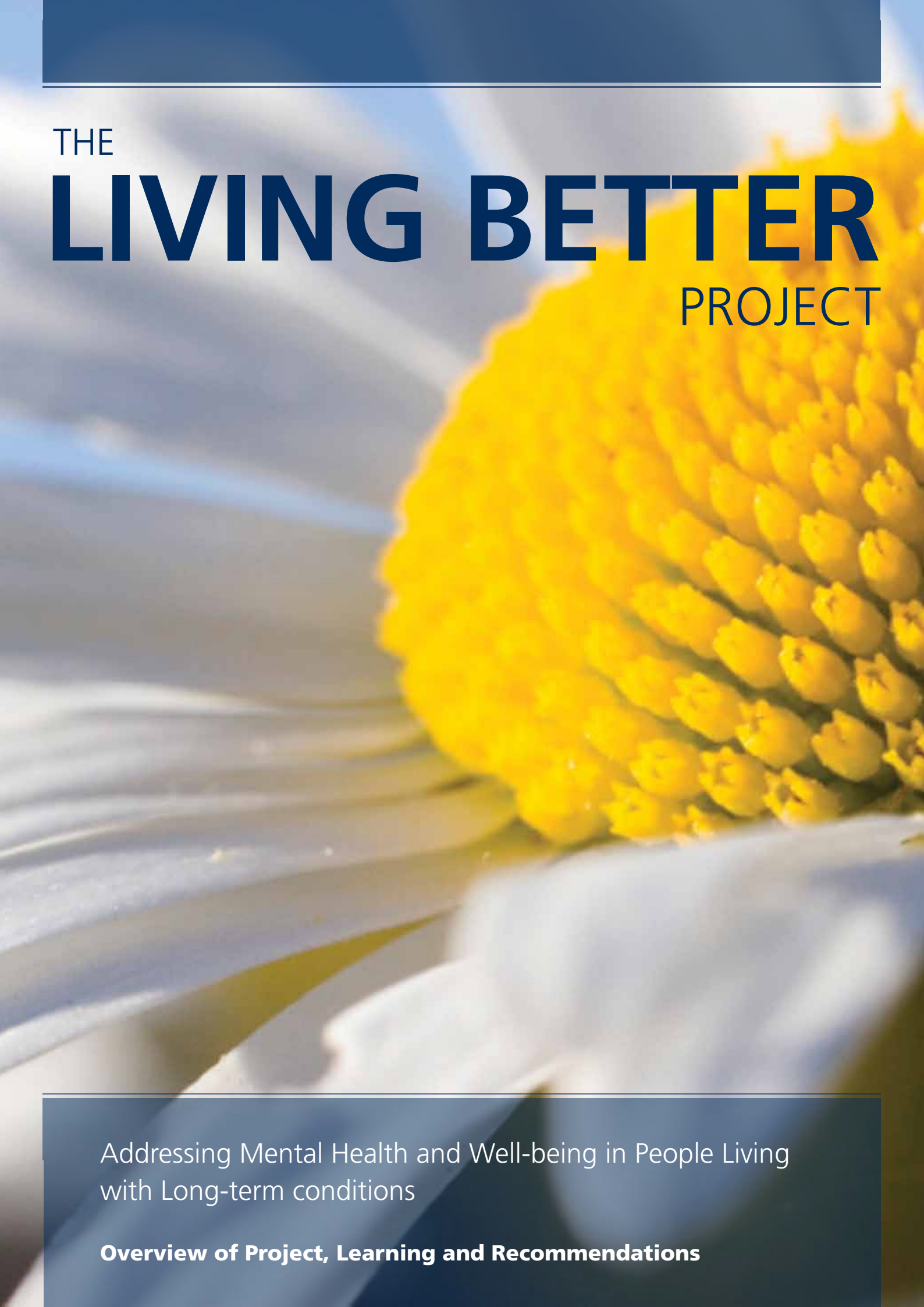


THE LIVING BETTER PROJECT

Addressing Mental Health and Well-being in People Living with Long-term conditions

Overview of Project, Learning and Recommendations

Living Better Project

Living Better Partners

- The Royal College of General Practitioners (Scotland)
- The Universities of Stirling, Glasgow and Edinburgh
- The Scottish Development Centre for Mental Health, now the Mental Health Foundation
- The Scottish Government Mental Health Division and Primary and Community Care Directorate
- Depression Alliance Scotland
- The British Heart Foundation Scotland
- Chest Heart & Stroke Scotland
- Diabetes UK Scotland

Living Better Aims

- To improve the detection and diagnosis of mental health problems in primary care among people with long term physical conditions, principally Chronic Heart Disease, diabetes or COPD
- To improve the provision of appropriate interventions and treatment including medical and non-medical options
- To ensure that responses reflect patient choice
- To improve the Community Health Partnership's responses in terms of flexibility, communication, and shared learning
- To strengthen partnership working within the CHPs
- To share the learning across Scotland

OVERVIEW OF PROJECT, LEARNING AND RECOMMENDATIONS

In recent years, growing attention has focused on the importance of addressing mental health and wellbeing in people who live with long term conditions. Living with a long term condition is a challenge in and of itself. When combined with depression and anxiety, the negative effect on people's health and lifestyle is substantial. It is against this backdrop that the Living Better project was launched in 2008 as a three year, Scottish Government funded research and development initiative to help local primary care services to respond to the mental health needs of people living with long term conditions (LTCs) such as diabetes, coronary heart disease (CHD) and chronic obstructive pulmonary disease (COPD).

The principle aim of the project was:

To work with primary care health services to improve the way they address mental health and wellbeing – and in particular the detection and management of depression and anxiety - among people living with long term conditions across Scotland.

The Living Better project worked within 5 Community Health Partnerships (CHPs) and 7 General Practices across Scotland each addressing specific LTCs:

- **Western Isles** (CHD and diabetes)
- **Angus** (CHD and diabetes)
- **North Lanarkshire** (CHD and diabetes)
- **South East Glasgow** (CHD and diabetes)
- **East Dunbartonshire** (COPD)

Living Better CHP Reference Groups

FIVE LOCAL REFERENCE GROUPS WERE ESTABLISHED TO:

- **Assess how existing services within the CHP were addressing mental health and wellbeing in people living with CHD, diabetes or COPD.**
- **Develop local plans and initiatives to improve the way existing services addressed mental health and wellbeing in people with CHD, diabetes and COPD in their respective CHPs.**

The Living Better reference groups consisted of (i) health and social care practitioners and planners in primary care who work with, or whose work is linked with, people with LTCs. This involved GPs, practice nurses, specialist nurses, Managed Clinical Network (MCN) nurses, organisers and planners of local CHP long term condition services; (ii) patients living with one or more of the three long term conditions selected to focus on; (iii) representatives from voluntary sector health organisations working with people living with LTCs.

Living Better Research and Evaluation

The research team contributed expert academic support to the local sites to help determine patient defined needs. This indepth research illuminated how people with LTCs perceive both their mental health and their views towards how they can best be supported. The research also included a valuable process evaluation of the development and implementation of activities within each CHP, to contribute to wider learning from Living Better project and to make this accessible to other primary care environments across the UK. The following is a summary of key learning from the process evaluation.

LIVING BETTER: KEY RESEARCH FINDINGS

Patient & Carer Focus Groups:The Experience of Living with a Long Term Condition

Twenty focus groups, attended by over 200 people with long term conditions and their carers were held across Scotland. A consistent finding to emerge across all 5 CHP sites was that living with one or more long term condition can be both an acute and chronic stress to individuals and their families. People with COPD, diabetes or CHD talked about how living with lomg term conditions can result in experiencing a range of emotions – '*frustration', 'anger', 'feeling down', 'isolated', 'financial worries', 'loss of confidence', 'lack of energy', 'frightened', 'having to make major lifestyle changes'*. The stigma of mental illness made it difficult for many with long term conditions to reveal the true extent of their emotional distress and have the confidence to seek appropriate help.

Patient Survey Findings

Our structured questionnaire survey of 500 people living with COPD, diabetes or CHD found (i) over 50% lived with more than one long term condition; (ii) more than one third scored mild/moderate/severe for depression and anxiety based on the Hospital Anxiety Depression Scale (HADS); (iii) more than one third reported that their social and leisure activities were significantly impaired due to their illness; (iv) when asked whether they felt optimistic about the future, over a quarter of respondents replied 'none of the time or rarely'.

People with Long Term Conditions: What Type of Support Did They Want?

(i) **Emotional support:** people to show understanding and appreciation of the effects of living with a long term condition; (ii) **Informational support:** helping the person understand their illness better and how to access available resources and coping strategies to help self-manage their condition; (iii) **Assistance and Practical support:** e.g. information about services to help them be socially active and pursue activities beneficial to their physical and emotional wellbeing, e.g. attending exercise or breathing classes, help with transport to get out of the house more (iv) **Peer support:** sharing experiences and information with people with the same condition was seen as helpful both in terms of information exchanged and empathy; (v) South Asians with diabetes and CHD wanted **bilingual, religiously appropriate and gender sensitive local support services**.

Primary Care Health Professional Focus Group Findings

Ten focus groups attended by approximately 80 health professionals found that (i) the stigma of mental illness can often make it difficult for many Primary Care based nursing staff to address mental health and wellbeing in people with long term conditions; (ii) many Primary Care nursing staff lack the time, skills and confidence to address mental health and wellbeing when managing chronically ill patients, and the Quality Outcomes Framework (QOF) screening questions for chronic disease management are perceived by many as a 'tick box' exercise'; (iii) there is a need for greater awareness of, and how to access locally, appropriate social support services especially those provided by Local Councils and the Voluntary Sector; (iv) there was a recognition that **Partnership Working** between primary healthcare organisations, Local Councils and Voluntary Agencies will become increasingly important to successfully address mental health and wellbeing in people with long term conditions.

Living Better: Key Training Findings

FIVE NEW TRAINING COURSES WERE DEVELOPED AND DELIVERED THROUGH THE LIVING BETTER PROJECT:

- **Mental health awareness for primary care and specialist nurses (half day)**
- **Culturally appropriate mental health assessments for patients with diabetes (half day)**
- **Living better with a long term condition (half day)**
- **Living better with COPD (six week course)**
- **Living Better: Training the Trainers (one day course)**

A total of 16 training workshops / courses were delivered through the Living Better pilot sites with 136 participants (85 professionals, 49 patients and 2 carers).

Overall the Living Better training courses evaluated very positively, with over 90% of respondents indicated that the content of the courses was relevant to their educational needs and over 95% viewing the training being of high quality.

Key learning points for health professionals included: greater understanding about mental health and mental illness; increased knowledge about screening and assessment tools; increased confidence about how to talk about mental health with patients and colleagues; and, better knowledge about local sources of support.

The most important learning points for patients were greater understanding about the link between physical and mental health, how to look after your mental wellbeing.

KEY LEARNING

- Living Better had clear overall aims and objectives which appealed to many local Reference Group members with interest in LTCs. This helped to galvanise their initial interest. However, the process of developing these into *local* aims and action plans was essential to maintain this interest and sustain commitment.
- The strategic buy-in to this project was a pre-requisite to it succeeding as this enabled the project to tap into existing local capacity. However, passing on the sense of ownership of the project to local sites was key to its longer term success and potential sustainability.
- Working with the Living Better project team required substantial local commitment by a range of partners over an extended period of time. The input from the project research support and project coordinator to facilitate goal setting and the development of activities, and to keep up motivation and momentum was instrumental in delivering Living Better activities. The project coordinator was an essential element in keeping everyone on board and focused on the agreed tasks.
- The three year timespan of Living Better was reported as too long by some participating sites, however this duration proved necessary given the multiple roles and responsibilities of those who were involved in local sites as well as intervening crises which often diverted staff to more pressing priorities [such as Influenza A (H1N1)]. Many sites are still in the implementation stages of Living Better activities.
- General practices were recruited to facilitate patient focused research within the project and to participate in project interventions. Their involvement may have been encouraged by the role of the RCGP within the project. Engaging more directly with General Practitioners and other primary care (nursing) staff still remains a challenge for wider NHS structures and for policy makers.
- Primary and specialist nursing services play a large role in supporting the needs of people with LTCs. Having key leads or champions within these professions is a helpful interface with primary care practice staff who often have little time to connect with others outwith their practice. Roles such as the Practice Nurse lead within the Primary Care Development Team (unique to NHS GG&C) and the MCN specialist nurses are examples of these key leads who can help facilitate change within primary care nursing staff. Participation from the lead GPs was important especially facilitating research and development initiatives at local GP practice level.
- This project highlighted the lack of (primary care) nurse confidence and skills in raising mental health issues with patients (despite the majority of QOF screening for depression being conducted by nurses). Consequently, training and learning opportunities were initiated within Living Better. This training was highly valued and evaluated extremely positively.
- Nurses would benefit from working more in tandem with the GPs when it comes to detection and management of depression in patients with multiple morbidity. Both GPs and nurses often assume that the other is more skilled in mental health related tasks and there can be uncoordinated effort when multiple physical conditions are involved. The opportunities for multidisciplinary training produced positive knowledge sharing among GPs and their nurses.
- Patient focus groups identified the early stages of diagnosis and adjustment to illness as being particularly stressful, fearful and anxiety provoking. Longer term impact is the decline in social activities with resulting social isolation. The research highlighted patient defined needs around social and peer support and community activities to address issues of isolation. Two of the Living Better sites have signposting services which were present in local training sessions to spread awareness of their services. Where voluntary sector partners had more input to Living Better projects there was a more assets based approach to local activities. These project sites were also more patient oriented in their development activities.

Key Learning from Training Initiatives

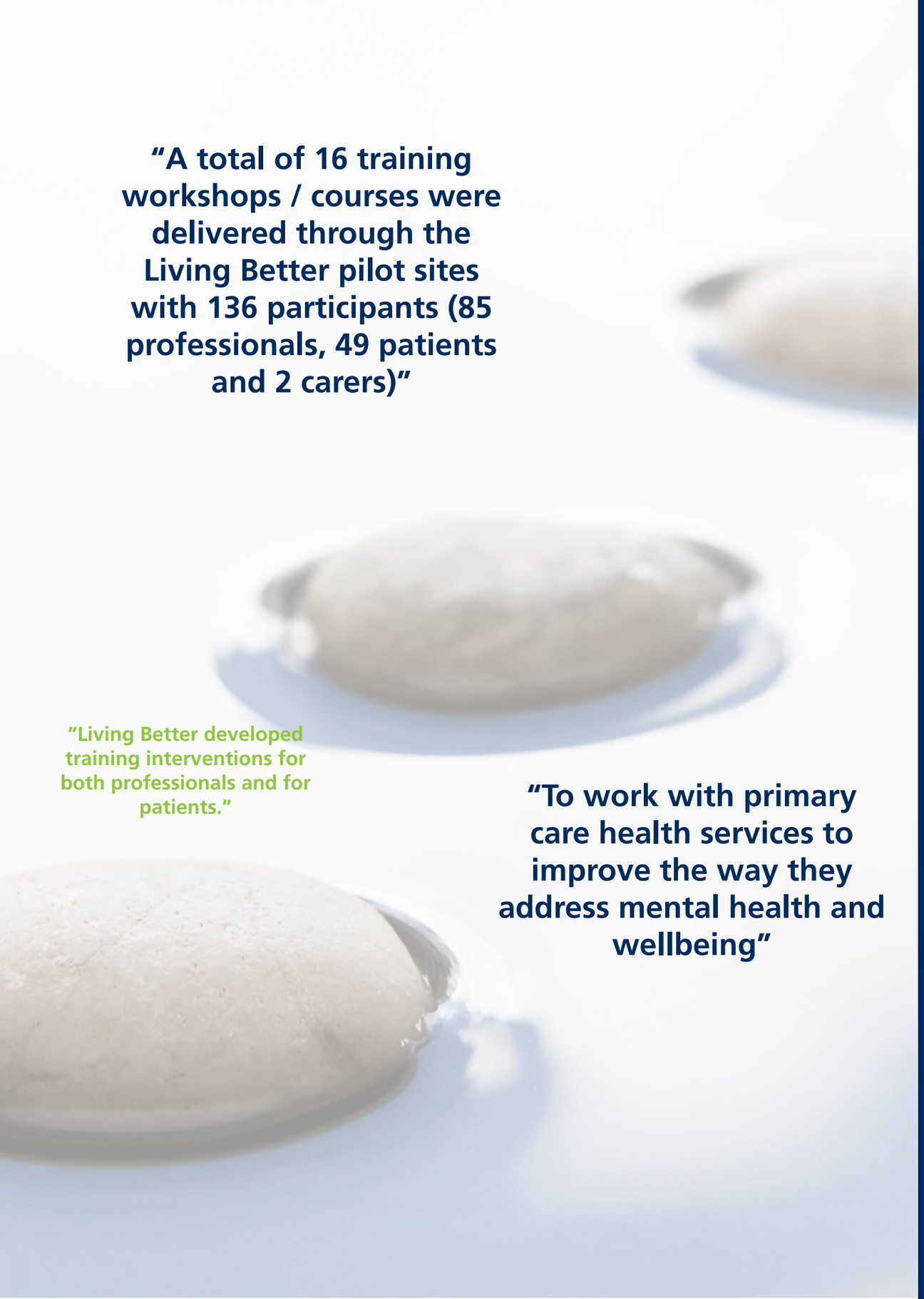
Living Better developed training interventions for both professionals and for patients. There was a great deal of enthusiasm and support for both, with both groups emphasising that their preference was for training delivered in an informal and supportive manner. Both groups welcomed the opportunity to talk with their peers and to share advice and problems.

Stigma associated with mental health was a key area highlighted within the research activity, therefore any patient activity was designed in a way which acknowledged this. The training was promoted in a way which underplayed the mental health aspects, and when mental health issues were discussed, the emphasis was on how to support positive wellbeing. This was also an assets based approach, working with people and their potential strengths as individuals, and as a group.

Training had to be adapted to meet local circumstances and population needs. For example, the group format was not appropriate for remote and rural locations where patients were less able to remain anonymous and patients felt there would be real issues with confidentiality. The development of the idea of 'social networking' as an approach emerged from this local need. Stigma was a greater issue within he South Asian population in Glasgow which impacted on how training and awareness raising activities were delivered.

RECOMMENDATIONS

- The Living Better project has produced some key resources for wider dissemination, with local adaptations of their delivery. These have essentially been tested for their acceptability amongst patients and professionals, and their feasibility of implementation. The next stage is to assess their impact and effectiveness, most notably on patient outcomes and professional behaviour and practice, and their potential for sustainable roll-out in ways that are not resource intensive. We recommend this should be conducted in partnership with other organisations, using Train the Trainer models and possible Expert Patients as partners in their delivery.
- The combined research support and facilitator input to Living Better were key to developing and delivering locally based interventions. Future patient focused service developments would benefit from similar project support. We recommend that this should be obtained from local patient involvement partnerships and/or voluntary sector partners.
- Primary care nurses require training and confidence building to integrate mental health screening and signposting into their role in managing LTCs. However, their contractual relationship with GPs means that they require to be supported by GPs to attend training. We recommend at least one practice learning session per annum is devoted to mental health, in addition to increasing nurse confidence and skills in mental health.
- Managing long term conditions and multiple morbidities well needs both the right contractual arrangements and the right organisational (practice arrangements) and education. The opportunities for multi-disciplinary training within Living Better produced positive knowledge sharing among GPs and their nurses. We recommend that future training in managing long term conditions or multiple morbidity should be multi-disciplinary to encourage more day to day knowledge sharing, and reviewing of practice organisational arrangements for managing long term conditions.
- Improvements are needed in partnership working between primary healthcare, local authorities and the voluntary sector to improve and develop links with community resources. The developing agenda for health and social care should enable this. There are some new initiatives being developed nationally which will help local GP practices to identify and link with community resources. We recommend expansion and awareness raising regarding these new initiatives (such as ALISS and other local resource toolkits) among GP practices. We also recommend more use of community resources by GP practices as part of usual care options. We also recommend that more emphasis be placed on providing peer supported activities within these care options.
- Scotland's growing black and minority ethnic (BME) population are vulnerable to a long term condition and, as we found in South East Glasgow with the South Asian community, the emotional strains of living with diabetes nd CHD are significant. We recommend that primary care health service provision and advice must be tailored in accordance with BME peoples' ethnic, religious and cultural orientations.



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