stuffs... my system can’t handle that or it handles it incredibly quickly. That’s the other bit about the diabetes and the bowel cancer, that if you eat certain foods, it comes out of your system straightaway, so that has an impact on your blood sugars, so you may have to, sort of, top up which might spike your blood sugars.”

He has found it particularly challenging to balance the competing demands of his different physical health issues and there has been little support available.

“The problem is that nobody quite knows when you’ve got multiple conditions. So, people who are very good with, you know, helping me with

the bowel cancer aspects aren't very good with helping you with diabetes. It's, you know, the crossover. I found that you have to work it out yourself. You have to do a fair bit of research because things change."

However, Tariq previously worked in a health policy role in the NHS and quickly became a knowledgeable and confident advocate for his needs.

"About eight months ago, I did have a really bad patch where it [blood sugar] was just going through the roof but I managed to, sort of, talk the doctor into giving me three months to try and do a little bit more exercise, watch my diet a little bit more. It came back to where it was before the flare-up... I find with older health professions, you have to develop a relationship and be assertive, otherwise you won't get what you want... Yes, you have to keep on top of it, keep a notebook and questions."

Tariq experienced a period of poor mental health when he returned to work after his cancer treatment. He felt that he had returned too early and was not able to cope with the pressures of his role. At the same time, many of his colleagues were turning to him for advice and support with their own issues.

"I had a couple of phone sessions with the [community] mental health team... I made the decision that I really needed to make a lifestyle choice and not work full-time because I'm just going to feel the same thing. So, yes, I cut work... I think I just tried to switch off the stress or the need for any, kind of, talking therapy."

Tariq heard about the Building a Healthy Future course through a diabetes awareness event. By this stage, he had left his job and taken on a role as a full-time foster carer. This shift had many positive effects but he was still looking for support with his mental health. However, attending the course initially had a negative effect.

"The course actually caused some turmoil... I think one of the effects of the course is that you started thinking about things. That was a strange thing that I didn't expect, that it actually set me back, I think... I was a bit short-tempered and it wasn't because of low blood sugar... It [the course] makes you, sort of, think about issues in a certain way and gives you tools to deal with them but it still generates things for you... you

don't get time to process it during the course. It's, sort of, long enough but not long enough in a sense because outside the course, you'll hit your 9 to 5, your daily routine, so there are things that you need time to do. I find that I need longer to process things."

However, Tariq ultimately found the course helped him better manage the relationship between his mental health and diabetes.

"I liked the bit about managing stress and its impact on diabetes because for some strange reason I hadn't made that connection yet. Well actually stress has an impact on your health more than anything else, but I just hadn't sort of made that connection with me and looking at my stress levels and that impact on diabetes. I mean, I was fully aware it had an impact on my bowel. So yes, that was quite a bit of a sort of blind spot."

In particular, he realised that he had sometimes confused the symptoms of poor mental health with diabetes. In doing so, he may have actually been making his physical health worse.

"That was quite an important eye-opener – the impact of stress is similar to your blood sugars going up and down. So... you might be stressed and you think, 'oh my God, my blood sugars are low,' and you take a snack and you, obviously, send your blood sugars out into spiral. That's quite useful to know, just to, sort of, say, 'well, let's take a break for a minute,' or, 'let's just check this.'"

Outcomes

Based on the interview with Tariq, we conclude that attending the course has had a number of positive outcomes. We have estimated some of the costs/savings associated with these outcomes in order to model the economic impact of the course. These have been calculated on a one-year basis, because there is limited data on the longer-term impact of the course. However, for some outcomes it is very likely that the benefits will have long-term positive effects.

Early intervention for poor mental health

Tariq has previously experienced periods of poor mental health. This, in combination with his deteriorating physical health, led to him leaving his well-paid NHS role. The course had a positive

impact on his mental health and provided a number of coping strategies to manage difficulties in the future.

This early intervention to build his resilience reduces the need for more intensive mental health interventions and medication. If the positive effect is sustained, it also prevents the compounded costs of co-morbid physical and mental health problems.

This early intervention to tackle his poor mental health reduces the need for more intensive mental health interventions and medication. The average service costs for those with depression in contact with services is £2,395 (PPPY) at current prices (McCrone et al., 2007).

If the positive effect is sustained, it also prevents the compounded costs of co-morbid physical and mental health problems. Poor mental health is associated with a 103% increase in total annual medical costs for people with diabetes (Thomas et al., 2006). These costs are primarily caused by poorer glycaemic control, more diabetic complications, and lower medication adherence (Das-Munshi et al., 2007).

The prevention of this co-morbid cost-burden may lead to significant cost savings. However, there is currently no data about to demonstrate a prevention effect for this intervention, beyond the improved self-management savings discussed further on. Therefore, we made a more conservative assumption and not factored in further savings for Tariq.

Better self-management of physical health

Tariq no longer mistakes the impact of stress with low blood sugar. He is also carrying out more regular exercise. This leads to better self-management of his diabetes and reduces the chances of diabetes-related complications (e.g. damage to eyesight and poor circulation).

The cost of prescribing medication for diabetes complications is around three to four times the cost of prescribing diabetes medication (Kanavos, Aardweg, and Schurer, 2012). Clare et al. (2003) calculated the direct healthcare costs of different diabetes-related complications, resulting from poor self-management. These ranged from £1,212.00 to £11,750.00 at current prices. Annual inpatient care costs, to treat short and long-term complications of diabetes, are estimated at

between £1,800 and £2,500 per patient per year (PPPY). This compares to annual outpatient costs, which includes the cost of medications and monitoring supplies, estimated at between £300 and £370 per patient (Diabetes UK, 2014). Therefore, a conservative estimate of the saving produced by Tariq's improved self-management is £1,430 (PPPY). This is likely to be an underestimate given the compounding factor of Tariq's multiple physical health issues.

Costs/savings

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Better self-management of physical health (avoided cost of diabetes complications)	- £1,430.00
Total	- £3,275.07

Case study 4: Denise

Participant experience

Denise is a diabetes veteran. She was diagnosed with type 1 diabetes when she was 17, over 35 years ago. She is now insulin dependent but has embraced new technology.

"I now use the pump, which is fantastic, as opposed to when I was first diagnosed, glass syringe and needles and all that. It has come a long, long way."

She has found it difficult to manage her weight and get into a stable pattern of self-care.

"I've struggled with my weight over the years because you're prodding so much insulin in your body and basically it's a growth hormone, insulin. It just makes you get bigger, and bigger, and bigger... Basically I've just changed my whole regime. More exercise, just changed my diet totally. I've lost in excess of twenty kilos, which is over three stone, and I'm still on the move to do more. My GP asked me, 'what are you doing? It's fantastic.'"

She now prides herself on her knowledge about diabetes and wants to share that with other people.

“I’ve learned a lot over the years and I’m still learning now. I have plans to utilise this knowledge that I’ve got because there’s nothing like talking to someone who’s actually gone through issues... I’ll tell you, I think I could go in a lecture theatre and lecture people, seriously. In fact my consultant has asked me if I would be willing to work with him with some of the patients in the future, so I said to him, ‘yes, certainly.’ I like to give back.”

Despite the confidence that she has gained, Denise’s long period of ill health has had an impact on her mental health. After temporarily losing the sight in one of her eyes, she became increasingly anxious about losing her sight completely. Her employer was slow to make reasonable adjustments and Denise had to take six months off work due to stress and anxiety.

“I’m a strong character, me, so that’s why I was quite shocked [about needing time off work], when I look back now, ‘that could never happen to me,’ but it can happen to anyone. If I wasn’t a strong person, and you hear people say that they’re on the edge, I felt like I was on the edge... I mean stress is a big killer. It affects everything, like my circadian rhythm went totally out of sync. I wasn’t sleeping... You just don’t know where you are.”

Her poor mental health also began to have an impact on her physical health.

“I was getting up at six o’clock in the morning, not sleeping, and worrying about the job and all the rest of it. I became very ill... Actually I’d started having chest pains [due to anxiety] so I was admitted to hospital at one point, but I refused to stay. They did my referral [for community mental health services].”

Denise heard about the Building a Healthy Future course from a relative who worked for the city council. She began attending the sessions after work and found that the techniques she learnt could be applied to many aspects of her life.

“The course gave me these templates to reason a situation out-, I know I’ll use that for life... for instance, I catastrophize a lot. I’ve tried to recognise when I’m doing that... you take bits and pieces out and you can apply it to work and also to home life.... I’m still using the techniques now... We were given some sheets and actually I’ve started using them if I do have an issue or a problem. I can transfer them to any situation.

We did lots of relaxation at the end of each session, so now I just make it my business, every day I do a relaxation technique.”

Although Denise was already very knowledgeable about diabetes and confident in managing her condition, she felt that the course provided helpful support to improve her mental health.

“Those were dark days [whilst off work], I tell you. I realise I’ve got so much to look forward to, seeing my grandkids, this, that and the next. But you know, you start worrying about all these things, and I so wish I’d done this course before that and then I could have changed my negative thinking into more positive thoughts.”

Since attending the course, Denise has found a new role with her employer and is feeling more confident about the future.

“I have to take control, it’s my life and I want to live it. I’ve got a wonderful family. I want to be one of the long-livers... I went for an interview two weeks ago and the guy wanted me for the post... New Year, new start!”

Outcomes

Based on the interview with Denise, we conclude that attending the course has had a number of positive outcomes. We have estimated some of the costs/savings associated with these outcomes in order to model the economic impact of the course. These have been calculated on a one-year basis, because there is limited data on the longer-term impact of the course. However, for some outcomes it is very likely that the benefits will have long-term positive effects.

Early intervention for poor mental health

Denise’s mental health was quite poor before she attended the Building a Healthy Future course. This had resulted in her taking six months off work due to stress and anxiety. The course had a positive impact on her mental health and provided coping strategies to help her deal with negative thought patterns. Since completing the course, she believes that her mental health has improved.

This early intervention to tackle her poor mental health reduces the need for more intensive mental health interventions and medication. It also prevents A&E admission for the physical symptoms of mental health problems (e.g. chest

pains). If the positive effect is sustained, it will also prevent the compounded costs of co-morbid physical and mental health problems.

The average service costs for those with depression in contact with services is £2,395 (PPPY) at current prices (McCrone et al., 2007). This does not include lost employment and productivity, which is outlined below.

If the positive effect is sustained, it also prevents the compounded costs of co-morbid physical and mental health problems. Poor mental health is associated with a 103% increase in total annual medical costs for people with diabetes (Thomas et al., 2006). These costs are primarily caused by poorer glycaemic control, more diabetic complications, and lower medication adherence (Das-Munshi et al., 2007).

The prevention of this co-morbid cost-burden may lead to significant cost savings. However, Denise already felt confident managing her physical health before the intervention and so we made a conservative assumption of impact and not factored in further savings for prevention.

Job retention and improved career prospects

Since attending the course, Denise has secured a new role with her employer. This new role comes with the adaptations she requires and she is hopeful that it will reduce the stress and anxiety associated with her previous role. This job retention (on a relatively high salary of £35,000 gross) has very positive economic impacts.

There are a number of economic benefits of Denise maintaining her employment. The average productivity cost of sickness/lost employment due to depression is £10,690 (PPPY) at current prices (McCrone et al. 2007). Using this average is a conservative assumption because the economic cost of Denise’s recent six months on long-term sickness absence from work was much higher than this amount.

Denise is currently working full time and earning £35,000 per annum. This means that she will pay at least £4,840 in tax and £3,127 in national insurance contributions in 2016/17³. The combined saving and contribution is £18,657 (PPPY). Denise is continuing to claim Disability Living Allowance (DLA) and so changes in benefits are not factored into the calculation.

3. <http://www.thesalarycalculator.co.uk/hourly.php>

Weight loss

Denise has recently lost over three stone. Whilst this change began before she attended the Building a Healthy Future course, she feels that the intervention has helped her to sustain her motivation. This weight loss will have a positive effect on her physical health, including the prevention of further health complications.

Davis, Bruce, and Davis (2011) have calculated the economic impact of moderate weight loss in patients with type 2 diabetes. They concluded that the average medication and primary care cost saving is £65 (PPPY) at current UK prices.

Costs/savings

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Job retention and improved career prospects (avoided employer productivity losses and retained tax and national insurance contributions)	- £18,657.00
Weight loss (avoided cost of medication and primary care)	- £65.00
Total	- £20,567.07

Case study 5: Karen

Participant experience

Whilst the Building a Healthy Future course is designed to increase the resilience of people who do not have mental health problems, some of the participants have had their own personal experience. Karen was first diagnosed with mental health problems in the early 1990s. She has been receiving ongoing support from the Community Mental Health team and is currently taking anti-depressants.

“My mood is quite up and down. I mean I am fairly calm, but without wanting to seem too dramatic, if I felt I could die without causing too much fuss or anything, I would. Obviously some days I feel more like that than other days. I have in the past taken overdoses obviously pretty unsuccessfully... I don’t really see the point of

myself, it's one of those, but I'm fairly calm about it all day... The last time I took an overdose... I went to the hospital and they said that they thought I would be on anti-depressants for the rest of my life. I, like, shake, rattle, and roll because I'm on so many medications."

Around seven years ago, Karen was diagnosed with type 2 diabetes but has found it difficult to remain motivated to manage her condition.

"I am getting better at managing it, but I do have days where I think, 'I just can't be bothered'... My health seems to go in peaks a bit... It wasn't that I was ever in denial, but I like food and I like sweet things particularly. I was supposed to have an operation [hysterectomy] and it got cancelled because my blood glucose was far too high."

As well as having a negative effect on her health, Karen's condition has made it difficult to maintain a job. Her last role was in 2011, working as a benefits advisor.

"I was supposed to have a hysterectomy... it's not happened [due to diabetes]. I'd been really ill for the year before where I just had horrendous bleeding which led to me losing my job in a way. I mean, they would deny it, but they sacked me, but it was a political thing, they had to get rid of people and anybody that had had a sick note or time off sick was gone."

Karen heard about the Building a Healthy Future course from her diabetic nurse. Whilst she has received extensive mental health support in the past, she often found the material in the Mind course more accessible.

"I have had cognitive behavioural therapy before and there were things that I didn't necessarily understand from those, which I then-, I saw it this time, and I was like, 'yes!'... Some of those [therapy sessions] are going back a few years. On the Mind course, I was like, 'oh right, that's what they meant by that, no wonder I couldn't get it the first time.'"

In particular, she enjoyed the peer support from other group members and the course facilitator, who had her own experience of physical health problems.

"It was good to get together with people that were going through the same thing, and you know, finding new techniques. Maybe some of them I didn't know about already... I liked [the course facilitator], I mean she obviously has her

own health problems and she would say, you know, 'this is what I've found,' which I think made it a lot easier for people to say, 'oh yes'... That is one of the positives about doing this sort of course when it's people who have, you know, the same symptoms. You can go, 'I've had this,' you know, and they're like, 'I know what you mean,' whereas otherwise you feel like you're whinging to someone."

Whilst her mental health is still poor, Karen felt that her wellbeing has improved since attending the course and she now feels she has more resources to help her cope with some of the challenges she faces.

"[The course] made me calmer... and it's probably helped with my mental state. I mean, [the depression] is always going to be there. It's also going to intensify this, 'What's the point of me?' because, in a couple of months' time, I have to go for a procedure which means I certainly won't be able to get pregnant. So I might be delving into these kind of mental resources for that, because I haven't got children and I've always wanted them."

Karen took part in the programme over a year ago but has regularly attended follow-up sessions and since co-founded a walking group to provide peer support for people who have physical health issues. She and some other regular attendees have also received training from the local Mind to help them continue their peer support once the programme ends.

"[After the course] my friend and myself set up a Walk and Talk group... It's just once a month, we just walk around [a local park], which isn't actually very big once you start walking round it. We just talk about anything. If any people have any problems with their diabetes, we can talk about that or any other problems.... That's what we want, to carry on being able to think about things and maybe remind ourselves about the things that have been on the course, and how in bad times I can say, 'yes, let's talk about that,' you know."

This peer support is very important for Karen who often finds it hard to recognise her own self-worth.

"Sometimes I do think, 'Why am I doing this [looking after diabetes] when I don't want to be here?'... Maybe now that I've made friends on the course, that maybe I need to be there for them."

Outcomes

Based on the interview with Karen, we conclude that attending the course has had a number of positive outcomes. We have estimated some of the costs/savings associated with these outcomes in order to model the economic impact of the course. These have been calculated on a one-year basis, because there is limited data on the longer-term impact of the course. However, for some outcomes it is very likely that the benefits will have long-term positive effects.

Improved mental health

Karen has experienced poor mental health since the early 1990s. She is taking anti-depressant medication and is receiving support from the Community Mental Health Team. However, she feels that the Building a Healthy Future course has improved her wellbeing and given her new coping strategies. She intends to use these coping strategies to mitigate the psychological impact of a distressing surgery that she has scheduled. She also finds that the friends she has made through the course and the regular peer support that she continues to receive help her to feel there is more purpose to her life. This may limit the need for further secondary mental health interventions and A&E admissions for self-harm.

There are high costs associated with secondary mental health care. Even making conservative assumptions and not factoring in costs for the emergency services and A&E who are frequently involved in mental health crises, the estimated cost of crisis care in secondary mental health services is £7,359 (PPPY). This is based on the average length of stay of 33 days (NAO, 2007) and unit cost of £223 per bed day (Curtis and Burns, 2015). These costs increase significantly (almost double) if a secure bed is required. However, using Karen's previous experiences of secondary mental health, we have made a conservative assumption that this would not be required if she was required further support in the future.

If the course's positive effect on mental health is sustained, it may help to prevent the compounded costs of co-morbid physical and mental health problems. Poor mental health is associated with a 103% increase in total annual medical costs for people with diabetes (Thomas et al., 2006). These costs are primarily caused by poorer glycaemic

control, more diabetic complications, and lower medication adherence (Das-Munshi et al., 2007).

The prevention of this co-morbid cost-burden may lead to significant cost savings. However, there is currently no data about to demonstrate a prevention effect for this intervention, beyond the improved self-management savings discussed below. Therefore, we made a more conservative assumption and not factored in further savings for Karen.

Better self-management of physical health

Karen finds it hard to manage her physical health. This is consistent with the findings of Das Munshi et al. (2007) who found that people with mental health problems and diabetes are four times more likely to have difficulty with self-management than people with diabetes alone. However, since attending the course, Karen feels more confident and motivated to manage her physical health. She is taking more regular exercise – including her monthly 'Walk and Talk' groups. She is also being more aware of the food she is eating. This reduces the chances of diabetes-related complications (e.g. damage to eyesight and poor circulation).

The cost of prescribing medication for diabetes complications is around three to four times the cost of prescribing diabetes medication (Kanavos, Aardweg, and Schurer, 2012). Clare et al. (2003) calculated the direct healthcare costs of different diabetes-related complications, resulting from poor self-management. These ranged from £1,212.00 to £11,750.00 at current prices. Annual inpatient care costs, to treat short and long-term complications of diabetes, are estimated at between £1,800 and £2,500 per patient per year (PPPY). This compares to annual outpatient costs, which includes the cost of medications and monitoring supplies, estimated at between £300 and £370 per patient (Diabetes UK, 2014). Therefore, a conservative estimate of the saving produced by Karen's improved self-management is £1,430 (PPPY).

Reduced isolation

Karen's mental health problems mean that she often finds it difficult to leave the house. However, the course provided a motivation to meet new people and she has since been actively engaged with follow-up sessions for over a year. She has

also helped to establish a peer support ‘Walk and Talk’ group, which further reduces her isolation.

Reducing isolation can have positive impacts on physical and mental health. Bauer et al. (2012) calculate that the combined public purse and quality of life saving from reducing isolation is £2,900 at current prices (PPPY). It is important to note that this figure includes relatively small cashable savings for the public purse (£45 (PPPY)) because the majority of economic benefits come from quality of life improvements. Quality of life savings have not been calculated for other intervention impacts due to the lack of directly convertible outcomes data. We have extended this decision to savings relating to reduced isolation and will only credit the public purse savings calculated by Bauer et al. (2012). This is likely to be a considerable underestimate of the full impact of the intervention. However, we have opted for a more conservative approach in the absence of further outcomes data.

Weight loss

Karen has become more physically active since the Building a Healthy Future course and she feels that the intervention has improved her motivation. This activity, if sustained, will help her lose weight and prevent the development of further health complications.

Davis, Bruce, and Davis (2011) have calculated the economic impact of moderate weight loss in patients with type 2 diabetes. They concluded that the average medication and primary care cost saving is £65 (PPPY) at current UK prices.

Costs/savings

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Improved mental health (avoided cost of secondary mental health care)	- £7,359.00
Better self-management of physical health (avoided cost of diabetes complications)	- £1,430.00
Reduced isolation (avoided health and social care costs)	- £45.00
Weight loss (avoided cost of medication and primary care)	- £65.00
Total	-£8,349.07

Case study 6: George

Participant experience

George is in his late 80s but he is still an active member of his local community and enjoys meeting new people.

“I’m a friendly person, I like to make new friends... I go along to a local Methodist church, I’m not a member of the Methodist church, but they have a full-sized snooker table and I’ve been going there for twenty years. Now, although I’m slightly handicapped, I can still try to have a game of snooker... One of my close friends lives in the same avenue as me. We bump into one another once or twice a week, and of course there is always the telephone. We help each other.”

George was born with a partially paralysed arm and has experienced asthma since he contracted pneumonia as a child. In the last ten years he has experienced increasingly severe pain from arthritis in his knees. However, he places great emphasis on self-care and has rarely sought extra support.

“When I was younger, it didn’t affect me very much because when you’re young you find other ways of doing things... Later on in life, when you get over 60 I would think, things change. You notice more restraints in the movement of your limbs and of course a bit of pain starts kicking in... I’ve got arthritis, of course. I’ve got that in my knees. I’m also very asthmatic... I felt a lot of the help was up to myself, to sort out the best way you can.”

George really values his independence and has refrained from seeking support, despite increasingly high needs. The chronic pain from his arthritis interrupts his sleep and limits his mobility. Fortunately, he has a network of close friends who provide informal support.

“I just rely on a friend. I’ve not asked for any help, physical help, as yet. I suppose if it got any worse I would have to do, but I try to do everything myself. I prefer it that way. I’m a bit on the independent side... I only take a bath if somebody is in the flat. It’s got that way now. With difficulty I can get in the bath, but it’s getting out.”

In particular, George is reluctant to seek support from health professionals. He is concerned about wasting their time but he is also nervous about medical procedures.

“I’m opposed to going to the doctors. Doctors and dentists, I’ve never really been to them... I’m a ‘heal yourself’ person, yes. If things were very, very serious, of course, I would go, but if I get a cold or anything or a cut or something that isn’t really necessary for the doctor, then I do it myself... I haven’t been to hospital in years. That’s another thing that scares me, I don’t like hospitals.”

However, his physical health continues to deteriorate and he has recently had difficulties with his balance – taking a fall in the week before the interview. He feels that he has limited options to address these issues, particularly the pain.

“The doctor I’ve got, a nice doctor, very abrupt, he said, ‘all I can give you are painkillers and if it gets any worse you’ll have to have the operation for the knees.’ Well, I’m a bit of a coward actually, and it will have to be very severe before I’ll have any operation.”

His age and physical health have begun to have a negative impact on his mental health.

“Sometimes you do get a bit stressed. It’s no use saying you don’t, you do... People start worrying for worrying sake, as you might say. When you’re young and carefree nothing seems to worry you and little things when you’re getting older, you dwell on them. I don’t think that does your health much good.”

George heard about the course through his housing association and was keen to learn more.

“I went on that little course, the six week course, which I enjoyed very, very much indeed... The best bit, I thought, was we reminisced. We closed our eyes and thought about different things that were very helpful, very restful. We did simple exercises to make your mind more clear. Yes, it was quite good.”

He was a diligent participant and made particular effort to apply the new techniques he had learnt.

“I have actually continued to use some of those things [course materials]. Because when you’re getting on, again, you’re inclined not to go out very much at night. You can only watch so much television and read so much in the paper or listen to the wireless, and then I do simple exercises and do simple mind thoughts as well... I’m trying simple exercises in the house and go out, weather permitting of course, and go on short walks and socialising with other people is a great

help... I’m trying to enjoy the good times and try to be brave when things change.”

Outcomes

Based on the interview with George, we conclude that attending the course has had a number of positive outcomes. We have estimated some of the costs/savings associated with these outcomes in order to model the economic impact of the course. These have been calculated on a one-year basis, because there is limited data on the longer-term impact of the course. However, for some outcomes it is very likely that the benefits will have long-term positive effects.

Whilst George enjoyed the course, there is little evidence that it had much impact beyond his improved mental health. Therefore, only one outcome has been costed below.

Early intervention for poor mental health

George was feeling increasingly anxious before he attended the Building a Healthy Future course. The course had a positive impact on his mental health and gave him coping strategies to deal with negative thoughts. Since completing the course, George is feeling more positive and becoming more active.

This early intervention to tackle his poor mental health reduces the need for more intensive mental health interventions and medication. If the positive effect is sustained, it also prevents the compounded costs of co-morbid physical and mental health problems.

The average service costs for those with anxiety in contact with services is £1,268 (PPPY) (McCrone et al., 2007) at current prices. This does not include lost employment and productivity, which do not apply to George because he is retired.

Costs/savings

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of anxiety treatment)	- £1,268.00
Total	- £718.07

Case study 7: Joan

Participant experience

Joan is in her mid-60s. She was diagnosed with arthritis about 10 years ago but it did not affect her too much until she received an injury to her leg and this led to a severe flare-up. The pain has been getting progressively worse over the last six years and she now has very limited mobility. Her type 2 diabetes was picked up early during regular blood tests six months ago.

“My most debilitating condition... is the leg pain I get, which I think is partly arthritis and... a bit like fibromyalgia, because I've got constant muscular pain unless I'm dosing myself up. Even in my sleep, I have it.... That's the thing that's impacted on my life more than anything.... I can manage a couple of steps but I can't manage stairs. If I'm going out browsing around shops, or anything like that, I have to go in a wheelchair.”

In addition to her limited mobility, Joan also has to use strong painkillers to dull the chronic pain. These make her feel very tired and have had an impact on her social life.

“I think the thing that makes me most fed up, is the amount I've got to sleep to get through a day because I feel like I'm missing out on so much... There are a few people that drop off from your social because you can't do the fun things that you used to do. So, from work, I had a few friends who I don't see much of now. They were good friends. It's because they want to go out and do lunch, and I can't do that. I'm a bit of a sitting duck. I need people to come and see me.”

The forward planning required has made Joan increasingly anxious about social events and she is often reluctant to leave the house.

“I don't get out much... If you're doing something new, you've got to go and 'recce' the night before or the day before, you know? You've got to go and find out where the disabled parking is. You've got to make sure that there's ramps, although I can manage a few steps. So everything's got to be planned... If I went to a party, I would have to take a lot of painkillers and go in a wheelchair and get my husband to take me, or a friend. In the end, I probably would not go to a party because there's no way I can manage the pain, and I won't be able to maintain a brave face for more than an hour.”

These limitations have had a negative effect on her mental health.

“I don't think I tell them [my friends] how bad it is really. I don't think I really tell anybody what a struggle it is, except for my husband. I think I try and put on a brave face for other people... I don't think they realise that I'm in pain and how debilitating that is physically and emotionally and, well it makes you tired for a start. Everything's a struggle so you're tired and then you can get depressed. I have to, you know, really try to cheer myself up to make myself go out, if I'm having a bad time. I do have really depressing days, and they're probably days where I feel I've achieved nothing or the pain has been bad.”

Joan feels very lucky to have a supportive husband but she can also feel guilty about needing help.

“I feel guilty when, you know, I take up a lot of his [husband] time as well, and he can't maybe go out fishing, or whatever, for the day that he might like to have done... It changes the balance in a relationship, really... You know, he's really good because he always makes me feel better that I do the online shopping and it means he doesn't have to go shopping. So, you know, he tries to point out the positives for me.”

Despite her deteriorating physical and mental health, Joan was not prioritising her self-care.

“I didn't look after myself properly, I look after other people too much, but that's the way I was brought up really, with a disabled brother, and I probably worry too much and get involved with my sons. I've got two sons, and they come first. So I tend to put myself last about everything, and then I get fed up about being last.”

Joan was a little hesitant about attending the Building a Healthy Future course because she did not know what to expect.

“I was and I am ready to start trying to look after myself a bit better, so I just wanted a bit of direction and that seemed to be it... The course was a little bit more than I expected. It went a bit deep into your feelings and your problems, but there was always something positive after that that helped you.”

Given the shrinking of her social circle, the peer support from other group members was particularly important.

“They were nice, they were really supportive and I missed everybody... There are people who are walking about and don’t wear a label, and there could be somebody who is going through something similar to you, struggling just as much as you, and they’ve walked past you and you didn’t know... We shared something, and we really cared about each other. We got to really care about each other... It’s such a shame to let those people out of your life when you’ve made such a connection to them.”

Joan feels that the course has been a good prompt to take better care of herself.

“I used to be such a victim to the pain... But I think I probably put things [from the course] into practice because I managed to get through Christmas without too much trouble, and birthdays and everything... I think it has made me feel more confident about solving problems, and it’s also made me feel a bit more determined to look after myself... It’s all looking very positive really this year.”

The positive impact of the course has been supplemented by Joan’s work with a personal trainer to improve her fitness.

“I have a personal trainer who comes to see me once a week and he does a workout with me that’s specific to me... It’s only half an hour, I can manage, and also it’s been good psychologically, because I know I’m getting stronger even though it’s not actually helping with the pain... So working with this bloke is very, very slowly turning it round, but that makes you feel a bit more optimistic.”

Outcomes

Based on the interview with Joan, we conclude that attending the course has had a number of positive outcomes. We have estimated some of the costs/savings associated with these outcomes in order to model the economic impact of the course. These have been calculated on a one-year basis, because there is limited data on the longer-term impact of the course. However, for some outcomes it is very likely that the benefits will have long-term positive effects.

Early intervention for poor mental health

Joan’s mental health was quite poor before she attended the Building a Healthy Future course.

This had resulted in her feeling increasingly isolated and hopeless. The course had a positive impact on her mental health and boosted her self-esteem. Since completing the course and regaining some of her independence, Joan believes that her mental health has substantially improved.

This early intervention to tackle her poor mental health reduces the need for more intensive mental health interventions and medication. It also prevents A&E admission for the physical symptoms of mental health problems (e.g. chest pains). If the positive effect is sustained, it will also prevent the compounded costs of co-morbid physical and mental health problems.

The average service costs for those with depression in contact with services is £2,395 (PPPY) at current prices (McCrone et al., 2007). If the positive effect is sustained, it also prevents the compounded costs of co-morbid physical and mental health problems. Poor mental health is associated with a 103% increase in total annual medical costs for people with diabetes (Thomas et al., 2006). These costs are primarily caused by poorer glycaemic control, more diabetic complications, and lower medication adherence (Das-Munshi et al., 2007).

The prevention of this co-morbid cost-burden may lead to significant cost savings. However, there is currently no data about to demonstrate a prevention effect for this intervention, beyond the improved self-management savings discussed. Therefore, we made a more conservative assumption and not factored in further savings for Joan.

Reduced isolation

Joan’s limited mobility and chronic pain had led her to become increasingly isolated. She finds it hard to walk and becomes anxious about the forward planning required to leave her house. The painkillers she has been prescribed also require her to sleep for large portions of the day. However, she has made a number of friends on the course and feels more confident to communicate her needs. She has become much more positive and has even booked a holiday.

Reducing isolation can have positive impacts on physical and mental health. Bauer et al. (2012) calculate that the combined public purse and quality of life saving from reducing isolation is

£2,900 at current prices (PPPY). It is important to note that this figure includes relatively small cashable savings for the public purse (£45 (PPPY)) because the majority of economic benefits come from quality of life improvements. Quality of life savings have not been calculated for other intervention impacts due to the lack of directly convertible outcomes data. We have extended this decision to savings relating to reduced isolation and will only credit the public purse savings calculated by Bauer et al. (2012). This is likely to be a considerable underestimate of the full impact of the intervention. However, we have opted for a more conservative approach in the absence of further outcomes data.

Costs/savings

Outcome	Cost/saving
Cost of intervention per participant	+ £549.93
Early intervention for poor mental health (avoided cost of depression treatment)	- £2,395.00
Reduced isolation (avoided health and social care costs)	- £45.00
Total	- £1,890.07

Appendix 4:

Additional data tables

Table 22: Mean change in score from baseline to post-stage by sex

	Males	Females		
	Mean change in score baseline-post (SD) (n)	Statistically significant change P=<0.001	Mean change in score baseline-post (SD) (n)	Statistically significant change P=<0.001
Wellbeing	3.0 (SD=4.25) (n=47)	✓ P=<0.001	4.02 (SD=4.67) (n=113)	✓ P=<0.001
Problem solving and achieving goals	3.50 (SD=5.05) (n=44)	✓ P=<0.001	3.91 (SD=4.93) (n=109)	✓ P=<0.001
Social support	3.36 (SD=5.54) (n=45)	✓ P=<0.001	3.22 (SD=5.41) (n=112)	✓ P=<0.001
Management of long-term conditions	2.68 (SD=4.67) (n=47)	✓ P=<0.001	3.21 (SD=4.14) (n=108)	✓ P=<0.001
Overall combined score	13.94 (SD=15.78) (n=36)	✓ P=<0.001	14.86 (SD=14.72) (n=90)	✓ P=<0.001

Table 23: Mean change in score from baseline to three-month follow-up by sex

	Males	Females		
	Mean change in score baseline-3M follow-up (SD) (n)	Statistically significant change P=0.02	Mean change in score baseline-3M baseline-post (SD) (n)	Statistically significant follow-up P=<0.001
Wellbeing	2.58 (SD=6.04) (n=33)	✓ P=0.02	4.05 (SD=5.59) (n=59)	✓ P=<0.001
Problem solving and achieving goals	3.90 (SD=5.38) (n=31)	✓ P=<0.001	4.83 (SD=6) (n=58)	✓ P=<0.001
Social support	3.87 (SD=5.70) (n=31)	✓ P=<0.001	3.67 (SD=5.24) (n=60)	✓ P=<0.001
Management of long-term conditions	3.17 (SD=3.82) (n=30)	✓ P=<0.001	3.98 (SD=3.96) (n=56)	✓ P=<0.001
Overall combined score	15.96 (SD=15.30) (n=23)	✓ P=<0.001	16.78 (SD=17.02) (n=46)	✓ P=<0.001

Table 24: Mean difference in change from baseline to post-stage by sex

	Male-Female mean difference in change baseline to post	Statistically significant change
Wellbeing (Male, n=47); (Female, n=113)	-1.02	x P=0.20
Problem solving and achieving goals (Male, n=44); (Female, n=109)	-0.41	x P=0.65
Social support (Male, n=45); (Female, n=112)	0.13	x P=0.89
Management of long-term conditions (Male, n=47); (Female, n=108)	-0.53	x P=0.48
Overall combined score (Male, n=36); (Female, n=90)	-0.91	x P=0.76

Table 25: Mean difference in change from baseline to three-month follow by sex

	Male-Female mean difference in change baseline to 3M follow-up	Statistically significant change
Wellbeing (Male, n=33); (Female, n=59)	-1.48	x P=0.24
Problem solving and achieving goals (Male, n=31); (Female, n=58)	-0.92	x P=0.48
Social support (Male, n=31); (Female, n=60)	0.20	x P=0.87
Management of long-term conditions (Male, n=30); (Female, n=56)	-0.82	x P=0.36
Overall combined score (Male, n=23); (Female, n=46)	-0.83	x P=0.85

Appendix 5:

Impact evaluation interview matrix

Stakeholders	
Centre	Role
Manchester	1. Project coordinator
	2. Facilitator of community based course for Asian women
	3. Project coordinator (one year later)
	4. Project facilitator (delivery)
	5. Project facilitator (delivery)
Birmingham	1. Project coordinator
	2. Local GP practice office manager
	3. Project coordinator's line manager
	4. Pharmacy manager (location for recruitment and delivery of course)
	5. Local GP practice office manager (10 months later)
National	1. National partner organisation (condition specific)

Course participants and condition	
Diabetes	13
Arthritis	6
Arthritis and diabetes	1
Arthritis and diabetes and heart condition	1
Heart condition	2
Heart condition and diabetes	1

Appendix 6:

Impact evaluation discussion guide

Thank you for agreeing to be interviewed.

My name is and I am part of the Project Team at Leeds Beckett University and I am currently undertaking interviews as part of the evaluation of Mind's local resilience programme.

We are interested in finding out about your experiences of the local Mind project. Are you still happy to be interviewed?

Your responses will remain anonymous. Are you happy for the interview to be recorded? The interview should take approximately 45 minutes.

Interview topics

1. Can you say a little about yourself and how you have come to be involved in the project?

(POSSIBLE PROMPTS AND FOLLOW-UPS) Were you referred? Did you find out from word of mouth from someone (who was that), or by other information or media? What is your LTC; how long have you been living with this?

2. What made you decide to get involved when the opportunity came up?

(PROMPTS) What were you looking for? Any particular activities? To meet people? How were you feeling at the time? (Your physical health? Your emotional wellbeing?) Was the location and time suitable and convenient?

3. What does the project have to offer you, overall?

(PROMPTS) Coping skills and techniques? Activities? Social? All of equal interest to you? Particular aspects you value? What is best on the project so far?

4. Can you tell me more about your experience of being involved – and the different things you have been doing on the project?

(PROMPTS) How long have you been involved now? The coping skills course 'Building a Healthy Future' – examples? Is it quite structured? Are most activities in groups? How does this work for you? How is it different from any other programme or support group for LTC you have been on? Examples?

5. How has your involvement changed since you started?

(PROMPTS) Have you come regularly? Have you felt more engaged over time?

6. What do you feel you have gained overall since getting involved? How are you feeling now?

(PROMPTS) Impact? More able to bounce back? Wellbeing (relaxation, mood)? Self-management? Particular practical coping skills? Goals for Action in particular areas of your life? New contacts? Confidence? Examples? Feel positive about yourself? Coping better physically or emotionally? Examples? Include this: What might you be doing or feeling if you were not attending this programme?

7. Can you tell me more about any particular course activities that were very valuable?

(PROMPTS) What you have you done and learned particularly? What do you particularly like? E.g. any particularly good activities about anxiety, stress, relaxation, setting goals, esteem? (e.g. mood activities, relaxation activities, etc.) Are these the kind of activities you want to do? Any improvements you could think of in the way course activities take place?

8. What has been your experience of the social aspect on the project?

(PROMPTS) Does the group process help you feel better linked to other people? Those with similar conditions and concerns? Do you think it works best with others with your condition only or with more than one condition in the group? What about the male/female balance? Example? Do you feel it helps you to come out of yourself? Relax? How does this happen? Any challenges for this aspect of the programme? Will you keep in touch with these people or will it affect the ways you connect with people?

9. Are you developing new coping strategies? Different ways of managing your life?

(PROMPTS) Can you tell me how this has worked for you as something to take away? How does this help you with your feeling of resilience about life; emotional wellbeing? Managing your condition or conditions? Practical examples? Ways of controlling your thoughts? Adapting to changes, problem solving, feeling resourceful? More calm or in control? Is this an approach you feel comfortable with – please explain?

10. Is the project helping with planning next steps in your life as you move forward?

(PROMPTS) How is it helping with your resilience? Making you feel you can set and achieve goals? Move forward (living with your condition)? What kind of next steps for you? (Specific examples – social activities, practical activities)? Practically? Social connections, links to your community? Big changes or smaller ones?

11. What support do you think would help you going forward?

(PROMPTS) Peer support? Ongoing contact with people from the course?

12. Are there any further ways projects like this could be improved for the future?

(PROMPTS) Any different priorities? Different offers of support? Number of weeks? Amount of personal support? Way of promoting the course (is it about mental health or life skills)? Time? Location? Choice? Mix of people? Recruiting more people? Further resources, activities? Please explain?

Are there any further areas you would like to mention?

Thank you

Appendix 7:

Impact evaluation questionnaire

Mind resilience questionnaire

By answering these questions, you will help the evaluation team to know if the projects are making a difference. The questions should take ten minutes or less to complete.

1. Your wellbeing

Below are some statements about your feelings and thoughts. Please tick the box that best describes your experience of each over the last two weeks.

Statements	None of the time	Rarely	Some of the time	Often	All of the time
Example: I've been feeling...	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input checked="" type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been feeling optimistic about the future.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been feeling useful.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been feeling relaxed.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been dealing with problems well.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been thinking clearly.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been feeling close to other people.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been able to make up my own mind about things.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

2. How positive you feel and how well you feel you can solve problems and achieve goals

Next here are some statements about whether you feel positive about yourself and about solving problems and achieving goals. Please tick the box that best describes how you have been feeling about each during the last two weeks.

Statements	Not true	A bit true	Moderately true	Exactly true
Example: I can...	1 <input type="checkbox"/>	2 <input checked="" type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I have clear aims and goals for my future.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
It is easy for me to stick to my aims and goals.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I am confident that I can deal well with unexpected events.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I can remain calm when facing difficulties because I can rely on my coping abilities.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I have the skills to manage my thoughts and feelings.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
When I am confronted with a problem, I can usually think of ways forward.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I can achieve the things I want to.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I feel comfortable with who I am.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

3. Your levels of social support

Next here are some statements about the level of support from friends, family and people around you. Please tick the box that best describes your experience of each over the last two weeks.

Statements	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Example: I have...	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input checked="" type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I have friends who are available when I am in need.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I have friends with whom I can share my feelings.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I can talk about my problems with friends.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I can talk about my problems with my family.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I feel supported by my family when I have an important decision to make.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I can get practical support to achieve my goals.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I am comfortable attending local activities.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I feel like a valued member of a community.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

4. Your feelings about managing your long-term condition

Statements	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about living with my long-term condition or conditions.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
I've been managing challenges related to my condition well.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Statements	Not true	A bit true	Moderately true	Exactly true
I can manage well when challenges arise in dealing with services.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I can remain calm when facing difficulties in managing my condition.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I am confident in my ability to manage thoughts and feelings about my condition.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Statements	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I feel supported emotionally about living with my long-term condition.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

About you

Now there are just a few questions about you to finish off.

a) Please mark the box to show your main health condition.

- | | |
|---|---|
| <input type="checkbox"/> Diabetes type 1 | <input type="checkbox"/> Heart disease |
| <input type="checkbox"/> Diabetes type 2 | <input type="checkbox"/> Osteoarthritis |
| <input type="checkbox"/> Inflammatory arthritis | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Other | |

b) Please mark the box to show which age group you fall into.

- | | |
|--------------------------------|---|
| <input type="checkbox"/> 18–29 | <input type="checkbox"/> 60–69 |
| <input type="checkbox"/> 30–39 | <input type="checkbox"/> 70–79 |
| <input type="checkbox"/> 40–49 | <input type="checkbox"/> 80+ |
| <input type="checkbox"/> 50–59 | <input type="checkbox"/> Prefer not to answer |

c) Please mark the box to show whether you are:.

- | | |
|-------------------------------|---------------------------------|
| <input type="checkbox"/> Male | <input type="checkbox"/> Female |
|-------------------------------|---------------------------------|

d) Please mark the box to show your ethnic origin.

White

- 1. British
- 2. Irish
- 3. Any other White background

Black or Black British

- 4. Caribbean
- 5. African
- 6. Any other Black background

Chinese

- 7. Chinese

Any other group

- 8. Any other

Asian or Asian British

- 9. Indian
- 10. Pakistani
- 11. Bangladeshi
- 12. Any other Asian background

Mixed

- 13. White and Black Caribbean
- 14. White and Black African
- 15. White and Asian
- 16. Any other Mixed background
- Prefer not to answer

e) Please write the first part of your postcode below e.g. AL1, if you are happy to share this.

Prefer not to answer

Anything to add?

Is there anything else you would like to add about your experience of the Mind project?

Thank you

Appendix 8:

Impact evaluation case study template

Building a Healthy Future – record of your experience

The information you write here will be used to give the team who are evaluating the Mind Building a Healthy Future programme evidence about how the course has been valued by the people who took part. Your story will be used to develop short individual stories (what we call case studies).

The information will be written in a way that you will not be able to be identified (it will be anonymous) – with your permission some of these anonymous cases will be written up and

used in the final report which will be presented to Mind. The report may eventually be made available to be read by others outside Mind.

Please keep a short record of your experience – your story – over three months since the course finished.

Please write as much or as little as you like – just tell your story using the headings provided.

Please write in box a, box b, box c, and box d as soon as you have time, now you have finished the course.

Later, after one month and three months we will ask you to write some more.

a) How was your physical health in the months before you came on the course?

b) How was your mental health in the months before you came on the course?

c) Why did you join the course? What did you hope to get from it?

d) What did you particularly value about the course?

Building a Healthy Future – record of your experience after one month

Thanks for agreeing to be one of the case studies for the Building a Healthy Future evaluation. These are a few questions asking how things have been since you completed the course. Please fill them out honestly and with as much or as little information as you feel comfortable with. Remember that your response will be kept completely anonymous.

a) How do you feel a month after the course has finished? Has anything changed for you?
If you need some pointers, think about the bullet points below:

- Wellbeing?
- More confident, in control?
- Accepting my condition?
- More calm?
- More clear what I want to do?
- Other feelings?

b) Since the course finished are you doing anything differently or doing different things? Try and address some of the bullet points below.

- Social activities?
- Different or same ongoing use of services e.g. GP, A&E, other health service?
- When and where am I accessing support?
- Self-management of emotional or physical health?
- Practical or physical activities?
- Other areas?

Building a Healthy Future – record of your experience after three months

Thanks for agreeing to be one of the case studies for the Building a Healthy Future evaluation.

These questions are about how you feel three months on from the course finishing. As before, please fill them out honestly and with as much or as little information as you feel comfortable with.

Remember that your response will be kept completely anonymous.

a) How do you feel three months after the course? Do you feel that anything has changed for you? If you need some ideas of what to write, think about addressing some or all of the bullet points below:

- Wellbeing?
- More calm?
- Other feelings?
- More confident, in control?
- More clear what I want to do?
- Acceptance of my condition?

Three months on from the course, are you doing anything differently or doing different things?

b) What would you say has changed for you – if anything?

c) What sort of things are you doing now that you might not have done before the course?

- Social activities?
- When and where am I accessing support?
- Practical or physical activities?
- Different or same ongoing use of services e.g. GP, A&E, other health service?
- Self-management of emotional or physical health?
- Other areas

d) Which one of the changes in your life is most important to you after three months?
Why is this particularly important?

e) What difference has the course made to your life three months later?

- Are any changes you have described due to the Mind programme?
What else has happened that may have made a difference in your life?
- Do you think these changes would have happened without the Mind Building a Healthy Future course?

Appendix 9:

Economic evaluation discussion guide

Note on using the discussion guide

This discussion guide illustrates the structure and flow of the interviews. It is intended to show how the researchers will talk through these individuals' experiences and the impact of the programme. The guide has been designed to enable the researchers to sensitively gather insight and information around the key research questions.

The document is designed to be dynamic and flexible: researchers will use it as a guide for discussions and will pursue interesting or relevant insights or topics as they emerge rather than sticking rigidly to this discussion guide. The document does not prescribe the exact 'question' or wording that will be used. Researchers will frame questions on the topic in response to the language used by interviewees. Some themes and questions will be more or less relevant, depending on the background and experiences of the individual participant.

Introduction

- **Introductions**
- Introduce interviewer
- Introduce observer and their role (if applicable)
- **Introduce audio recorder**
- Record to ensure accuracy and full coverage of points
- Explain what will happen with file – kept securely, used by Mind team for analysis
- We would also like to be able to use quotes in media, training, and campaigns work – but will always do so anonymously
- Questions?

Switch on recorder

- **Reiterate purpose of the research**
- Mind's 'Building a Healthy Future' programme is delivering targeted support to build the resilience of people with long-term physical health conditions (diabetes, heart disease, and arthritis).
- We are interviewing a range of participants in order to look at the economic impact of the programme
- We will be asking questions about your experiences of the programme, your health and wellbeing, and your use of a range of services
- **Nature of ongoing consent.**
- No right or wrong answers – want to hear range of views and experiences.
- Can choose not to answer questions
- **Confidentiality**
- Confidential answers
- Anonymous reporting
- Limits to confidentiality & onward disclosure (in case of risk of extreme harm or danger either to participant or someone else)
- Questions?

Social

- **Where do you live?**
- How long have you lived in this area?
- **What is your current living situation? (e.g. living alone, living as a couple etc.)**
- How long for?

- **Can you describe your home?**
- Is it fit for your needs?
- Recent changes?
- **Do you have friends or family who live close by?**
- How often do you see them?
- Does a friend or family member provide any care for you?
 - What support provided?
 - How often?
 - Ever taken time off work as a result?
 - Recent changes?

Physical health

- **Can you describe your physical health?**
- Physical health diagnoses?
- When did you receive these?
- How has your physical health changed over time?
 - Recent changes?
 - Anticipated changes?
- Do you take any medication?
 - Has this changed recently?
- Previous treatment
 - Potential prompts:
 - Inpatient services
 - Outpatient services
 - Day activity services
 - Community care services
 - Voluntary sector support
 - Services for older people
 - Services for adults with physical disabilities
 - Care packages
 - Community based health care
 - Community based social care

- Do you currently use any of these services?
- How would you describe your current physical health?
- **How would you describe your current wellbeing?**
- Changes recently?
- Mental health diagnosis?
- Previous/current mental health service use?

Work and benefits

- **What is your current employment status?**
- If employed:
 - How long employed?
 - What is occupation?
 - How long in occupation?
 - How many hours a week?
 - What is salary?
 - How many days absent due to illness?
 - Recent changes?
- If unemployed:
 - How long for?
 - Recent changes?
- **Do you currently do any volunteering?**
- If yes, what, how long, and how often?
- Recent changes?
- **Do you currently receive any benefits or tax credits?**
- If yes, what?
- For how long?
- Recent changes?
- **What is total personal gross income from all sources?**
- Household income?
- Recent changes?

Course

- How did you find out about the 'Building a Healthy Future' programme?
- Did anyone refer you to the programme?
- Why did you decide to join the programme?
- When did you join?
- How long did it take to join?
- Was it easy to join?
- Logistics of attending course
 - Travel, childcare, work etc.
 - Hours?
 - Where did you take part in the course?
 - Was it easy to get to?
- How does course compare to other services or support?
 - If not previously specified, what other services and support?
 - When did you receive this?
- Highlights
 - What did you like best about the course?
 - Did you attend a follow-up session?
 - If yes, was this helpful?
 - If no, why not? Would you like to?
 - What do you remember most clearly about the programme?
 - Have you continued using any of the techniques?
 - Have you stayed in touch with anyone you met on the programme?
- Barriers
 - Were there any barriers to your participation?
 - Did you miss any sessions?
 - Is there anything you would change about the course content?
 - Is there anything you would change about the course practicalities?

Effects

- Did the programme have any impact on your physical health?
- Potential prompts:
 - Self-management
 - Confidence to seek support
 - Peer support
 - More information
- Did the programme have any impact on your wellbeing?
- Potential prompts:
 - Confidence
 - Knowledge
 - Empowerment
 - Coping techniques
 - Friends and relationships
- Have any of these effects changed?
- Bigger change shortly after programme?
- Have you sustained improvements?
- Anticipated changes?

Conclusion

Do you have any key messages for Mind about the programme and your experiences?

Any final thoughts?

Switch off recorder

Next steps

- Explicit check on participants' welfare and signposting as relevant
- Reiterate how the interview responses will be used and next steps for the project
- Findings will be published in April 2016 and will be used to shape and tailor support for people with long-term physical health conditions
- Ask if they would like to receive the final report
- Encourage participant to complete demographic monitoring form
- Collect information about travel expenses and describe process for reimbursement
- Provide incentive voucher and receive participant's signature as acknowledgement of receipt

We won't give up until everyone experiencing a mental health problem gets both support and respect.

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