

# THE LIVING BETTER PROJECT

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

## **Overview of Project, Learning and Recommendations**



Royal College of  
General Practitioners



mental  
health  
foundation



UNIVERSITY OF  
**STIRLING**



University  
of Glasgow

# FOREWORD

The report presents the outcomes of a three year work programme looking at the mental health and wellbeing of people with long term conditions across Scotland. It was funded by the Mental Health Division as part of the Scottish Government's on-going commitment to improving the mental health and wellbeing of people in Scotland. We know that people with long term conditions are particularly vulnerable to developing poor mental health and this report provides important evidence about the mental health issues people with conditions such as diabetes, heart disease or COPD face. It also provides valuable information about the types of support and interventions that may help to improve both diagnosis and mental health support for people with long term conditions.

As a government we are taking steps to ensure the recommendations from this report are acted on. Projects funded through the Long Term Conditions Self Management fund are developing additional resources to support the wellbeing of people with long term conditions, and the ALISS project (Access to Local Information to Support Self Management) is working to ensure that information about support and self management resources is accessible to GPs and other primary care workers. The new Mental Health Strategy also offers a good opportunity to ensure that people with long term conditions have good access to mental health support when and where they need it.

I welcome the findings from this report and am grateful to the Royal College of General Practitioners (Scotland), the Mental Health Foundation and the Universities of Edinburgh, Glasgow and Stirling for their commitment to this issue and their work to complete this ambitious research and development programme.

**Angiolina Foster, Director of Primary and Community Care, Scottish Government**



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We thank our voluntary sector partners who have been on board since the inception of Living Better: British Heart Foundation Scotland; Chest Heart & Stroke Scotland; Diabetes UK Scotland; and Depression Alliance Scotland.

The Living Better National Steering Group members receive sincere thanks for their time and input to the project. Again, many people stayed throughout the life of Living Better and others joined for specific periods. The names of all past and present members are listed in an Appendix to this report.

Special thanks go to the local Reference Group members in each of the Community Health Partnerships (CHP)/Community Health Care Partnerships (CHCP) Living Better sites. There were many changes in membership across the study period and as the project moved into different phases. This study could not have been possible without their help, support and enthusiasm and the success of Living Better is their achievement, not ours.

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Professor Margaret Maxwell University of Stirling, Project Research Lead  
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Euan Bailey, Projects Administrator, RCGP Scotland.

A final review of the report was provided by:  
Professor Stewart Mercer and Dr John Gillies, Chair of RCGP Scotland.

Further information about Living Better is available at [www.livingbetter-scotland.org.uk](http://www.livingbetter-scotland.org.uk) or by contacting RCGP Scotland on 0131 260 6800, email [ebailey@rcgp-scotland.org.uk](mailto:ebailey@rcgp-scotland.org.uk)

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# CHAPTER 1:

## INTRODUCTION TO LIVING BETTER

### 1.1 THE LIVING BETTER PROJECT

In 2008, the Scottish Government's Mental Health Division initiated the Living Better project with a grant of £548,228 to address mental health issues in people living with long-term conditions. This primary care based project involved five CHPs (and seven GP practices) across Scotland.

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.*

To achieve this aim, two key groups of people were identified and engaged with;

- (i) People living with a long-term condition – the project specifically focused on people living with coronary heart disease (CHD), diabetes and chronic obstructive pulmonary disease (COPD).
- (ii) Health and social care practitioners and planners and voluntary sector organisations in primary care, specifically, across community health partnerships (CHPs), who work with, or whose work is linked with, people living with long-term conditions.

The project has involved the following key partners:

- The Scottish Government Mental Health Division and Primary and Community Care Directorate
- The Royal College of General Practitioners (Scotland)
- The University of Stirling
- The Scottish Development Centre for Mental Health (until December 2010), now known as Mental Health Foundation
- Depression Alliance Scotland
- British Heart Foundation Scotland
- Chest Heart & Stroke Scotland
- Diabetes UK Scotland

## 1.2 THE LIVING BETTER CHP SITES

There were five CHPs involved in the Living Better Project. These and the associated long-term conditions addressed in each site were:

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

The five CHP areas selected were done so with a view to addressing Scotland's diverse socio-economic, demographic and geographic characteristics, all of which impact on a long-term condition and its management. Invitations to participate were sent out to all NHS Boards across Scotland and sites were chosen from among those expressing an interest in the project and who represented an area of specific socio-demographic interest.

The project selected sites that were rural (Western Isles), semi-rural (Angus), socially deprived (North Lanarkshire & South East Glasgow), areas with high levels of black and minority ethnic communities (South East Glasgow), areas with a higher than average number of older people (Western Isles), and areas not strongly associated with high levels of social deprivation (Angus and East Dunbartonshire). **Appendix 1** provides information on CHP site profiles and **Chapter 2** provides further information of CHP site activities.

## 1.3 LIVING BETTER GOVERNANCE AT NATIONAL AND LOCAL LEVELS

The Living Better Project had a three tiered governance structure, with a core Executive Project team whose purpose was to manage and deliver the project within agreed budgets and timescales, a wider project partnership involving four key voluntary sector partners, and a National Steering Group whose remit was to oversee the successful implementation of the project. At a local (CHP/CHCP) level local Reference groups were established to steer local priorities and activities. Membership of the reference groups varied from site to site, but was broadly made up of the following perspectives:

- Long-term conditions leads
- Representatives from participating GP practices (GPs, practice managers, practice nurses)
- CHP clinical lead
- Patient representatives
- Primary care mental health leads / managers
- Diabetes and / or Heart Disease Managed Clinical Network (MCN) Co-ordinators / Managers
- Voluntary sector organisations
- Representatives from the national Executive Project Team, usually the Project Officer, with input from Researcher and Strategic Lead as appropriate.

Full details of the governance and operationalisation of Living Better at national and local levels is contained in **Appendix 2**, which also contains information on the learning points regarding project structure and governance. **Appendix 3** contains details of the National Steering Group members.

### 1.3.1 Voluntary Sector Partners

Recognising the considerable role of the voluntary sector in supporting people with long-term conditions, the Living Better project worked in partnership with four key voluntary sector agencies throughout the life of the project: British Heart Foundation Scotland, Chest Heart & Stroke Scotland, Depression Alliance Scotland and Diabetes UK Scotland. The voluntary sector partners provided support and input into the project in a number of ways:

- Providing guidance and support through membership of the steering group.
- Facilitating the recruitment of patient representatives to the steering group.
- Writing and production of two patient information leaflets: *Diabetes and Mood* and *Heart Disease and Mood*.
- Providing guidance, advice and input into patient education courses.
- Providing information, leaflets and materials for Living Better exhibitions, training sessions and events.
- Presenting and representing the Living Better project at national events and conferences.

The good will and commitment to the project shown by key voluntary sector links helped to ensure that the needs and priorities of people living with long-term conditions were kept at the heart of Living Better activities and priorities.

### 1.3.2 Living Better Partnership in Action: Patient leaflets

A working group consisting of the Living Better Project Officer and Administrator, voluntary sector links and patient representatives was convened from July 2008 to July 2009 to write and produce two patient information leaflets covering diabetes and mood and heart disease and mood. The work was led by Chest, Heart & Stroke Scotland and Depression Alliance Scotland, with input from other partners. Paper and electronic copies of the leaflets were produced and disseminated through pilot sites, voluntary sector networks and conferences and events. Electronic versions of the leaflets are available to download from [www.livingbetter-scotland.org.uk](http://www.livingbetter-scotland.org.uk)



## 1.4 BACKGROUND TO LIVING BETTER

A long term condition is one that lasts longer than a year, impacts on a person's life and may require ongoing care and support<sup>1</sup>. It is estimated that approximately two million people in Scotland are currently living with a long-term condition. These numbers are projected to keep rising over the next decade. Someone living in a deprived area is more than twice as likely to have a long-term illness compared with someone in an affluent area, and people living with a long-term condition are likely to be more disadvantaged across a range of social indicators such as employment, educational qualifications, home ownership and income<sup>2</sup> (Better Health Better Care, 2007).

The vast majority of people with long-term conditions are cared for in the community by primary healthcare services. In their 2007 report '*Managing Long-term conditions*', Audit Scotland reported that people with a long-term condition account for 80% of all GP consultations.

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 these conditions can result in acute and chronic stress which can impact negatively on how people feel, making them vulnerable to depression and anxiety. Research has shown that approximately 30% of people with Diabetes and 33% of people who have had a heart attack will experience depression.<sup>3,4</sup> Living with a long-term condition is a challenge in and of itself. When combined with depression and anxiety the negative affect to people's health and lifestyle is exacerbated. Depression, for example, is associated with a doubling of mortality in people with CHD<sup>5</sup>.

The association between long-term conditions and mental health problems have been known for some time. However, organisations like Long-Term Conditions Alliance Scotland (LTCAS) have stated, that the mental health needs of people with long-term conditions in Scotland were still not being adequately addressed<sup>6</sup>. One reason for this may be the ongoing under-detection of mental health issues in primary care. A recent study on depression in Scotland found that around half of patients with significant depressive symptoms were not identified by their GP as suffering from a depressive disorder<sup>7</sup>.

<sup>1</sup> Scottish Government (2009) *Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan*, Edinburgh: Scottish Government

<sup>2</sup> Scottish Government, 2007. Better Health, Better Care. SGHD.

<sup>3</sup> Davies SJC, Jackson PR, Potokar J, Nutt DJ. Treatment of anxiety and depressive disorders in patients with cardiovascular disease BMJ 2004;328:939-943

<sup>4</sup> Lin EHB, Katon W, Rutter C et al. Effects of enhanced depression treatment on diabetes self-care. *Ann Fam Med* 2006;4:46-53.

<sup>5</sup> Barth J, Schumacher M, Herrmann-Lingen C. Depression as a Risk Factor for Mortality in Patients With Coronary Heart Disease: A Meta-analysis. *Psychosomatic Medicine*, 2004;66:802-813.

<sup>6</sup> Long Term Conditions Alliance Scotland: 2010 Policy Briefing: Long Term Conditions and Mental Health And Wellbeing

<sup>7</sup> Cameron et al (2009) Appropriateness of antidepressant prescribing: an observational study in a Scottish primary-care setting. *Br J Gen Pract*. 2009 September 1; 59(566): 644-649.

Specific studies on undiagnosed depression in people living with long-term conditions have demonstrated a similar trend. One large scale study of people with diabetes for example found that half the people with depressive symptoms went undetected (Katon, 2003<sup>8</sup>).

The Living Better project was established to work with local CHPs to improve mental health awareness, knowledge and management among primary care professionals, and particularly nurses, working with people living with long-term conditions.

## 1.5 THE ROLE OF COMMUNITY HEALTH PARTNERSHIPS IN SCOTLAND'S HEALTHCARE

The National Health Service Reform (Scotland) Act 2004 provided for each Health Board to establish CHPs<sup>9</sup>. Consequently, CHPs became a key mechanism through which primary and community based healthcare services are planned and delivered. They have a central role with their partners in improving health and reducing health inequalities. Scottish Ministers have reaffirmed the central role of CHPs in shifting the balance of care, which is a prerequisite for the delivery of many HEAT targets<sup>10</sup> and joint outcomes with Local Authorities.

In Autumn 2007, after reviewing the management of long-term conditions across Scotland, Audit Scotland published their report and recommended improved partnership working at primary care level between health, social and voluntary care providers in order to integrate services for people with long-term conditions. The report also recommended that CHPs should have a key role in co-ordinating this.

It is within this context that the Living Better project was conceived and delivered: to use the framework of CHP/CHCP's to help address the mental health and wellbeing of people living with long-terms condition in Scotland.

<sup>8</sup> Katon W (2003) The Institute of Medicine "Chasm" report: implications for depression collaborative care models. *Gen Hosp Psychiatry*. 2003;25:222–9.

<sup>9</sup> National Health Service Reform (Scotland) Act 2004

<sup>10</sup> <http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/17273/targets>

## CHAPTER 2: LOCAL PILOT SITE ACTIVITY

Five pilot sites were recruited through the project to explore different perspectives on the needs of people with long-term conditions, current practice in responding to these needs, and opportunities for further development in this area. Sites were selected to give a range of different levels of deprivation, rural and urban geographies, and health profiles.

Each of the five pilot sites set up local reference groups to steer activities and worked through five project phases to complete the work, outlined in Diagram 2a below.

*Diagram 2a: Pilot site phases of activity*



### 2.1 ANGUS

The Angus pilot was led by a core reference group which included representatives from primary care development, health improvement, mental health services and the Angus Cardiac Group. The pilot worked with the Kirriemuir and Edzell practices through all stages of the project.

Through a series of focus groups, open meetings and reference group discussions the following needs for people living with long-term conditions in Angus were identified:

- Support groups to enable people to share their experiences with others.
- Training for staff in how to initiate conversations about mental health with their patients.
- Greater awareness of local community resources and sources of support.

In response to these needs, an Angus action plan was agreed and implemented, incorporating the following activities:

- Mental health awareness training for people with CHD / Diabetes registered at Kirriemuir and Edzell practices.
- Mental health awareness training for practice staff in Kirriemuir and Edzell and for other primary care and specialist health professionals across Angus.
- Promoting and distributing the Angus Self Management Toolkit.
- Writing and supporting the implementation of a mental health component to Angus' Pulmonary Rehab course.

A summary of Angus training activity is provided in Table 2b. The training sessions evaluated very positively, both by staff and patients. Further information about training outcomes is available in **Section 3** of this report.

Table 2b: Summary of Angus Training Delivery

Where	When	Who	Numbers
Edzell Practice	May 2010	Patients Staff	24 3
Kirriemuir Practice	June 2010	Patients Staff	13 4
Angus PLT	September 2010	Staff	15
<b>TOTAL</b>			<b>59</b>

Following the completion of the Angus pilot, it was agreed that the priority for future action to address the mental health needs of people with long-term conditions was to develop further opportunities for local peer support.

### 2.1.1 Key learning from Angus pilot

- Practice staff valued the opportunity to hear about mental health issues raised by ‘their’ patients. In Edzell, the desire, expressed by patients, to set up a local support group was supported by the GP who offered a room in the practice for this purpose.
- The involvement of local support services, such as the Positive Pathways Project and Angus Cardiac Group, in patient training sessions enabled participants to develop links with services they could utilize in the future.

## 2.2 EAST DUNBARTONSHIRE

East Dunbartonshire was the last pilot to come on stream. The reference group was led by the Lead Occupational Therapist for East Dunbartonshire CHP and involved two participating general practices (Kessington in Bearsden and Southbank in Kirkintilloch), NHS Greater Glasgow & Clyde representatives (long-term conditions, mental health, primary care development), the clinical lead, the primary care mental health team, Carers Link, patient representatives and older people’s co-ordinator.

East Dunbartonshire was the only pilot to focus on the needs of people with COPD, a decision driven by locally identified needs and the rate of hospital admissions for people with this condition. However, the needs identified through the focus groups were similar to those found in other areas:

- People with COPD need information about their condition and coping strategies.
- Health professionals require training on how to integrate meaningful mental health conversations within their appointments.
- Patients and health professionals require information about local sources of support.

In response to these needs an East Dunbartonshire action plan was developed and approved, which prioritized the development of a new, locally run self-management course for people with COPD.

### 2.2.1 Living Better with COPD

Living Better with COPD was devised as a six week course to cover a range of topics including physical activity, low mood, breathing control, local sources of support, and support for carers. The course was designed so that mental health messages would be explicit within wider health improvement content.

Fifteen different presenters and two district nurse facilitators were involved in designing and delivering different aspects of the course, including representatives from Respiratory Services, Pulmonary Rehab, Live Active, Health Promotion, Primary Care Mental Health Team, Carers Link, Chest, Heart & Stroke Scotland and Living Better.

The course was tested with a cohort of nine patients and two carers in from the Kessington and Ashfield practices in Bearsden and Milngavie. The course was evaluated positively by participants and course providers. Key strengths were seen as being:

- The informal atmosphere which encouraged the sharing of experiences between participants.
- The goodwill and flexibility of presenters who brought together a complex course in a short timescale.
- The consistent emphasis on breathing and relaxation techniques during each session.

Challenges included ensuring good communication across all the course presenters, low take up for the carers component of the course and providing transport to enable patients to attend training. Further details of the course content and outcomes are presented in **Section 4** and a full evaluation report of the course is available on request from Amy Woodhouse at the Mental Health Foundation<sup>11</sup>.

The reference group intends to run a second 'Living Better with COPD' pilot in Kirkintilloch, with the longer term vision of extending the remit of the course to support people with a range of long-term conditions.

### 2.2.2 Key learning from East Dunbartonshire

- Joint provision of training between different agencies facilitates communication and learning between the professionals involved, but demands greater administration and management input.
- Seasonal exacerbations of COPD, especially in winter, need to be considered when programming training for people with this condition.
- Transport provision should be included when providing training and support to people with COPD, especially for those in the more advanced stages.

<sup>11</sup> Email: awoodhouse@mhf.org.uk

## 2.3 NORTH LANARKSHIRE

North Lanarkshire reference group involved representation from the participating practices (John Street Practice in Bellshill and Dr Menon's Practice in Motherwell), clinical lead, CHD Services, Diabetes Services, MCN Manager, and the ICP Co-ordinator. The two key links for the pilot came from the Mild to Moderate Mental Health Project and Service Development within NHS Lanarkshire.

Focus groups undertaken with patients and professionals highlighted the need for:

- Information about local services.
- Training for staff on mental health awareness, assessment and signposting.
- Improving access to social support.

In response to the needs identified in the focus groups, the North Lanarkshire reference group developed the following programme of work:

- Development of a new pathway to place greater emphasis on the role of practice and specialist nurses in mental health assessment and signposting.
- Development of a training programme to support the knowledge and confidence of health professionals to address the mental health needs of people with long-term conditions.
- Test the new pathway through participating practices, diabetes and CHD services.
- Review and revise pathway if required and look to roll out across North Lanarkshire.

### 2.3.1 Staff Training

Twenty-two health professionals from a range of backgrounds including practice nurses, specialist diabetes and CHD nurses, GPs, Keep Well Nurses and various allied health professionals took part in Living Better training in North Lanarkshire. The training covered sections on mental health awareness, screening and assessment and signposting. The signposting dimension was covered by local representatives of the Mild to Moderate Mental Health Project.

The course evaluated very positively with participants indicating that their confidence around discussing mental health issues had increased and they were more aware of local signposting options. The workshop also went on to become the standard Living Better training course for health professionals and was utilised in other pilot sites such as Angus and Western Isles.

### 2.3.2 Pathway Testing

The new pathway was piloted over a three month period with a cohort of CHD specialist nurses, diabetes specialist nurses and the John Street practice. Pathway packs given to participants included the new pathway and guidance on how to use it, assessment tools, Living Better patient leaflets and information about local community resources such as the Healthy Reading scheme. All pathway testers had completed the training course described above.



Participants were requested to complete and return a monitoring form each time they used the pathway to indicate what, if any, changes to existing practice had been made and what, if any, advantages these changes had given. Returned forms indicated that:

- Mental health concerns were frequently raised by patients in appointments with long-term condition health professionals.
- The pathway appeared to be most useful in its provision of reading materials and signposting information, which were utilised in more than half of assessments recorded.

A number of measures have been taken to ensure the sustainability of the North Lanarkshire programme of work:

- There was representation from North Lanarkshire in the national Living Better: Training the Trainers course to enable further roll-out of Living Better training within local diabetes services.
- The mental health needs of people with long-term conditions has been recognised within the generic Mental Health Integrated Care Pathway in Lanarkshire

### **2.3.3 Key learning from North Lanarkshire**

- Changing assessment processes within primary and secondary care settings requires strategic buy-in and ongoing support from GPs and other line-managers.
- Promoting local sources of emotional support continues to be an important function for health professionals to perform.

## 2.4 SOUTH EAST (SE) GLASGOW

The reference group was led locally by the Head of Mental Health for the (then) SE Glasgow CHCP with membership from the Managed Clinical Network (MCN) Manager and co-ordinators for Greater Glasgow & Clyde, the Mental Health Collaborative, Health Inequalities Pharmacist, primary care development, the CHCP clinical lead, patient representatives and the Keir Street practice. It was agreed at an early stage that the SE Glasgow pilot would focus on supporting the needs of the local South Asian community.

The scoping phase for the South East Glasgow pilot was undertaken in a number of stages, exploring the needs of both the indigenous and South Asian communities. The findings from the South Asian focus groups revealed that:

- South Asian women wanted access to culturally sensitive support that was locally accessible.
- South Asian men preferred to access broad social support services (exercise classes, etc.) rather than those which explicitly addressed emotional wellbeing.
- Health professionals felt there was more that could be done to raise awareness of mental health issues in the South Asian community.
- GPs, practice nurses and specialist nurses lack the time to tease out emotional issues with South Asian patients.
- Not all primary care staff are aware of local services and available resources.

In response to the issues identified in the focus groups, the following priority areas were agreed by the South East Glasgow reference group:

- Conduct a mapping of local culturally sensitive sources of support.
- Develop mental health awareness information for the South Asian community.
- Develop culturally sensitive mental health screening and assessment training for health professionals.
- Disseminate learning across NHS Greater Glasgow & Clyde.

### 2.4.1 Mapping Local Culturally Sensitive Sources of Support

A mapping exercise was undertaken by an independent researcher to gather information about culturally appropriate services in neighbourhoods with a high South Asian population, such as Govanhill and Pollockshields. A copy of the mapping report, containing information about the 27 services included in the mapping exercise is available on request from Amy Woodhouse at the Mental Health Foundation<sup>12</sup>.

<sup>12</sup> Email: [awoodhouse@mhf.org.uk](mailto:awoodhouse@mhf.org.uk)

### **2.4.2 Mental Health Awareness Information for the South Asian Community**

In June 2010, the South East Glasgow Living Better reference group ran an information stand at the Glasgow Mela, an annual multicultural arts festival attracting approximately 40,000 visitors. The primary aim of the stand was to give out information about mental health and sources of support to the local South Asian community, but also to gather information about self-help strategies and things that people can do to improve their mood. Outcomes from the day included:

- Gathering 176 self help tips and suggestions.
- Distributing mental health information in English and Urdu.
- Achieving new referrals to the Minority Ethnic Long-term Medicines Service (MELTS) service.
- Raising awareness amongst health professionals as well as members of the public. for example, a South East Glasgow GP was made aware of translated leaflets.

### **2.4.3 Culturally Sensitive Mental Health Screening and Assessment Training for Health Professionals**

The Living Better project commissioned Dr Saima Ali, Researcher from Southampton University, to write and deliver a half day training course designed to:

- Raise awareness of the prevalence of depression and diabetes in the South Asian community.
- Explore cultural understandings of depression and diabetes.
- Discuss methods of diagnosing depression in the South Asian community.
- Provide information about available culturally appropriate sources of help and support.

The course, the first of its kind in Scotland, supported nine local health care professionals including GPs, Practice Nurses, Community Pharmacists and Specialist Nurses, the majority of whom were from South Asian communities.

### **2.4.4 Key Learning from South East Glasgow**

- Community events such as the Glasgow Mela provide a useful and affordable means for distributing positive mental health information within to diverse audience.
- Because best practice in supporting the mental health of South Asians with long-term conditions is still emerging, there is a strong argument for partnership working across the UK to address this issue.

## 2.5 WESTERN ISLES

Unlike other pilot sites, the Living Better Western Isles pilot began as a 'practice-up' project, following interest expressed by the Stornoway Group Practice. Representatives from the Community Health and Social Care Partnership (CHaSCP) and NHS Western Isles were subsequently brought on board. Membership also includes Diabetes and CHD Service co-ordinators, local GPs and representatives from the Western Isles Carers Users and Supporters Network.

Focus groups undertaken with patients and professionals revealed that:

- The stigma of mental health issues and some long-term conditions on the Western Isles makes talking about emotional concerns difficult.
- Patients would like greater access to 'one-to-one' support with health professionals.
- Patients and staff alike require more information about sources of support.
- Staff would benefit from training to enable them to engage with patients around mental health issues.

As a consequence of these findings, the following activities were prioritised by the reference group:

- Patient awareness raising events in Lewis and Uists.
- Training for professionals on mental health awareness, assessment and signposting.
- Scoping out potential for social networking activity to support people with long-term conditions.

### 2.5.1 Staff and Patient Training

The staff and patient training programmes delivered in Western Isles were based on those developed and implemented in North Lanarkshire and Angus. They were delivered in two sites (Stornoway and Benbecula).

Twenty-seven health professionals participated in the staff training events, more than in any other Living Better pilot site. Participants were primarily nurses (practice, specialist, district etc) but also included GPs, mental health outreach workers and other allied health professionals. The training received positive evaluation from almost all participants and across all professions who attended. Participants appreciated information about how to assess for mental health issues and use listening skills to facilitate more open discussion about these issues. Personal outcomes included increased confidence in clinical settings and greater understanding of mental health and mental illness.

Unlike the staff training, the numbers of individuals participating in the patient workshops was very low on both occasions, with only three individuals in total taking part. Several possible explanations can be given for the low turnout:

- The training was promoted through newspapers and 'word of mouth' rather than through direct invitations from GP practices.
- Lack of anonymity and the stigma surrounding mental health issues may have acted as a deterrent.

### **2.5.2 Social Networking Pilot**

In recognition of the difficulties (both geographical and cultural) which exist in the Western Isles in bringing people together to form support groups, the reference group suggested the Living Better pilot explore the potential for developing social networking based support for people with long-term conditions. A small sub-group was formed to take this work forward with the agreement that a brief online survey aimed at people with long-term conditions would be set up to help gather evidence of local enthusiasm for this proposal.

### **2.5.3 Key learning from Western Isles**

- Stigma relating to both to mental health and individual long-term conditions continues to act as a barrier for some to attending face-to-face support groups.
- More anonymised forms of support, such as those offered online, may be more acceptable within rural and remote settings, although they will not be accessible to all.

# CHAPTER 3: LIVING BETTER: MENTAL HEALTH AWARENESS TRAINING

## 3.1 IDENTIFIED TRAINING NEEDS

Living Better focus groups with health professionals and patients with long-term conditions highlighted a number of training needs across all five sites:

- The need to increase skills and confidence of health professionals (particularly primary care and specialist nurses) to initiate conversations about mental health with patients.
- The need for increased signposting to guide individuals to relevant support.
- Culturally sensitive mental health assessment.
- Self-management skills, particularly regarding maintaining good emotional health, for people with long-term conditions.

## 3.2 LIVING BETTER TRAINING PROGRAMMES

In response to these needs, the Living Better team commissioned expert trainers and practitioners to produce a series of training courses:

- *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)*

Further detail about each course is provided below.

A total of sixteen training workshops / courses were delivered through the Living Better pilot sites with 136 participants (85 professionals, 49 patients and 2 carers) (see Table 3a).

Table 3a: Living Better training provision

Course	Where	Number of Courses	Number of Participants
Mental health awareness for primary care staff and long-term condition specialist nurses	Angus N Lanarkshire Western Isles	7	71
Culturally appropriate mental health assessments for patients with Diabetes	SE Glasgow	1	9
Living better with a long-term condition	Angus Western Isles	6	40
Living better with COPD	East Dunbartonshire	1	11
Living Better: Training the Trainers	National	1	5
<b>TOTAL</b>		<b>16</b>	<b>136</b>



### 3.2.1 Mental Health Awareness for Primary Care Staff and Long-Term Condition Specialist Nurses

This half day course covered three core themes: mental health awareness, screening and assessment, and signposting to local resources. The course was delivered seven times across three sites, with 71 professionals participating in total.

The training was delivered in a number of different ways:

- In practice – small groups of practice based staff (Edzell, Kirriemuir and Group Practices)
- Protected Learning Time sessions – part of the formal PLT programme (Angus and North and South Uist)
- Open access – open invitations to practices, specialist teams etc (North Lanarkshire)

Participants in the courses included practice nurses, GPs, specialist nurses, Keep Well nurses, health promotion specialists, mental health outreach workers, occupational therapists and community psychiatric nurses.

Sixty four completed evaluation forms were returned by participants on the seven courses. Responses were generally very positive, with over 90% of respondents indicating 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 participants included: greater understanding about mental health and mental illness, increased knowledge about screening and assessment tools, increased confidence in how to talk about mental health with patients and colleagues, and better knowledge about local sources of support.

Overall, the evaluations were very positive for the Living Better training courses, with participants feeling that their skills and knowledge had improved, and that there could be opportunities for more positive promotion of mental health. Areas of improved skills and knowledge were described by participants as follows:

*'Mental health does not mean being mentally unwell or having a mental health problem. Not to take a negative view of 'mental health'.'* (Practice Nurse, Western Isles)

*'More confidence in asking questions and ability to identify a mental health problem.'* (Diabetes Specialist Nurse, North Lanarkshire)

*'We all find introducing 'mental health' issues complex. I therefore feel supported and will find discussing such issues with colleagues less threatening.'* (MacMillan Nurse, Western Isles)

In terms of what participants thought they would do differently as a consequence of the training, individuals suggested that they would openly discuss mental health issues with patients, listen and be more aware of cues that might indicate a patient was not coping emotionally, and promote local resources and self-help materials more.

*'I will probably ask more questions regarding mental health wellbeing as I now feel more equipped.'* (Practice Nurse, Western Isles)

*'Be better at remembering to ask screening questions and get them in earlier in consultation.'* (GP, Western Isles)

*'Raise awareness and highlight issues re mental health.'* (Practice Nurse, Angus)

*'Raise patient awareness of self help materials, will also share this with colleagues.'* (District Nurse, Lanarkshire)

*'Give appropriate reading material/ signpost to library etc.'* (Nurse, Lanarkshire)

There was little negative feedback or suggestions for improvements received from participants. Three participants indicated that they would have liked the session to be longer and three GPs thought that the course was better suited to nurses than GPs. However, other GP participants indicated that they found the course very useful.

### **3.2.2 Living Better with a Long-Term Condition**

This half day course was designed for people living with diabetes and / or CHD. It was developed by independent trainer Margaret Hart, and delivered on 6 occasions in Angus (in Edzell & Kirriemuir) and Western Isles (in Stornoway and Benbecula) to a total of 40 individuals and was the most commonly run course in the Living Better project for patients.

Participants were recruited for the training in a number of ways, including personal invitations from the practice (Angus) and through local services and media (Western Isles). Larger take up in Angus might indicate that a personalised invite from a GP is more likely to encourage attendance than a general advert.

The course covered mental health awareness-raising and the connections between physical health and mental health. It also looked at self-help strategies participants could use to keep themselves mentally well, and local sources of support available if needed, with direct input from local service providers on the day. The sessions encouraged participants to share their own experiences with others in an informal and supportive setting.

Thirty four feedback forms were received from participants, which were all very positive about the training experience. The most important learning for individuals was greater understanding about the link between physical and mental health, how to look after your mental wellbeing, and that support is available if needed:

*'Now I think about it, it makes sense. When you're not well it's bound to affect your mood.'* (Patient, Angus)

*'Concentrate on strong not what's wrong.'* (Patient, Angus)

*'You are not alone in your predicament or illness.'* (Patient, Angus)

Two participants recognised that they needed additional help around their mood, and stated that they were going to contact their GP after the workshop. Others indicated that they would contact local sources of support highlighted in the workshops. Participants in Angus particularly valued the opportunity to share experiences with each other, and indicated that they would like to have access to support groups locally.

*'This has really cheered me up. It's good to talk to others in the same boat.'* (Patient, Angus)

This differed from experiences in Western Isles, where the numbers of participants were much smaller. There was a sense that support groups 'don't work' in the Western Isles because of lack of anonymity and ongoing stigma against both mental health issues and also against having a long-term condition. This suggests that while those attending valued the course, it would not be appropriate for everyone with a long-term condition and other mechanisms for imparting self-help information and guidance may need to be found.

Of the 21 patients who answered the question as to whether they would be more or less likely to talk about emotional issues with someone else as a result of taking part in the course 15 people indicated that they would be more likely to talk, and six indicated that it had made no difference to them in this regard.

### **3.2.3 Living Better with COPD**

The 'Living Better with COPD' six week course was developed in East Dunbartonshire and was put together by a wide range of voluntary and statutory local service providers with support from the Living Better Executive Project team. This course involved 15 different presenters and 2 district nurse facilitators, most of whom worked within local health, social care and voluntary sector services. Living Better acted as course coordinator, bringing all the different course dimensions together, recruiting participants and evaluating the impact of the course.

The central aim of the 'Living Better with COPD' course was to improve the mental health and wellbeing of people with COPD through:

- Giving participants the tools to better manage their physical conditions.
- Teaching participants about the emotional impact of living with COPD, how to spot the early warning signs for depression and anxiety, and where to go for help.

Individual sessions were provided on understanding mental health and long-term conditions, understanding COPD, food and mood, physical exercise, low mood, financial advice and local sources of support. A parallel session was also run in Week 4 for the carers of participants.

The course was run once in Milngavie in East Dunbartonshire with 9 patient participants and 2 carers. Participants were recruited through the COPD registers on the Kessington and Ashfield practices. Evaluation forms completed by participants indicated that participants felt the course to be of good quality and relevant to their needs. In terms of what was most useful from the course content, respondents indicated the breathing techniques, other coping strategies and further sources of help and support were the most useful:

*"All the breathing advice was most helpful"*

*"I now know how to cope"*

*"All the exercises were very good and really helped also the information was excellent"*

*"One was made aware of the 'dos' and 'don'ts' as well as available help"*

Participants were asked whether, having attended the course, they were more or less likely to do something about the emotional stresses of living with COPD. Four participants responded that they were more likely to do something and two said it had made no difference in this respect.

The course presenters plan to run another course in Kirkintilloch, with the hope that the course can then be adopted as part of core practice by the CHP thereafter and extended to people with other long-term conditions.

### **3.2.4 Culturally Appropriate Mental Health Assessments for Patients with Diabetes**

This half day course aimed to raise awareness of the prevalence of depression and diabetes in the South Asian community, cultural understandings of depression and diabetes, methods of diagnosing depression in the South Asian community and available culturally appropriate sources of help and support. See section 3.4.4 for further details of this course.

### **3.2.5 Living Better: Training the Trainers Course**

Living Better: Training the Trainers one day course was developed as a mechanism for increasing capacity for delivering the training courses developed through the Living Better project, particularly Mental health awareness for primary care staff and long-term condition specialist nurses and Living better with a long-term condition.

The course was developed by Margaret Hart and implemented on a one-off basis in January 2011 with a small group of 4 trainers from within the core Living Better partner organisations and a Diabetes Psychologist from North Lanarkshire with a training remit in her role. Participants felt the training gave them the information and skills necessary to deliver the course themselves and have agreed to provide data about when and where they use the materials.

### 3.2.6 National Living Better Dissemination Event 'Living Better Together'

In March 2011 the Living Better project ran a national dissemination event in Edinburgh to share findings emerging from the project with key stakeholders. Ninety seven individuals participated from across the UK. A programme for Living Better Together is available in **Appendix 4**.

## 3.3 SUMMARY AND KEY LEARNING POINTS FROM LIVING BETTER TRAINING

In response to training needs identified in the five pilot sites, the Living Better project team developed a suite of training packages to support health professionals and help patients understand mental health and increase their knowledge of sources of support. Five courses were developed and delivered to 136 participants (85 professionals, 49 patients and 2 carers) between October 2009 and January 2011.

The courses were generally very well received and viewed as meeting participants needs in terms of increasing:

- Health professional and patient knowledge about the links between physical health and mental health.
- Health professional confidence in terms of talking about mental health issues with patients.
- Patient awareness of self help strategies.
- Health professional and patient awareness of local sources of support.

The experience of developing and delivering the training courses highlighted a number of learning points:

- In practice training with practice nurses was labour-intensive, but provided an in-depth and supportive mechanism for imparting information and guidance around mental health and long-term conditions.
- Larger multi-disciplinary training sessions provided the opportunity to network and had greater reach, but could be dominated by more senior members of the team and were less likely to please all.
- Recruiting patients through practice registers may encourage a larger take up than open adverts but does require greater time input from the practice.
- Not all patients will want to take part in group training, and other ways of imparting self-management knowledge should be offered.
- Running patient courses prior to staff training enables the findings from one to be imparted to the other.
- There is a need for more culturally sensitive training for primary care staff.

Living Better developed training courses for both professionals and for patients. There was a great deal of enthusiasm and support for all courses, with both groups emphasising a preference for the training to be 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 both 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.



# CHAPTER 4:

## LIVING BETTER RESEARCH AND EVALUATION

### 4.1 OVERVIEW

At the outset of the Living Better project it was envisaged that the stages of research and evaluation would include:

- Scoping of needs and priorities to help establish local action plans.
- Process evaluation of development and implementation of local action plans.
- Outcomes study based on patient and professional perspectives of the project and its interventions.

The research and evaluation was designed to be flexible and to accommodate local needs, priorities and circumstances.

It was also envisaged that pre and post intervention patient outcomes could be obtained for a sample of patients within the CHP to determine the impact of the interventions. However, this pre and post intervention study also required sequential and strictly timetabled stages of work to operate within each location. In reality, the first three stages outlined in Diagram 2a, Page 9 took much longer than anticipated, as did the implementation stages (reasons for this are explained below).

As a result, significant changes were made to the research and evaluation of the project. More emphasis was put on researching the needs and experiences of local patients living with long-term conditions to aid primary care professionals and service development managers in understanding these needs. Emphasis was also placed on the process evaluation of implementation of facilitated local development projects to provide transferable learning to other sites interested in developing initiatives for people with long-term conditions.

The research team contributed materials and research resources to local CHP sites, as a form of 'action research'<sup>1314</sup> on behalf of the local sites to help practitioners and managers reflect on their practice and services. Action research is useful during the developmental process of deciding what to do, following through on an idea and checking on how well it is achieving its aims and objectives. The research team also had a dual role of project evaluation, looking at both the process of development and implementation and also the outcomes of the Living Better initiative.

Within this, the research team had to remain outside of the interventions, observing their development and implementation, what worked well and where and how problems arose. This included evaluating what local participants thought of the project initiatives; and what local participants (healthcare professionals and service development managers) thought of the process of being involved in the Living Better project. In this way, the key learning from participating in such a process could be captured and shared more widely across the NHS.

<sup>13</sup> Lewin, K. (1946). 'Action research and minority problems'. In Lewin, G. W. (Ed.), *Resolving Social Conflict*. London: Harper & Row.

<sup>14</sup> Burnes, B. (2004). 'Kurt Lewin and the planned approach to change: a re-appraisal' *Journal of management Studies* 41 6: 977-1002

The limitation of the adapted research and evaluation plan is that the intended pre and post implementation outcomes evaluation following the implementation of activities could not take place within the timescale of the project. Indeed some CHP sites are still in the process of implementing activities. In addition to this, the type and scale of activities within CHPs has differed across all sites, and the original 'one size fits' all design of pre and post outcomes questionnaires to patients would not have been appropriate.

However, all sites have baseline data on a sample population and this may afford opportunities to re-run this questionnaire at a future date to assess whether there have been any changes or improvements in the scales used over time. This is an appropriate next step in line with an action research framework.

## 4.2 SUMMARY OF METHODS

The research and evaluation consisted of:

- Patient focus groups involving people with CHD, diabetes or COPD in the 5 CHP sites. The purpose of these focus groups was to obtain local views and insights into how living with long-term conditions affected patients' mental health and wellbeing. The groups also asked what type of services local people wanted to support their mental health and wellbeing, and which would help them address the emotional strains of living with these conditions.
- Professional focus groups involving health and social care practitioners and planners who work with, or whose work involved, people living with CHD, diabetes and COPD. These focus groups gathered data on how healthcare practitioners felt about addressing mental health and wellbeing in people with long-term conditions, their perspectives on patients' needs, and what the barriers and facilitators were to improving the way local services addressed the associated issues.
- A structured postal patient questionnaire survey to gather quantitative data on the mental health and wellbeing of people living with CHD, diabetes and COPD. The survey asked people how living with their condition affected their lifestyle and the type of services they believed would help them with the emotional strains of living with their particular condition.
- A structured online questionnaire to key reference group members. This online survey explored the opinions of reference group members on the Living Better project and evaluated which aspects of the process had gone well or less well.
- Semi-structured interviews with key local leads, reference group members and local healthcare professionals. These interviews provided more in-depth local perspectives on the Living Better project and its achievements, the process of involvement and lessons learned.

- Observation of reference group meetings and other key local planning meetings, supplemented by minutes of meetings. Attendance of the project researcher at reference group meetings kept the process evaluation informed of key decisions regarding Living Better and any local barriers or facilitators that arose during the project and how problems were addressed.

Sections 4.5 to 4.12 summarise findings from the patient focus groups and the structured questionnaires. These will be of relevance to the wider primary care audience across Scotland in developing appropriate pathways of care to meet the needs of people with long-term conditions. This is followed by findings from professional focus groups in Sections 4.13 to 4.14, which highlight issues of concern from the perspectives of professionals in raising and managing mental health issues in people with long-term conditions. Finally, key findings of the process and outcomes evaluation relating to the overall process of involvement within the Living Better project, key barriers and facilitators encountered during development and implementation, and an assessment of the project and its achievements is presented in Sections 4.15 to 4.16.

### 4.3 ETHICS

Ethical opinion from the Scotland A Research Ethics Committee advised that this project did not require full ethical approval as it was deemed to be an evaluation and audit of practice development activities (Ref 09/MRE00/35 A letter of confirmation of this opinion was obtained on the 8th April 2009). Ethical review and approval of study methods was provided by the Department of Applied Social Science Ethics Committee at the University of Stirling.

### 4.4 LINKING RESEARCH AND DEVELOPMENT TO IMPROVE PRACTICE

Research and developmental work was closely linked and dovetailed to inform and influence the development of initiatives in the five separate CHP sites. Therefore, the focus groups were planned and conducted by both the researcher and project development worker to ensure their focus would be of direct use in the development work undertaken by the local reference groups. Additionally, a process of continual feedback from the evaluation team to the development activity was established via regular Executive Project Team Meetings and research input to local reference groups.

Two GP practices in each of the CHP/CHCP sites were approached to facilitate and conduct the research. However, in some CHP sites only one practice was able to participate. The diabetes, CHD and COPD populations within participating practices were recruited to focus groups and the questionnaire study. Staff within these practices were also invited to participate in training initiatives delivered through Living Better.

## 4.5 PATIENT EXPERIENCES OF LIVING WITH A LONG-TERM CONDITION: FOCUS GROUP SAMPLE

Data on people's experiences of living with a long-term condition, its effect on their mental health and wellbeing, and what type of support they wanted to help live with their condition were gathered. Qualitative data was gathered through patient focus groups and quantitative data through a structured questionnaire postal survey of people in participating GP practices CHD, diabetes and COPD registers. The data presented in this section relates to the majority of focus groups conducted with predominantly white Scottish populations. Specific methods were employed to engage with populations of predominantly South Asian origin in South East Glasgow. These findings have been analysed and written up separately and are included in a separate report in **Appendix 5**.

### 4.5.1 Patient Focus Groups in the Five CHP Sites

A total of 20 focus groups involving patients with CHD, diabetes and COPD were held in the five CHP sites. Patients on the CHD, diabetes and COPD registers were randomly selected and received a signed letter on local GP practice notepaper from one of the practice GPs and from Living Better inviting them to take part in a focus group. An information form outlining the nature of the project and what it involved was also attached. Consent forms were signed by participants attesting to their approval for participation and their anonymity and confidentiality being assured.

The 20 focus groups were attended by 201 people living with CHD, diabetes and COPD and their carers. The attendees at the focus groups are outlined in tables 4a, 4b and 4c below.

*Table 4a Patient Focus Group - Age Range*

Age Range	Number
35-44yrs	8
45-54yrs	14
55-64yrs	30
65-74yrs	89
75yrs +	60
<b>Total</b>	<b>201</b>

*Table 4b Patient Focus Group - Gender*

Gender	Number
Female	106
Male	95
<b>Total</b>	<b>201</b>

*Table 4c Patient Focus Group - Conditions*

Condition	Number
Diabetes	59
CHD	58
Diabetes & CHD	37
COPD	36
Carers	11
<b>Total</b>	<b>201</b>

The focus groups lasted approximately one hour and discussed:

- i. What is it like to live with CHD, diabetes, COPD?
- ii. What were the emotional strains and mental health issues that living with their condition brought and how did they manifest themselves?
- iii. What type of support systems would people living with these conditions like to see available to help them live with their condition and reduce the associated stresses?
- iv. Whether people believed health, social care and voluntary sector professionals were aware of mental health and wellbeing issues in these patients and how confident they were in addressing these issues.
- v. Whether people believed local services at CHP level were equipped to address the mental health stresses associated with living with their long-term condition.

#### **4.5.2 Focus Groups with South Asian People in South East (SE) Glasgow CHP**

From a review of the literature and through discussions with health workers working with South Asian people with diabetes and CHD in SE Glasgow, it became apparent that, as a result of religious orientation, cultural values, language and lifestyle, there were different challenges in addressing mental health and wellbeing in this community. Furthermore, regarding diabetes and CHD, research suggests there are differences in illness causation and health-seeking behaviours between white Europeans and South Asians<sup>15,16,17</sup>.

The Living Better reference group made a decision to conduct separate focus groups with South Asian people in SE Glasgow CHP. It was thought that this would better address the specific issues that people from this community experienced in living with diabetes and CHD. This decision was also based on the high proportion of South Asians living in areas like Pollockshields and Govanhill, and the high rates of diabetes and CHD in these communities. In addition, two focus groups took place with white Scottish people in Castlemilk.

Four separate focus groups were organised with Muslim males, Muslim females, Hindu/Sikh males, and Hindu/Sikh females and attended by 40 people with diabetes and/or CHD. These focus groups were facilitated by a bilingual South Asian researcher experienced in conducting research on mental health issues in the South Asian community.

<sup>15</sup> Lawton, J., et al., 2006. Diabetes service provision: a qualitative study of the experiences and views of Pakistani and Indian patients with type 2 diabetes. *Diabetic Medicine*, 23, 1003–1007.

<sup>16</sup> Lawton, J., et al., 2007. Contextualising accounts of illness: notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociology of Health & Illness*, 26, 891–906

<sup>17</sup> Goenka, N et al (2004) Cultural barriers to diabetes care in South Asians: arranged marriage –arranged complications? *Practical Diabetes Int* 2004; 21(4): 154–156

The following principal findings emerged from the focus groups:

- Living with diabetes and/or CHD can be both an acute and chronic stress for South Asian people.
- The stigma of mental illness can make it difficult for many South Asian people to verbally express their emotional feelings regarding the stresses of living with diabetes and/or CHD.
- South Asian people with a diabetes and/or CHD are, in the main, looking for support to help them live as socially active and fulfilling lives as possible.

This is not to suggest that the life experiences of South Asians living with long-term conditions are entirely different from those experienced by white Europeans, or that the types of supports wanted differ radically. Rather it takes into account the importance of addressing cultural and ethnic diversity when addressing health and social care issues in black and minority ethnic groups. Full findings from the South Asian focus groups are presented separately in **Appendix 3**.

### **4.5.3 Data Analysis**

The focus groups were conducted by the project researcher and the project development worker, recorded on digital recorders and then transcribed verbatim. Analysis of the data was thematic. Thematic content analysis is a validated and effective approach for answering questions about the most significant issues raised by a particular group of respondents and/or for identifying typical responses from interviews and focus groups<sup>18</sup>.

<sup>18</sup> Strauss A, Corbin J. 1998. Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory (2nd edition) Sage Publications: London

## 4.6 FINDINGS FROM PATIENT FOCUS GROUPS

Living with COPD, diabetes or CHD can be both an acute and a chronic stress on a person as they move through stages of illness, from diagnosis and acute episodes to the continual, day to day challenges they face.

*Box 4.1 Summary of key themes from focus group data*

- Shock of being diagnosed with diabetes, COPD or CHD.
- Restrictions to lifestyle and employment opportunities.
- Frustration over lifestyle changes.
- Loss of confidence.
- Feeling that sometimes family and friends do not understand the strains of living with the illness.
- Strains on family and wider personal relationships.
- Anger.
- The stigma of mental illness could often make it difficult for people to admit feelings of depression and anxiety.
- Stress in lead up to and after the annual or 6 monthly medical review.
- Fear – especially among CHD and COPD patients.
- Financial concerns.
- Social isolation.
- Loss of purpose in life.
- Embarrassment.
- Guilt – some people felt they had brought the condition on themselves due to their lifestyle.
- Accessibility and transport problems

### 4.6.1 The Shock of Diagnosis

For many people the initial experience of being diagnosed with a long-term condition had a huge impact and was seen as a serious and stressful life event. The same feelings were also described in relation to initial or subsequent acute episodes necessitating hospital admission. These incidents often instigated an immediate re-assessment of their lives and their future.

*'I thought I'm getting home because I feel better, I'm brand new after the night in the ERU [Emergency Recovery Unit] and the guy came out and says 'no, you've had a heart attack'..... my brain wasn't taking it in. I said 'not me, how have I had a heart attack... I'm only 35, how can this be...?' He said 'Believe me, you've had a heart attack'..... it was if somebody just pressed a big pause button on your life'. (NL Male CHD)*

*'I got diagnosed when I was 27...Horrendous. That was it; 'contact your insurance company' 'you can't drive' 'can't do this, can't do that'.' (NL Female Diabetes)*

These findings indicate there could be opportunities for emotional support around the time of diagnosis to help people discuss the shock and fear they described and to help put things in perspective.

### 4.6.2 Restrictions to Activities and Lifestyle

*'I just konk out, and that cracks me up; I don't have the energy'. (NL Male Diabetes)*

The emotional trauma of long-term conditions is caused by loss of a valued level of functioning, for example the ability to drive, dance or play sport. The chronically ill person not only feels the loss of immediate capabilities but can also feel entail a re-adjustment of their lifestyle which can affect their job, hobbies, and personal relationships. Our focus groups included people with diabetes who had lost their sight, or their limbs.

In the focus groups people often referred to the strain that living with a long-term condition can place on close personal relationships. Changes to lifestyle and long-term plans can also impact on spouses or partners, making people with long-term conditions feel guilty as a result. Other situations that were referred to include some chronically ill people feeling their spouse, partner or children didn't fully understand the emotional and physical strains of their illness. This could cause friction or, in severe cases, resentment.

*'It was very difficult; in fact I still find it difficult now. I've been out of teaching for five years... and I'd been teaching for 30 years and it was something I loved doing. Obviously it's a matter of coming to terms with things all the time, finding alternatives and luckily I've got interests and hobbies which I've managed to divert my creative instincts into. But it's something that I've had to work out myself, and I don't think it's been easy for me .. or my partner for that matter'. (WI Male CHD)*



People living with long-term conditions can live with their condition for 20 to 30 years. During this time span there can be acute situations that exacerbate their condition, which can in turn impact on their general wellbeing. These acute episodes can result in a loss of confidence and a reduction in activity, which are then embedded long-term and can be difficult to reverse.

*'I was 49 when I was diagnosed with COPD so I've had it for a long time, but it's getting worse as I'm getting older obviously, I'm 74 now. And sincerely speaking, the winter time is an absolute nightmare. I have chest infection after chest infection. I used to go out with friends, now you think 'I won't bother' because I'm too slow, not that they say that, but you feel it within yourself, so you're inclined to retreat into yourself. So it has a dreadful impact when you've had it for a long time. In every respect it completely and utterly destroys your life'. (ED Female COPD)*

Recovery from acute episodes could be aided by advice to help people regain previous levels of physical strength, and to maintain previous levels of social activity where possible. In some cases, people may require support in rebuilding confidence, in order to regain previous levels of activity. Others may need help in developing new activities that can accommodate any reduced functioning. Overall support to help all people with long-term conditions minimise the impact of their illness on their lifestyle would be helpful. Links to alternative social activities that provide social contact and stimulation should be encouraged.

#### **4.6.3 Living with Fear**

Because of the acute impact of many long-term conditions, some people can experience physical situations where they are genuinely fearful for their own future.

*'I thought 'diabetes there's a course of antibiotics and that's it gone sort of thing', really. He (the doctor) went 'oh no, you can have toes and things start dropping off, you can have heart attacks' and I was like 'what?' It stung me, and every article... it's featured a lot in the newspapers, television, a lot of articles in different... like if you're sitting in the dentist or the doctor's surgery, there's always magazines. Everything that comes out, I'll read about it. I bought myself diet books etc. It's frightening the things that you hear, and it's worrying.' (NL Female Diabetes)*

*'The only thing that does concern me is the fear that I might lose a leg or something like that or go blind, I wouldn't want that. My mother cared for my father for many years and I wouldn't like to subject my wife to that.' (WI Male Diabetes)*

*'It's frightening as well when you suddenly feel you're on your own and maybe you're not going to make it back... you'd suddenly feel 'oh my God, I shouldn't have walked...' and you're sitting on a wall thinking, you know, I'll phone my wife 'can you come round and pick me up?' I find that actually... when I feel I lose control, I don't like being exposed like that.' (ED Male COPD)*

These focus groups enabled people to speak to peers with similar fears and experiences. It was very apparent that, for many patients, this was the first time they had been given the opportunity to do so. Patients with long-term conditions would also benefit from opportunities to discuss these fears with healthcare professionals, who can allay some fears and discuss ways in which to minimise or cope with others.

#### 4.6.4 Financial Concerns

The link between social deprivation, health inequalities and long-term conditions is well established within the UK. Concerns around managing daily budgets, especially for people living in CHP areas with high levels of social deprivation, were often cited as daily stresses. A key factor for many in their ability to manage financially was their disability allowance, and the process of obtaining this or renewal of this was a high source of stress for most people with a long-term condition who received this benefit.

*'Well I'm having terrible problems with disability allowance right now. You know the way you've got to renew it every so many years, mine's is up for renew and I got a letter back, they took everything off me. And you get all upset if you've got to face all these people it's like being in a court. I'm waiting every day for a letter. I'm fighting with them just now, so that's quite stressful'. (Female CHD)*

Patients would benefit from easy access to support for managing their financial concerns or their disability allowance review. In circumstances where there was to be a sudden loss of disability allowance, some help in managing the transition from disability benefit onto other benefits, or onto employment opportunities would be beneficial.

#### 4.6.5 Mobility and Transport problems

Many long-term conditions can impact on people's health in such a way that even participating in normal physical activities can be problematic. Their reliance on transport was essential but access to transport was often problematic and resulted in greater social isolation even when people were willing and actively seeking social contact. This was especially the case with people who had COPD.

*'Getting out and about, well if you could walk properly with good breathing it's no problem. I'd go for a walk or something else, but when you do have a bit of a problem going up hills it's necessary that you can get a bus. But you don't always get a bus to the exact place, and if you don't have a car you're a bit scuppered unless you've got someone there that will give you a lift. So it's not always possible to use some of the facilities they've got unless you're paying for taxis all the time which is out of the question... So you're stuck in the house which is no good really.' (Female COPD)*

Improved access to transport facilities would indeed be beneficial. However, developing or linking in with alternative modes of social contact might also provide solutions where lack of transport leads to increasing social isolation. Social networking and other internet based solutions could be encouraged.

#### 4.6.6 Suggestions for Support

Across the five CHP sites, four broad categories of support were commonly cited by patients as being desirable to help address the emotional strains of living with their long-term condition. These types of support were broad social support services reflecting Levels 1 and 2 social and psychosocial interventions, as outlined in the 2009 NICE guidelines for clinical depression<sup>19</sup>. These were:

- (i) **Emotional support:** warmth, understanding and appreciation of the patient's illness and their consequent behaviour as a result of their illness. People could receive such emotional support from friends and family, healthcare professionals or others with similar experience of a long-term condition. However, support external to their friends and family, particularly from people with shared experiences, was emphasised as being particularly important.
- (ii) **Appraisal and informational support:** helping the person understand their illness better and signposting resources and coping strategies which could be adapted to help self-manage their condition. This type of support could be provided by healthcare professionals, but also by peers with similar illness experiences. A combination of both types of support would be preferable.
- (iii) **Assistance and practical support:** material or other practical help, such as information on dial-a-bus services to help them get out of the house and pursue everyday activities, would be valued. Other desired assistance and practical support included: financial advice, especially around benefits, exercise or breathing classes, and receiving general assistance and information in order to maintain as 'normal' a lifestyle as possible.
- (iv) **Peer support:** sharing experiences with people with similar conditions and realising that others experienced the same difficulties was seen as helpful by many, although not all, people living with a long-term condition. As well as meeting the needs of emotional support and information provision described above, general opportunities to simply meet and engage with their peers was seen as beneficial but often not possible. This engagement with peers could extend to social activities, such as cooking or exercise classes, built around improving their self-management. Such peer activities were seen as offering a more supportive and 'illness specific' context which could reduce the embarrassment or stigma they often felt about undertaking such activities with others.

<sup>19</sup> NICE CG 91, 2009. Depression in Adults with a Chronic Physical Health Problem: Treatment and Management. National Collaborating Centre for Mental Health. [www.nice.org.uk/CG91](http://www.nice.org.uk/CG91)

These supports were wanted in different forms; one to one confiding relationships with a health or social care worker; sharing experiences and exchanging information with people with the same condition; receiving assistance to address a specific stressor caused directly by their condition or as a secondary consequence of their condition.

*Box 4.2 Examples of specific suggestions for support*

- Support classes such as dietary classes for people with diabetes, light exercise classes for people with CHD and breathing classes for people with COPD.
- General support classes to share experiences and exchange information about the best ways of addressing the strains of living with their condition.
- Easier and more rapid access to a health or social care worker to confide about their feelings and ask for advice to help self-manage their condition.
- General talking support, either face to face or on the telephone with a health or social care worker.
- Peer support was seen as helpful by patients because they felt that they were not alone and that there were others who had been through similar experiences.
- Access to condition specific exercise classes to help self-manage their physical condition and to help prevent patients feeling awkward in the event of getting into physical difficulties, for example coughing bouts in COPD patients.
- Financial and benefits advice to address financial consequences of living with their condition.
- Greater support with and access to transport to get out of the home more, from example dial-a-bus or help with taxi expenses.
- More information about locally appropriate support services provided by health, social care and voluntary sector services.
- More 'talking time' with nursing or other health/social care staff.
- Help with shopping and daily household chores.
- Support to help maintain a hobby which, due to their physical illness, is restricted.
- Greater advice and information about drugs they have to take for their condition.

## **4.7 POSTAL SURVEY OF PATIENT MENTAL HEALTH STATUS AND PATIENT DEFINED NEEDS: CONTENT AND SAMPLING**

Building on the focus group findings, structured quantitative data was collected on the mental health and wellbeing of living with CHD, diabetes and COPD and the type of support people would like to help them live with their condition.

A sample of patients on the diabetes and CHD registers of the participating practices in each CHP were randomly selected and contacted by post and asked to participate in a questionnaire survey about living with a long-term condition. Due to the smaller number of patients on the COPD registers in participating GP practices, all COPD patients were approached to take part. The questionnaire was accompanied with a letter from the patient's GP practice explaining the nature of the survey, that it was entirely voluntary and asking them to complete the questionnaire and return it in the self addressed stamped envelope supplied.

### **4.7.1 Survey Content**

The postal questionnaire survey gathered data on the following;

- Demographic questionnaire to collect data on Gender, Age, Postcode, Multi-morbidity, Living Arrangements.
- Depression and Anxiety – using Hospital Anxiety and Depression Scale (HADS).
- Work & Social Adjustment – using Work and Social Adjustment Scale (WASAS).
- Mental wellbeing – using Warwick-Edinburgh Mental Wellbeing Scale (WEMWEBS).
- Emotional feelings associated with the consequences of living with their long-term condition – derived from phrases commonly cited in the patient focus groups).
- Types of support that they believed would help to live with their long-term condition – derived from types of supports commonly stated in the patient focus groups).
- Patient Complexity Tool – a pilot of the Minnesota and Edinburgh Complexity Assessment Method – Patient version (MECAM-P) assessing social determinants of health.
- Patient Satisfaction with Health Services (Client Satisfaction Scale (CSQ)).

### 4.7.2 Target Populations and Recruitment

In each of the participating GP practices a target sample size for the questionnaire study was set based on the size of practice and an estimate of numbers on the COPD, diabetes and CHD registers. The target number of participants were then randomly selected from the registers. In one of the GP practices, because of the relatively small numbers on their COPD register, all COPD register patients were included. The target numbers and the response rates are outlined below:

*Table 4d – Target populations and response rates*

CHP Site	GP Practices	Target Number	Total Posted Questionnaires	Questionnaires Returned	Response Rate
Western Isles	1	170 - 85 Diabetes 85 CHD	170	86	51%
Angus	2	200 - 100 Diabetes 100 CHD	200	122	61%
East Duns	2	170 – 170 COPD	170	89	53%
North Lanks	1	200 – 100 Diabetes 100 CHD	200	90	45%
Total across 4 sites	6	740	740	387	52%

It is not possible to establish the profiles, and therefore representativeness, of responders from non-responders as the researchers did not have access to patient data from the practices. However, the profiles of patients generally match national patient profiles within these disease categories.

### 4.7.3 Structured Questionnaire Survey with South Asian People in South East (SE) Glasgow CHP

Following a review of literature and discussions with researchers in England, it emerged that postal questionnaire surveys with sections of the South Asian community, in particular those living in socially deprived areas, generally received a poor response rate. Consequently it was decided to carry out the patient questionnaire survey face to face using a bilingual South Asian researcher experienced in conducting research on mental health issues in the South Asian community.

Quantitative patient surveys were completed in person with 100 South Asian diabetes and CHD patients registered at the participating practice. Survey responses indicated that:

- 45% of respondents had a HADS (Hospital Anxiety and Depression Scale) score which indicated depression and approximately half (49%) had a score registering anxiety
- Living with long-term conditions can affect people's outlook with only 22% feeling optimistic about the future and over half (62%) of SE Glasgow respondents feeling physically drained with no energy to spare.
- Half of SE Glasgow respondents replied that living with a long-term condition made them feel 'down', 'frustrated' and 'stressed' as a result of their condition.

The findings from the structured questionnaire survey with South Asian people in SE Glasgow CHP are presented in Appendix 5 and are compared to the aggregated results of the predominantly white Scottish population.

## 4.8 FINDINGS FROM THE PATIENT SURVEY

### 4.8.1 Gender

Of the 387 respondents, 45% were female and 55% male. For COPD, 43% were female, and 57% were male; for diabetes, 44% were female and 56% were male; and for CHD, 49% were female and 56% were male.

### 4.8.2 Age Range

As expected the majority of respondents fell into the 65 years and over age range category, mirroring the higher proportion of older people living with a long-term condition in Scotland. The age categories were as follows: 55 years and below (10%), 56-64 years (24%), 65-74 years (38%), 75-84 years (22%), and 85 years and over (6%). The condition with highest proportion of people below 65 years was diabetes with 51% of the sample. The condition with the highest proportion of people aged 65 years and over was COPD with 78% of the sample. These figures are generally representative of the aetiology and epidemiology of the conditions.

### 4.8.3 Living Arrangements

The majority of respondents lived with their immediate family in most cases a spouse or partner. Almost one third of respondents, 29% lived on their own, and 2% in supported accommodation.

Table 4e – Living Arrangements by Condition

	Live with Family	Live Alone	Supported Accommodation
<b>COPD</b>	72%	26%	2%
<b>Diabetes</b>	70%	28%	2%
<b>CHD</b>	65.5%	31.5%	3%
<b>Across all 3 conditions</b>	69%	29%	2%

The living arrangements of people who live with long-term conditions are an important consideration in the context of addressing mental health and wellbeing. Research has shown that people who live alone are more likely to be unhealthy compared with people who live with a spouse or partner, but also more susceptible to developing mental health problems such as depression and anxiety<sup>20,21</sup>. Living arrangements of people with long-term conditions must be considered in any assessment of their circumstances and advice on how to address their mental health and wellbeing tailored accordingly.

### 4.8.4 Employment Status

The majority of people were aged 65 years and over and were therefore more likely to be retired (60%) with higher proportions of those with COPD being retired. However, a significant proportion of our sample (almost a fifth) were still working, and this rose to 30% of people with diabetes, reflecting the younger population with diabetes. Approximately one tenth (9%) were retired on medical grounds and fewer people with COPD were receiving Daily Living Allowance than those with CHD and diabetes.

Table 4f – Employment Status by Condition

	Retired	Medically Retired	Working	DLA	Unemployed
<b>COPD</b>	74%	9%	11%	4%	2%
<b>Diabetes</b>	50%	6%	30%	8%	6%
<b>CHD</b>	61%	11%	13%	9%	6%
<b>Across all 3 conditions</b>	60%	9%	19%	7%	5%

<sup>20</sup> P. Demakakos, S. Nunn, and J. Nazroo, "Loneliness, relative deprivation and life satisfaction," in *Retirement, Health and Relationships of the Older Population in England: The 2004 English Longitudinal Study of Aging*, J. Banks, E. Breeze, C. Lessof, and J. Nazroo, Eds., Institute for Fiscal Studies, London, UK, 2006.

<sup>21</sup> E. Y. Cornwell and L. J. Waite, "Social disconnectedness, perceived isolation, and health among older adults," *Journal of Health and Social Behavior*, vol. 50, no. 1, pp. 31–48, 2009.



This data can help primary care and community services to target social activities to those more likely to require out of work activity. People living with COPD may be receiving less support than other chronic conditions even though they are generally older. Review of the financial circumstances and support for daily living to those with COPD may benefit patients.

#### 4.8.5 Multi-Morbidity

Multi-morbidity<sup>22</sup> occurs when people live with more than one physical condition and was common in respondents to our postal survey. In our postal survey a majority, 57% had more than one long-term condition. People in East Dunbartonshire living with COPD constituted the oldest group of respondents and more than half of respondents with COPD lived with more than one long-term condition. In North Lanarkshire, which as previously highlighted is one of the most deprived CHP areas in Scotland, this figure rose to 63%, demonstrating that people living in socially deprived areas are not only more likely to develop a long-term condition but are also more likely to have multi-morbidity.

Table 4g – Multi-Morbidity by CHP

	YES	NO
<b>North Lanarkshire</b>	63%	37%
<b>Angus</b>	45%	55%
<b>East Dunbartonshire</b>	53%	47%
<b>Western Isles</b>	48%	52%
<b>Across 4 CHP Sites</b>	57%	43%

Living with more than one long-term condition is important in the context of addressing mental health and wellbeing in primary care. Numerous research studies have shown the existence of an inverse relationship between multi-morbidity and health related quality of life<sup>23</sup>. Recent research on multi-morbidity in deprived areas of Scotland has identified an 'endless struggle' of patients trying to manage illnesses in the midst of 'chaotic lives' with limited personal, social, and material resources. The struggle of professionals trying to manage these patients and the need for whole system changes to improve the effectiveness of primary care services for patients with multi-morbidity in deprived areas was also highlighted<sup>24</sup>.

This research helps to quantify the scale of multi-morbidity in our study sites and affirms the need to address multi-morbidity in the context of additional social deprivation, requiring input from more than the health sector alone.

<sup>22</sup> As defined by Van den Akker et al "multi-morbidity" is used to describe the co-occurrence of two or more *chronic* conditions. Akker M vd, Et al: Co-morbidity or multi-morbidity: what's in a name? A review of literature. European Journal of General Practice 1996, 2:65-70

<sup>23</sup> Fortin et al (2009) Multimorbidity and quality of life: a closer look. Health Qual Life Outcomes. 2007; 5: 52.

<sup>24</sup> O'Brien, R et al (2011). An "endless struggle": a qualitative study of GPs' and practice nurses' experiences of managing multimorbidity in socio-economically deprived areas of Scotland *Chronic Illness* 2011 [Special edition on equity and long-term condition self-management] 7 45-49

#### 4.8.6 Screening for Depression and Anxiety (using HADS)

The Hospital Anxiety and Depression Scale (HADS) is a validated, commonly used screening tool often used by doctors, nurses and a range of therapists to assess levels of anxiety and depression. It should be emphasised that self-assessment scales such as HADS are only valid for screening purposes and confirmation of depression and or anxiety must rest on the process of clinical examination. The HADS comprises statements from a list of four options which the patient is asked to assess based on their experience of the past week. There are 14 statements; 7 relevant to feelings associated with anxiety and 7 to feelings linked with depression. Responses are scored from 3 to 0. There are 4 ranges; normal 0-7; mild (8-10); moderate 11-15; and severe 16-21<sup>25</sup>.

#### 4.8.7 HADS Screening Scores for Depression

Approximately 30% of respondents in the survey reached the threshold for depression within HADS scores. This is at the higher end of levels associated with depression and long-term conditions as outlined by NICE in their 2009 guidelines<sup>26</sup>. The majority of people (17%) scored on the mild scale. However, research indicates that even feelings of mild depression, especially in people with long-term conditions, can, when unaddressed, lead to the development of moderate to severe depression<sup>27</sup>.

The table below shows that approximately one third of respondents screened positively for feelings linked with depression;

*Table 4h – HADS Depression Scores by Condition*

	None	Mild	Moderate	Severe
<b>COPD</b>	68%	13%	13%	6%
<b>Diabetes</b>	69%	20%	9%	2%
<b>CHD</b>	67%	18%	12%	3%
<b>Across all 3 conditions</b>	68%	17%	11%	4%

That around one third of respondents had scores associated with feelings of depression, with 15% of these scoring moderate to severe, is indicative of the challenge primary healthcare services face in managing people who live with long-term conditions. As noted in the introduction, experiencing depressive feelings can mean recovery from the long-term condition is impeded. Pain can become more difficult to control, confidence to participate in rehabilitation programmes is reduced, and self-management, a core component of addressing the strains of living with long-term conditions, can become more difficult.

<sup>25</sup> Zigmond AS, Snaith RP: (1983) The hospital anxiety and depression scale. *Acta Psychiatr Scand*, 67:361-370.

<sup>26</sup> 12-month prevalence rates of Depression between 3% and 10%. In people with chronic illness depression rates 2-3X higher. New NICE guideline Depression in adults with a chronic physical health problem: Treatment and management (2009)

<sup>27</sup> Haddad, M (2009) Guest editorial New NICE guideline Depression in adults with a chronic physical health problem: Treatment and management. *International Journal of Nursing Studies* 46 1411–1414

This study confirms the high prevalence of depressive symptoms in people with a range of long-term conditions. The higher levels observed in the populations in this study might also reflect the higher levels of socio-economic deprivation in our Living Better sites. It leaves little doubt as to the imperative of addressing depressive symptoms in people with long-term conditions and to the opportunities for early intervention at the mild stage.

#### 4.8.8 HADS Screening Scores for Anxiety

As highlighted in the introduction, many people living with long-term conditions experience acute and chronic stresses as a result of the physical consequences of their condition. Not surprisingly, this can cause them to feel anxious and if these feelings are not addressed then their risk of developing a clinical anxiety disorder is increased. Taken across all three conditions, well over one third, 42%, of respondents to our postal questionnaire screened positively for feelings associated with anxiety disorders. A relatively high proportion of respondents also scored moderate to severe on the HADS anxiety scale – 20% across all three conditions.

The figures for the COPD respondents are strikingly high – almost half, 49%, screened positively for feelings of anxiety. Anxiety was reported as a key feature of living with COPD in the focus group data. Many focus group participants spoke powerfully about the physically debilitating effects of living with their condition and the anxious feelings this caused them.

*Table 4i – HADS Anxiety Scores by Condition*

	None	Mild	Moderate	Severe
<b>COPD</b>	51%	26%	<b>18%</b>	5%
<b>Diabetes</b>	63%	21%	<b>10%</b>	6%
<b>CHD</b>	57%	20%	<b>15%</b>	8%
<b>Across all 3 conditions</b>	58%	22%	<b>14%</b>	6%

In several studies involving COPD patients, anxiety has been associated with more frequent hospitalization and with more severe distress at every level of lung function. Even if anxiety doesn't affect the progress of the condition, it takes a substantial toll on quality of life<sup>28</sup>.

<sup>28</sup> Mannino, D. & Buist, S (2007) Global burden of COPD: risk factors, prevalence, and future trends *The Lancet*, Volume 370, Issue 9589, 765 - 773

Anxiety is also known to be highly prevalent in people with CHD. Estimates are as high as 70% to 80% during an acute cardiac phase, and it persists long-term in 20% to 25% of patients<sup>29</sup>. Many people living with diabetes can have tendency towards added anxiety about blood sugar levels. This anxiety is secondary to the disease, but potentially just as debilitating<sup>30</sup>. If untreated, feelings of anxiety can negatively impact on self-management in people living with long-term conditions<sup>31</sup>.

This study confirms the high levels of anxiety experienced by people with long-term conditions in Scotland. The extremely high levels of clinically significant anxiety in this population and especially in the COPD population require some immediate actions. Anxiety symptoms and their management have received less attention than depression over recent years yet anxiety is more prevalent. It is perhaps more prone to being viewed as being a 'normal' part of living with a long-term condition and therefore less likely to be addressed. Detection and management of anxiety in people with long-term conditions should be prioritised more and more efforts should be made to develop self-help initiatives for anxiety management.

#### **4.8.9 The Work and Social Adjustment Scale (WASAS)**

Collecting data on patients' perspectives concerning impaired social functioning provided important data in attempting to understand the impact that living with long-term conditions has on people's mental health and wellbeing. The Work and Social Adjustment Scale (WASAS) is a simple, reliable and validated assessment of impaired functioning and can provide valuable insight into the impact of living with long-term conditions<sup>32</sup>. People are asked to score work and social activities and how their illness affects them on a score from 0 (no affect) to 8 (very severely affected). A WASAS score below 10 indicates little effect on work and social functioning; a score between 10 and 20 indicates that that person's work and social functioning are significantly affected (or as often referred 'significant functional impairment'); a score above 20 can indicate an association for increased risk of mental health problems such as depression and anxiety.

The scale is not a mental health assessment tool in and of itself but it is commonly used in mental health studies to help understand people's immediate social situation regarding their work, home life and social activities. The majority of our respondents were retired and therefore the impact on their formal employment would be limited.

Across all 3 main conditions, a majority of 58% of respondents reported that living with long-term conditions resulted in impaired functioning to social life. This rose to 66% in those living with COPD.

<sup>29</sup> Halm, M (2009) *Relaxation: A Self-Care Healing Modality Reduces Harmful Effects of Anxiety*. *Am J Crit Care* March 2009 vol. 18 no. 2 169-172

<sup>30</sup> Diabetes UK (2010) *Diabetes in the UK 2010: Key Statistics on Diabetes*.

<sup>31</sup> UK ARC & RCP, 2009 UK Academy of Medical Royal Colleges & Royal College of Psychiatrists (2009) *No Health Without Mental Health*.

<sup>32</sup> Mundt, J. C., I. M. Marks, et al. (2002). "The Work and Social Adjustment Scale: a simple measure of impairment in functioning." *Br J Psychiatry* 180: 461-4.

Table 4j – WASAS Scores by Condition

	Little Effect on Work or Social Functioning	Significant Functional Impairment	Moderately Severe / Severe Functional Impairment
<b>COPD</b>	34%	24%	<b>42%</b>
<b>Diabetes</b>	48%	26%	<b>26%</b>
<b>CHD</b>	40%	23%	<b>35%</b>
<b>Across all 3 conditions</b>	42%	23%	<b>35%</b>

These findings are again in line with the qualitative findings from the focus groups where people with COPD had particular difficulties with getting out and undertaking social activities.

These findings highlight the scale of the problems of social isolation being experienced by people living with long-term conditions. This is likely to be exacerbated in the one third of our sample living alone. Help with addressing social isolation is required by this population which will require more integration and coordination of support across the health, social and voluntary sectors. Assessment of social contact/social networks and social activity is not routinely undertaken in primary care but should form part of a more holistic assessment of needs.

#### 4.8.10 Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

WEMWBS is a 14 item validated scale of mental wellbeing covering subjective wellbeing and psychological functioning, in which all items are worded positively and address aspects of positive mental health. The scale is scored by summing responses to each item answered on a 1 to 5 Likert scale ranging from 'none of the time' to 'all of the time'. The minimum scale score is 14 and the maximum is 70<sup>33</sup>.

Once again WEMWBS scores are important in the context of Living Better as they give a general picture of that individual person's general mental wellbeing. WEMWBS aims to measure mental wellbeing itself and not the determinants of mental wellbeing. It is not designed to identify people who have or probably have a mental illness. We present two responses which indicate how living with a long-term condition impacts on people's mental wellbeing. One is asking people to grade their responses to the statements 'I've been feeling optimistic about the future' and 'I've had energy to spare'.

Responding to the statement 'I've been feeling optimistic about the future', one quarter selected the options 'none of the time and rarely'. Approximately half of respondents replied 'none of the time and rarely' to the statement 'I've had energy to spare'.

<sup>33</sup> Stuart-Brown & Janmohamed, 2008

Table 4k – WEMWBS Scores by Condition - Question 1 'I've been feeling optimistic about the future'

	None of the Time/ Rarely	Some of the Time	Often/All of the Time
<b>COPD</b>	27%	38%	<b>35%</b>
<b>Diabetes</b>	26%	32%	<b>42%</b>
<b>CHD</b>	23%	37%	<b>40%</b>
<b>Across all 3 conditions</b>	25%	36%	<b>39%</b>

Table 4l – WEMWBS Scores by Condition – Question 5 'I Have Energy to Spare'

	None of the Time/ Rarely	Some of the Time	Often/All of the Time
<b>COPD</b>	57%	26%	<b>17%</b>
<b>Diabetes</b>	48%	27%	<b>26%</b>
<b>CHD</b>	51%	32%	<b>17%</b>
<b>Across all 3 conditions</b>	51%	29%	<b>20%</b>

Optimism and energy are two important factors to a person's mental wellbeing. That such high numbers responded this way indicates how living with a long-term condition is linked with negative mental wellbeing.

#### 4.8.11 Main Feelings as a Result of Living with a Long-Term Condition

In the thematic analysis of focus group data, a number of common descriptions emerged that people used to describe what it was like to live with a long-term condition. People very rarely if at all used words like 'depression'. People with a long-term condition who attended the focus groups used a range of everyday terms. Questionnaire respondents were asked to select from a range of these everyday descriptions to reflect how living with a long-term condition affected them emotionally. They could choose from a list of 10 options and select one or more or none. The most common descriptions are shown below.

Across all three long-term conditions approximately half said they experienced feelings of being frustrated and/or feeling down and one third to feeling stressed as a result of living with a long-term condition.

Table 4m – Main feelings experienced as a result of living with a long-term condition

	Frustrated	Feeling Down	Stressed
<b>COPD</b>	62%	55%	<b>30%</b>
<b>Diabetes</b>	40%	40%	<b>28%</b>
<b>CHD</b>	45%	43%	<b>35%</b>
<b>Across all 3 conditions</b>	49%	46%	<b>31%</b>

#### 4.8.12 Main Supports Wanted by Patients to Help Live with a Long-Term Condition

As mentioned earlier, respondents to the structured postal questionnaire survey were asked to choose from a list of supports they would like to help them live with their *long-term condition*. They could choose from a list of 12 options that were frequently cited in the patient focus groups and select one, more or none. The most commonly selected options are shown below.

Table 4n – Main supports wanted by patients to help live with long-term conditions

	Exercise/ Breathing Class	Regular Access to Friends	Support Group/ Person to Talk with about Condition	Finance/ Benefits Advice	Help with Transport to Get Out More
<b>COPD</b>	42%	23%	30%	13%	25%
<b>Diabetes</b>	28%	26%	29%	19%	18%
<b>CHD</b>	29%	29%	29%	22%	19%
<b>Across all 3 conditions</b>	30%	26%	29%	18%	21%

Respondents in both the focus group study and the survey consistently emphasise their preference for some form of peer support, either individual or in group form, as well as supports to help address the social determinants of general health and mental wellbeing. These types of support do not require 'medical' or healthcare professional input but could be provided in collaboration with other sectors, and access to such supports could be facilitated by primary care.

## 4.9 FOCUS GROUPS WITH HEALTHCARE PROFESSIONALS

As part of its research, Living Better conducted focus groups with primary healthcare staff whose work directly and indirectly involved people living with *long-term conditions*. A total of 10 focus groups were held with healthcare professionals and members of the reference groups. One focus group was held with the reference group members present and a second with wider healthcare professionals, not directly involved with the reference group work, but involved with participating GP practices and the CHP in working with people living with a *long-term condition*.

Seventy-six healthcare professionals, ranging from GPs, Practice Nurses, Specialist Nurses, Community Nurses, Allied Health Professional (AHP) staff, Community Pharmacists, Long-Term Condition leads, Voluntary sector staff, and CHP and Practice Managers attended and took part in the 10 focus groups. The groups discussed:

- The experiences of health professionals in addressing mental health and wellbeing generally.
- Whether health, social care and voluntary sector professionals were aware of mental health and wellbeing issues in these patients.
- How confident they were in addressing these issues.
- Whether health, social care and voluntary sector professionals believed services at CHP level were equipped to address these issues.
- What changes should occur locally, from the perspectives of both patients and health care professionals, to address mental health and wellbeing of people with *long-term conditions*.

Overall, there were four key areas which were represented consistently and characterize the discussions across the focus groups in all sites. These concerned:

- The process of screening (particularly nurse screening) for depression and how this was not necessarily leading to improved recognition of depression.
- The lack of knowledge of what to do when patients are screened for depression.
- Feelings of a lack of skills in raising and dealing with mental health issues.
- Recognising that in order to address the key problems affecting patients lives there needs to be more collaboration and links to other sectors.

### 4.9.1 Screening for Depression

Because the Quality Outcomes Framework (QOF) screening questions were introduced for diabetes and CHD in an attempt to improve how primary care health services addressed depression and anxiety in people with a *long-term condition*, the screening questions and their effectiveness became a focal point of discussion amongst health care professionals in the focus groups.



Many nursing staff involved in asking the screening questions:

- Had reservations (a) about the effectiveness of the questions generally.
- Believed they themselves should have been better prepared to answer such questions before they were introduced.
- Stated that they were usually asked at the end of a consultation and seen by many as a 'tick box' exercise rather than as a formal process of addressing the person's mental health and wellbeing.

*'I think the screening questions are seen as a sort of tick box exercise... I think the questions are 'do you have low mood?' maybe the wording of it, it's not about mental health it's about illness, and people maybe don't see that 'oh well no, I'm not depressed' that's not a word that they associate with their illness. Also there's not time, you know, the nurse has got twenty minutes/half an hour, she's got to do their feet, pulses, everything else [laugh] and it's 'are you depressed?' 'no', that's fine, move on!'* (CHD Nurse Specialist)

*'I think sometimes what they (patients) do is they would tell you what they think you want to hear... It's almost like it's contrived. And where we're talking about ten different things relating to their blood pressure, their eyes, their feet, etc and then its... 'oh by the way, are you feeling down?'. That's not going to work properly. But how appropriate is that question, they're not appropriate at all?'* (Practice Nurse)

#### **4.9.2 Lack of Knowledge, Confidence and Skills**

In addition to questioning the effectiveness of the way in which screening is being conducted, the healthcare professionals (again the majority being nurses) also expressed a level of fear or reluctance to raise mental health issues with patients because they did not feel confident in their abilities to know what to do or how to address the 'can of worms' or 'Pandora's Box'. They were also concerned that if they do identify a mental health problem that they may not have sufficient time to deal with this.

*'But I think one of the reasons why people don't ask or don't like asking those two (QOF) questions is I think they're either nervous about opening Pandora's Box and what may happen or they feel they don't necessarily have the skills to deal with whatever people say anyhow, and possibly the time issue as well. Because if they do open a Pandora's Box then they have to allow more time to discuss any problems that arise when they actually bring them out.'* (Specialist Nurse)

There was a general view that even if screening was effective, there is a lack of knowledge in terms of what to do next, particularly if the only options were antidepressants, as there was a recognition that patients do not always want to take such medications. They also expressed difficulties in knowing how to engage in discussions with patients about possible depression, as they often perceived that patients were reluctant to accept they might be depressed.

*'I think the annual review (screening questions) probably does give the chance to identify it (depression), but as we are saying, that's where maybe there's the gap. It's like 'okay, what do we do with this patient?' Because a lot of them, they don't want to go onto the anti-depressants as well, you know...they don't want to admit they're depressed'. (Diabetes Nurse Specialist)*

There was a strong consensus that in being made responsible for depression screening they were undertaking tasks and expected to engage in a topic in which they had little or no training.

*'The (QOF) depression screening came in without the training. We've been floundering for a couple of years.....the depression questions just came in handed down really, that's quite typical of the way things happen, its too top down'. (Diabetes Nurse Specialist)*

The need for training in raising awareness of depression, screening for depression and in the types of activities and interventions which could help support people with emotional problems is strongly highlighted in these findings. Mental Health Training or Depression Training for primary care nurses and other healthcare professionals dealing with people with *long-term conditions* should be developed and made available across CHPs in Scotland.

The findings from the professional focus groups has tended to focus on depression awareness, screening and management because this is the focus of the QOF in primary care and therefore now a routine aspect of nurse care. However, the patient data has emphasized the importance of anxiety for people with *long-term conditions*, which could be more prevalent than depression in this population. Training should therefore focus on similar issues in awareness, screening and management of anxiety in people with *long-term conditions*.

#### **4.9.3 Social Support Services and Improved Partnership Working**

The need for additional support services for those with *long-term conditions* is well recognized by healthcare professionals. However there are problems in knowing what is available, especially at a local level, and in being able to link up with and enable seamless transition to these services for patients.

*'When you're talking about getting patients to use other services to help them, there are so many things that are out there but people are not aware of what's available and I include us and patients in that. I didn't know about that exercise class for example.' (Practice Nurse)*

*'We have to be more cohesive in what we are providing, because as you said, the services are out there, but they're not linked together; if we could provide a resource pack or information or something that you can give to patients that they can refer back to, because their needs will change at different stages of the disease process. I think where we're not good at partnership either health or social work with the voluntary organisations. That is a massive gap and is inconsistent and sporadic, and that's a phenomenally on tap resource that we don't use.' (LTC Planning Manager)*

There is a need for greater awareness of local community resources and social support services among primary care staff, especially those provided by Local Councils and the Voluntary Sector. There is recognition that partnership working between primary healthcare organisations, Local Councils and Voluntary Agencies will become increasingly essential to successfully address mental health and wellbeing in people with *long-term conditions*. More practical local strategies need to be devised to enable closer collaboration. This may be facilitated by technological solutions to identifying available resources and to facilitate onward referral for patients.<sup>34</sup>

*Box 4.3 – Summary of key findings from healthcare professional focus groups*

- The Quality Outcomes Framework (QOF) screening questions are a step forward but they have limitations.
- For many practice nurses and specialist nurses the QOF mental health screening questions for depression felt like a *'tick box'*, a *'numbers'* or a *'paper exercise'*.
- The depression screening questions tended to be asked at the end of the 6 monthly or annual review patient assessments by most nurses. This didn't allow for much time to discuss mental health and wellbeing issues in people living with a *long-term condition*.
- Some nurses expressed concern that patients would open a *'Pandora's box'* when the screening questions were asked at the end of the annual or 6 monthly review, raising the question of whether this concern influenced the way the screening questions were posed to patients.
- Primary care nursing staff can lack confidence in addressing mental health problems in people living with a *long-term condition*, and would benefit from training to raise their awareness of mental health and wellbeing.
- There should have been a greater discussion at GP practice level about mental health and wellbeing in these patients and how this should be addressed before the QOF screening questions were introduced.
- Many nursing staff had a feeling of *'what do we do next'* after QOF questions or using Hospital Anxiety and Depression Scale (HADS) or Patient Health Questionnaire (PHQ9) screening tools.
- Even if HADS or PHQ9 was used with patients, many nurses did not know what happened to these patients afterwards.
- Practice and specialist nurses would like more time with patients to tease out mental health issues.

<sup>34</sup> See <http://aliss.org/> . A Scottish Government initiative to make information about self management more accessible.

- The stigma of mental illness remains a problem in addressing mental health and wellbeing in people living with long-term conditions. Some healthcare professionals suggest that a proportion of patients, especially older patients, actually resented being asked the QOF screening questions.
- There is a need for clearer signposting of existing social support services to facilitate access for people living with long-term conditions
- All staff commented on the need for greater integration of appropriate community health, voluntary and social care services, especially between CHPs, GP practices, social services and local authorities.
- Practice and CHD/Diabetes/COPD specialist nurses expressed a desire for more mental health and mental wellbeing awareness training.
- Stronger partnership working with local authorities is required to utilise and also develop social support services for patients with a long-term condition.

## 4.10 PROCESS AND OUTCOMES EVALUATION

A process and outcomes evaluation was conducted to identify what helped or hindered local sites in developing and implementing their local Living Better goals. This evaluation also identified benefits and achievements; outcomes which were perceived as having a positive impact on local service development managers, healthcare practitioners and patients. These benefits and achievements could be at a collective level, in terms of improved team working and improved collaborative working across sectors, or at individual level.

The evaluation recorded how members of the Living Better reference groups in the five participating CHPs viewed working within the Living Better project and what they perceived were the barriers and facilitators to achieving their locally derived aims.

This involved:

- A structured on-line questionnaire to CHP reference group members (n=22 participants).
- Semi-structured one to one interviews with key CHP reference group members (n=12 participants).
- Observation and participation by the researcher in many of the local reference group meetings.
- Analysis and assessment of reference group and other minutes, notes of meetings, and papers relating to the Living Better project in the five CHP sites.

- Outcome interviews: One to one qualitative interviews were conducted with Living Better reference group members across the five CHP sites, and also with members of the Living Better National Steering Group (n=36). These interviews discussed the role and functioning of the local reference groups, what had worked well within Living Better and what had worked less well.

Data from this evaluation has been combined in the boxes below to avoid repetition of similar points raised during reflections on the process of development and implementation of Living Better (Chapter 3) and reflections on the achievements (Chapter 5). Boxes 4.4 and 4.6 summarize key barriers and facilitators of implementing Living Better. Data exemplifying key points from the process and outcomes interviews are presented in Boxes 4.5 and 4.7.

The remainder of this Chapter discusses comments and reflections that are relevant to the sustainability and wider roll-out potential of Living Better in the current financial climate, with potential for cuts to budgets and services. We also summarise specific feedback on the role of the National Steering Group for the project.

*Box 4.4 – Summary of facilitators in implementing Living Better*

- Clear goals and objectives.
- Fits well with (and establishes links to) existing initiatives.
- Involvement and commitment of key stakeholders.
- A feeling of engagement and ownership among members of the CHP reference groups helped maintain membership and participation in local reference groups.
- Regular contact with key stakeholders out with reference group meetings.
- Contact with other key stakeholders at CHP level not on reference group.
- Scoping of existing services.
- Reference groups regularly reviewing progress regarding achievement of project's principal aim.
- Expanded networking opportunities.
- Cross boundary working with different partners.
- Feedback of research findings.
- Patient Involvement.
- Shared learning across the CHP/CHCP sites.

*Box 4.5 – Data extracts relating to facilitators in implementing Living Better*

*'The message from the top for the last seven or eight years is that long-term conditions and inequalities are the key areas for us at CHP level, especially in one like ours with high levels of deprivation. The good thing about this project is that we are not going out on a limb....there are three or four other initiatives that Living Better is linking in to. The aims and objectives are very clear and I think the fact that we are focusing on one section of the community is good because we are already generating good data that we think we know but now we do know because we've spoken with these people directly and the health professionals working with them.'* (Long-Term Conditions Planner)

*'Having the people we had on the group was good because they could spread their tentacles to the various groups and projects across the CHP. We had a good balance of people managers who work across the CHP, practice staff on the ground and the patient input was important.'* (Long-Term Conditions Manager)

*'The group worked well in, that I felt anyway, everybody contributed and we discussed everything before making a decision.'* (Patient representative)

*'As you know there is so much going on everywhere and a lot around long-term conditions. We were able to link in with the other initiatives in this area and tell them what we were doing and vice versa. That helped, I think we had good input to the reference group from other projects and so we were able to link this work and not go down our own wee corridor.'* (Specialist Nurse)

*'I think the fact that we are not trying to 're-invent the wheel' is good. It means our goal is more achievable and the fact that we are linking in with other initiatives is important. This one project isn't going to find all the answers or going to make all the necessary changes but the fact that it's linking with other relevant work across the CHP means we can have a better chance of making a difference.'* (Nurse Specialist)

*'The project brought people from different organisations together round the table to think about this.... So I think to me that's the positive thing. I think for the first time there has been a cross-survey, cross professional, joined up attention to this, and I hope that all this will influence central Government and hopefully they will support rolling out some initiative nationally.'* (Planning Manager)

*'Providing evidence from local people is important, that has given us the impetus to make specific plans I think that our discussions around the findings highlight what we've probably known but have had it confirmed by getting the data from people themselves. I think we've got some good ideas now about what to do next.'* (GP)

*'It's always good to gather research locally as it gives a sense of listening to local people and local health professionals. Getting the reports helped focus the group's work and reading what people with diabetes and heart disease said about the services they wanted was good as was what all the different health professionals said. It means we can go to the CHP and say look this is what we need to do and here is the evidence.'* (GP)

*'I think the scoping exercise has been really useful in that it demonstrates that there is a lot out there and I'd say half of it many key primary care staff like nurses will not know about. So it has to focus our attention on how do we let people know what's there that's a good thing.'* (Planning Manager)

#### *Box 4.6 – Barriers in implementing Living Better*

- Length of project led to difficulty in maintaining continuity.
- Project has taken time to get up and running.
- Too many competing local and national demands to free up sufficient time for the LB project, for example during H1N1 vaccination period.
- Turnover of staff on reference groups has negatively affected continuity.
- Change in developmental staff led to 'hiatus' in the projects.
- Sites feel more 'ownership' with the project at a local CHP level than at national level.
- Lack of GP involvement in CHP reference group meetings.
- GP autonomy can hinder CHP level initiatives.
- Competing demands on the time of reference group members.

Box 4.7 – Data extracts relating to barriers in implementing Living Better

*'I have a problem with the length of your project – it's way too long! Your losing initiative by having too big a gap between the meetings, it means that you have to re-visit areas already covered.'* (GP)

*'The project has been on the go for a while and with things like swine flu getting in the way and staff moving to new posts its been difficult to maintain a steady momentum. Being as rural as we are hasn't helped as well.'* (Manager)

*'And what the reference group is really tasked with, part of the reference group's remit to do actually a scoping exercise really, to sit down and say 'well these are the services, this is where we think we're missing out, this is what we're going to have to do to re-jig things slightly or plug this gap'. I personally think it's not feasible to do anything radical in terms of any significant change at this level, that has to be structural, higher up the chain.'* (CHP Manager)

*'I thought there was a lack of GP involvement in the reference group meetings and to an extent with the project and I know from the talking with others at the steering group that this was the case in the other areas. That's a hindrance because nothing can really happen at practice level without the GPs say so, the practice nurses for example are GP employees. We've said that more has to happen in the practices to improve detection and that's fine but you've got to get GPs on board and it was disappointing that they didn't.'* (Specialist Nurse)

*'I think the difficulty was, given how GP practices are sort of funded and operated and they're essentially their own little... I don't want to use the word... their own little conglomerates, whether they're a single practice or not they're like a wee conglomerate and they decide what they're going to do. So whilst they may well have a contract with the CHP, the CHP really doesn't have an awful lot of, I would say, power over them to influence their decision making as to whether they'll come on board with something.'* (Specialist Nurse)

*'If you asked a lot of GPs they'd tell you that the jury is still out about CHPs. There isn't a great relationship there and there is not a lot CHPs can do about this. To an extent there is even vagueness about what CHPs do. I think the links between Board and GPs is clearer than between CHPs and GPs. Living Better is a CHP based project but if you don't have a good relationship between the CHP and GPs then you will struggle, our relationship is good but I know for a fact they are not all like that in the city.'* (Planning Manager)

*'I think you are being too ambitious with what you want to achieve. I mean as it stands now nurses like me and I know lots of others are already too busy, we're struggling to cope with our present workload. You are asking us to take more time out to talk to people about their mental health – well that's a good idea and important but it's going to take a major change and you've got to get GPs on board for that and that is not easy.'* (Practice Nurse)



#### 4.10.1 Sustainability and Potential for Roll-Out or Expansion

Some reference group members raised concerns about existing factors which could hinder the project's goal of a real improvement in services. Firstly, the current financial climate affecting the NHS and local authorities means some of the recommendations around improved partnership working could be difficult to achieve. Secondly, many key staff, especially primary care nursing staff, who could play a role in improving the way mental health and wellbeing in people living with a *long-term condition* is addressed are already struggling to spend more time with patients.

*'Two key messages of the project are that we need to train nurses to spend more time assessing the mental health and wellbeing of people with one of these illnesses - but that takes time. Time is money and training is money and there isn't a lot of money around so how practical are projects like this one when you are saying what you are saying – as right as it may be? Its ok us agreeing this but if I go back to my boss and say – training – he'll say how are we going to pay for it.'* (Practice Nurse)

In addition to financial concerns, the capacity of CHP teams addressing *long-term conditions* was a concern for some reference group members. This was expressed as an over-reliance on certain individuals to carry out numerous roles. This often resulted in local knowledge and expertise being concentrated in a few key stakeholders who were often left 'spinning the plates'. Changes to such staff could hinder improvements in the way primary care addresses mental health and wellbeing in people living with *long-term conditions*.

*'Look at the problems we've had getting this going here its been up and down, all you need is one key person to fall by the wayside and you are in trouble because there are not enough people to do the job. The project here is a case in point, you are relying on one or two key people and ultimately that's not feasible in the long term unless the capacity is there built into the system so its part and parcel of the system not kind of outside looking in which Living Better is.'* (Specialist Nurse)

This very point came to the fore in some of the local reference groups when key individuals either moved to a new post or retired. This had a negative impact on the group's work until suitable replacements were identified and brought on to the reference group.

#### 4.10.2 CHPs and Local Authority Partnership Working

Whilst partnership working between local authorities (who provide much of the social support services that could help people with *long-term conditions*) and CHPs was seen as vital to achieve the project's aims, the tensions between the local authorities and the Health Boards about the share of spending towards CHP activity was seen as a barrier to the project achieving its goals. Pressures to tackle short term, immediate problems rather than using resources more strategically to provide early intervention and prevention, as argued by Living Better, could limit the effectiveness of the project.

*'Look we are already bracing ourselves for the budget restrictions that local authorities are going to have to face. From the research findings, we are arguing that we need to link with local authorities for the type of support services that will help them live with their illness. These types of services are at risk so it's difficult for us to go to the local authority and say we need more of them.'* (Practice Nurse)

#### **4.10.3 Changing Practice and Service Provision Requires Top-Down Support**

Some reference group members believed that projects like Living Better are overly ambitious because they are short term 'downstream' initiatives trying to bring about wider strategic structural change. This can be difficult to achieve without all the 'key stakeholder' organisations, such as Health Boards and GP Sub-committees, on board. Many argued that 'upstream' policy initiatives are what is required; measures to make considerably wider ranging changes in the way services are planned and provided.

*'For all the good work done locally, and there has been a lot, how do we sustain it? The reference groups aren't going to continue and for all the best will in the world the group members are going to get drawn into other areas of work, maybe new initiatives like Living Better. I'd like to have seen more representation from the Health Board on the reference group and I'd like to know what the Government is going to do with all the evidence – act on it or just keep it as a report? Living Better is arguing for some significant changes around training of nurses and that costs money which will have to come from central government because we don't have it.'* (Planning Manager)

In a similar vein, some reference group members believed that while the aim of the Living Better project was vitally important, projects of this nature tend to attract GP practices and healthcare staff who are already enthusiastic about, or have a special interest in, that project's goal. Consequently these practices fully engage and support the initiative, but when it comes to 'rolling out' any recommended changes on a CHP-wide basis, new barriers, not encountered in such pilot projects, will emerge which make effective service change difficult.

#### **4.10.4 The Role and Impact of the National Steering Group within Living Better**

A number of key factors in the work of the National Steering Group were perceived as facilitators in achieving the project's principal aim, while others were identified as barriers. These factors are outlined below.

##### **Facilitators:**

1. Regular feedback on research findings and developmental work from the CHP sites kept the steering group members up to date with on-going events and allowed for discussion of the key issues.

2. Many members liked the opportunity to ask questions and have a dialogue about some of the emerging research themes and developmental work.
3. The above two factors provided many, although not all, members with a sense of ownership and being engaged, listened to and of having their views taken on board.
4. For many steering group members, the participation of key stakeholders from the voluntary sector, patient groups, the Scottish Government, RCGP and academic input from the University staff gave the group the 'right balance' and 'authority'.
5. The generation of significant amounts of data from the research and developmental work was seen as a valuable resource to add to local and national bodies of knowledge around improving how our primary care services address mental health issues in people with *long-term conditions*.
6. The variation in research findings across the five CHP sites indicated that 'one size fits all' approach is unlikely to be the answer in Scotland. Varied, locally tailored approaches to improving how primary care services address mental health issues in people with *long-term conditions* were seen as a positive factor by many. Local socio-economic, ethnic, geographic and wider cultural factors must be considered when making plans to improve CHP and primary care services tasked with addressing this issue.

#### **Barriers:**

1. The project took a long time to 'get going'. There seemed to be a significant delay in initial discussions with key partners around the nature and extent of the project, and also whether the project was actually going ahead. However, it was recognized that this was to some extent due to having to seek out a new funder, after the initial bid to the original proposed funder was unsuccessful.
2. The steering group, with over 35 members, was thought to be too large. This hindered input and contributions at steering group level when the project was establishing itself, both at the five CHP sites and nationally.
3. For some steering group members the meetings were too prescriptive, with some issues 'appearing that they had been decided on before-hand'. There was, however, recognition that the size of the steering group, the fullness of the agenda and the distance some members had to travel left limited time for discussion at the meetings.
4. As a result of these three factors some steering group members felt that there wasn't the same sense of ownership with the project at the national level as there appeared to be at the level of the local CHP reference groups;
5. Because the project was so long, any steering group member missing one or two meetings could feel a little left behind in terms of being 'up to speed' with the issues facing the project;
6. Whilst the feedback on developmental work in the five CHP sites was always encouraging in terms of the work progressing, some felt that there was a lack of involvement of local CHP reference group members on the steering group.

## 4.11 PATIENTS' VIEWS OF TRAINING EVENTS

To assess the impact of patient awareness raising events 20 qualitative interviews with patients took place. These interviews added further qualitative data to the training evaluation forms gathered directly after the events took place. Patients spoke positively about their experiences in attending these events. Below are typical comments from patients as to why these events were important to them in addressing mental health and wellbeing issues as people living with a *long-term condition*.

(i) Realising how common mental health problems are, not only among society in general but also among people living with *long-term conditions* in particular. This was comforting to people and made them realise that there were other people like them going through the same or similar experiences.

*But coming along on the day and listening to peoples' different experiences – its reassuring to know I'm not the only one who feels like this. Its helped me understand some of the ways I've thought and acted and I know if I do certain things like we discussed I won't think or act like that again – hopefully.'* (CHP2 CHD)

(ii) Realising that there was more to mental health than simply mental illness, that there was such a thing as positive mental wellbeing, and especially how important this was in terms of patient self-management of their *long-term condition*.

*'I now realise, especially after the course that I need to look after what's in my head as well as all the other stuff I do, the walking, the breathing, watching where I go, what I eat. I'd been ignoring that and there were times I was thinking - I'm feeling really not up for anything - can't be bothered - type of thing. I have to watch that because that affects everything else. It's probably the most important because it affects your ability to do the other stuff. That was explained well and the woman answered the questions and explained it well. The booklet also explained that really well, so I know about that now. And what to do to prevent thinking like that.'* (CHP4 COPD)

(iii) Understanding why they felt emotionally drained and down and behaved the way they did as a result of the strains of living with their condition.

*'The slightest thing could set me back I used to feel quite guilty about feeling so bad . I now understand that first of all is ok to feel like this but more importantly there are things you can do that can help not only manage your blues. I used to give myself a hard time about how I was feeling 'pick yourself up' kind of thing but I now realise its natural, but also importantly again there are things that you can do to stop you thinking like that.'* (CHP2 Diabetes)

(iv) Realising that taking steps to look after their physical wellbeing, such as taking light exercise classes, eating better and carrying out breathing exercises would improve how they felt emotionally. These steps would help address the vicious circle of not feeling good physically leading to feeling down emotionally, which in turn made them feel worse physically. This circle, as was explained at the patient event, often starts when self-management of their *long-term conditions* is neglected.

*'At the course I went on the woman who did the talk spoke about what is mental health why it is so important not just to our mind. I've always thought what happened up there was totally different to the rest of my body but it's not - especially with my condition... there have been some really shaky times with my breathing and its not just wiped me out physically I'm done in my mind as well, but learning about the breathing, the relaxation, not getting uptight - it's important to talk about what's worrying you nobody is going to think less of you - are all linked - that's been really good.'* (CHP4 COPD)

(v) Being made aware of local services that could help them lead a more satisfying and fuller life was seen as important not just in terms of peoples' mental wellbeing but also their physical wellbeing.

*'I never knew about the exercise class the group puts on and the other events they do so that's a plus. Also there is a fair amount you can get help with that's going to help with this damn thing. What was good was the that I realise that I can do a bit more than I used to with not a lot of hassle for me because a lot of it is laid on already.'* (CHP2 CHD)

#### **4.11.1 Conclusion and Recommendations on Patient Outcomes**

Perhaps the biggest challenge in addressing mental health and wellbeing in people living with *long-term conditions* lies in tackling the stigma of mental illness. In the focus groups with people living with *long-term conditions*, it was difficult to address the issue directly. Many people didn't use terms like 'depression', 'mental illness', 'anxiety', preferring terms such as 'feeling down', 'frustrated', 'angry'. People were reluctant to admit they were experiencing emotional distress.

The patient events attempted to raise the issue of mental wellbeing, and were evaluated positively by patients who attended. The likelihood is that these events attracted those more willing than others to talk openly about their mental health and wellbeing. Nevertheless, those who attended the events realised the importance of looking after their psychological needs as well as their physical needs.

#### 4.11.2 The Essential Need for Patient Education on Mental Health and Wellbeing

An education programme targeted at people with, and those most at risk of developing, *long-term conditions* (and their carers) is a recommendation of the Living Better project. This should involve mental health educators, patient representatives who live with a *long-term condition*, and also be supported by CHPs and voluntary organisations. Innovative ways of communicating that there is '*no health without mental health*' can be developed, as the Living Better project demonstrated across the 5 CHP reference sites<sup>35</sup>. Special attention is required for hard to reach groups in socially deprived areas. For black minority and ethnic minority communities (especially South Asians), such a programme should be delivered in appropriate languages, and aim to be ethnically, religiously and gender sensitive.

<sup>35</sup> UK ARC & RCP, 2009 UK Academy of Medical Royal Colleges & Royal College of Psychiatrists (2009) *No Health Without Mental Health*.

# CHAPTER 5:

## CONCLUSIONS AND RECOMMENDATIONS

The principal aim of the Living Better project was:

***To facilitate primary healthcare 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 a long-term condition in Scotland.***

From the perspective of the overwhelming majority of reference group members, the project has achieved this principal aim in the following ways:

1. Local scoping exercises have identified what is lacking in the five CHP sites in terms of service provision to address mental health and wellbeing in people living with *long-term conditions*.
2. Multi-disciplinary health care practitioners and planners in the reference groups discussed the challenges of addressing the mental health and wellbeing in people living with *long-term conditions* and emerged with a greater understanding of this issue.
3. This greater understanding will be transferred across the CHP;
4. Research findings provided clear evidence of the impact of living with *long-term conditions* on the mental health and wellbeing of local people and the type of support services they wanted to help them live with their condition.
5. Reference groups have developed local initiatives and delivered recommendations to the wider CHP on how to improve the way they address the mental health and wellbeing in people living with *long-term conditions*.
6. Living Better has contributed to the national understanding of how to address mental health and wellbeing in people living with *long-term conditions* and has developed a series of training interventions that are now available for further roll-out.

### 5.1 KEY LEARNING

1. Living Better had clear overall aims and objectives which appealed to many local Reference Group members with interest in *Long-term conditions*. 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. Whilst some reference group members believed the project took time to get established, once underway the overwhelming opinion was that it had a clear goal and well established plans. The role of the project officer was highlighted by many as key in this. Because reference group members had other responsibilities, the project required someone facilitating and networking to achieve local reference group goals. A national facilitator would be required if the conclusions and recommendations of the project were to be acted upon across Scotland.

2. 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.
3. 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.
4. The three year time span 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 H1N1). Many sites are still in the implementation stages of Living Better activities.
5. Gathering local research data from patients and health professionals and data on local service provision around the issue of mental health and wellbeing in people living with *long-term conditions* was seen as an important catalyst to the local reference group's work. This helped to shape the direction of the reference groups and resulted in different approaches to service development being recommended across the five sites to reflect local socio-demographic characteristics and existing CHP plans and structures. Consequently, we conclude that there is no 'one size fits all' solution to this issue and it is essential that CHPs across Scotland undertake local research and scoping exercises before developing initiatives to address mental health and wellbeing in people living with *long-term conditions* in their areas.
6. General practices were recruited to facilitate patient focused research within the project and to participate in project interventions. Their involvement was encouraged by the role of the RCGP Scotland within the project. There is an ongoing need for policy makers and to engage with GPs and other primary care (nursing) staff.
7. Primary and specialist nursing services play a large role in supporting the needs of people with *long-term conditions*. 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 Greater Glasgow and Clyde) and the Managed Clinical Network (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.



8. This project highlighted the lack of nurse confidence and skills in raising mental health issues with patients in primary care (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.
9. Nurses would benefit from working more in tandem with the GPs when it comes to detection and management of depression in patients with multiple morbidities. 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 multi-disciplinary training produced positive knowledge sharing among GPs and their nurses.
10. The importance of linking in with other appropriate CHP and national initiatives was clearly important. This encouraged a positive view of the project as not trying to 're-invent the wheel'. An example of linking in with other projects were the submissions from voluntary sector groups and Living Better itself to a number of national policy initiatives around *long-term conditions* and mental health and wellbeing. A strong link with on-going initiatives such as Long-Term Conditions Alliance Scotland (LTCAS) is therefore strongly recommended.
11. Fostering effective working links and working in partnership with local authorities and voluntary sector agencies is essential if CHPs are to address the social determinants of health that impact on the physical and mental health and wellbeing of people living with *long-term conditions*. The focus group and patient survey research findings from people who live with *long-term conditions*, and the health care professionals who work with them, all point to the importance of the involvement of non-statutory NHS organisations, especially local authorities and voluntary sector agencies.
12. Reference groups which had strong GP involvement and support tended to produce the most effective work on the ground. CHP based GP sub-committees and the RCGP have a critical role to play in addressing mental health and wellbeing in people living with long-term conditions. This is especially the case regarding supporting Practice Nurses.
13. The General Medical Services (GMS) contract created many new opportunities for practices and for practice nurses who play a critical role in helping practices achieve quality targets, especially around QOF screening for long-term conditions. The current emphasis on long-term condition management is an opportunity for practice nurses to build upon existing expertise in this area. CHPs should be encouraged to build links with the Scottish Practice Nurses Association who have named representatives in each Health Board area of Scotland.

14. Patient focus groups identified the early stages of diagnosis and adjustment to illness as being particularly stressful, fearful and anxiety provoking. A longer term impact is the decline in social activities coupled with resultant 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 pilot 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 this led to a more assets based approach to local activities. These project sites were also more patient oriented in their development activities.
15. An education programme targeted at people with, and those most at risk of developing, a *long-term condition* (and their carers) would be of value. Further development and roll-out of this should involve patient representatives who live with a *long-term condition*, mental health educators and be led by CHPs.

## 5.2 RECOMMENDATIONS

1. The Living Better project has produced some key resources for wider dissemination, with adaptations for local delivery. These have been piloted or their acceptability amongst patients and professionals, and for 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<sup>36</sup> as partners in their delivery.
2. 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.
3. Primary care nurses require training and confidence building to integrate mental health screening and signposting into their role in managing *long-term conditions*. However, their contractual relationship with GPs mean 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.
4. 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*.

<sup>36</sup> <http://www.expertpatients.co.uk/>

5. 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<sup>37</sup> 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.
6. 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 and chronic heart disease 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.

<sup>37</sup> <http://aliss.org/>

# APPENDICES

## APPENDIX 1: CHP SITE PROFILES

Summary of Socio-demographic & Health and Wellbeing Profiles of the 5 Participating CHP Sites  
(Source: ScotPHO, 2010)

CHP	Western Isles	Angus	North Lanarkshire	East Dunbartonshire	South Glasgow*	Compared with Scottish Average
<b>Total Population</b>	26,180	110,250	326,320	104,680	220,489	-
<b>% Population 65yrs+</b>	21.5%	19.9%	15%	18.1%	13.7%	16.7%
<b>Life Expectancy Males 1</b>	72.7yrs	76yrs	72.6yrs	77.6yrs	70.8yrs	74.5yrs
<b>Life Expectancy Females 1</b>	80.1yrs	79.9yrs	77.9yrs	81.7yrs	77.3yrs	79.5yrs
<b>Early Deaths from Heart Disease (&lt;75 yrs) 2 (sr)</b>	58.7	42.2	72.3	32.1	78.0	57.2
<b>Patients hospitalised with COPD 2 (sr)</b>	144.1	123.9	188.6	96.4	259.5	158.6
<b>Patients hospitalised with CHD 2 (sr)</b>	336.2	330.5	434.9	270.9	368.7	347.0
<b>Prevalence of Diabetes sr2</b>	3.0	3.4	4.1	3.0	4.3	3.5
<b>Patients Prescribed Drugs for Anxiety/Depression/ Psychosis %</b>	9.4	9.3	10.7	8.7	10.2	9.7
<b>Smoking Prevalence 3</b>	24.0	24.0	30.0	17.0	32.0	25.0
<b>People (65yrs+) with intensive care needs cared for at home 3</b>	40.4	12.9	39.5	43.0	36.6	31.7
<b>Single Adult Dwellings %</b>	35.9	36.8	35.5	31.1	47.2	37.8
<b>Adults Claiming Incapacity Benefit/Severe Disability Allowance %</b>	4.7	4.4	7.0	3.5	8.2	5.6
<b>Population Income Deprived %</b>	15.1	12.8	18.2	8.5	25.0	15.1
<b>Dependence on out of Work Benefits or Child Tax Credit %</b>	48.2	45.2	52.2	30.8	62.8	46.6
<b>Adults Claiming Incapacity Benefit/Severe Disability Allowance %</b>	4.7	4.4	7.0	3.5	8.2	5.6

\*Data based on 2010 S South Glasgow CHP profile following changes to SE Glasgow CHP structure during course of Living Better Project

1. Five-year combined number, and 5-year average annual measure.
2. Three-year combined number, and 3-year average annual measure
3. Data available down to local authority level only.

sr = age-sex standardised rate per 100,000 population

sr2 = age-sex standardised rate per 100 population yrs = years

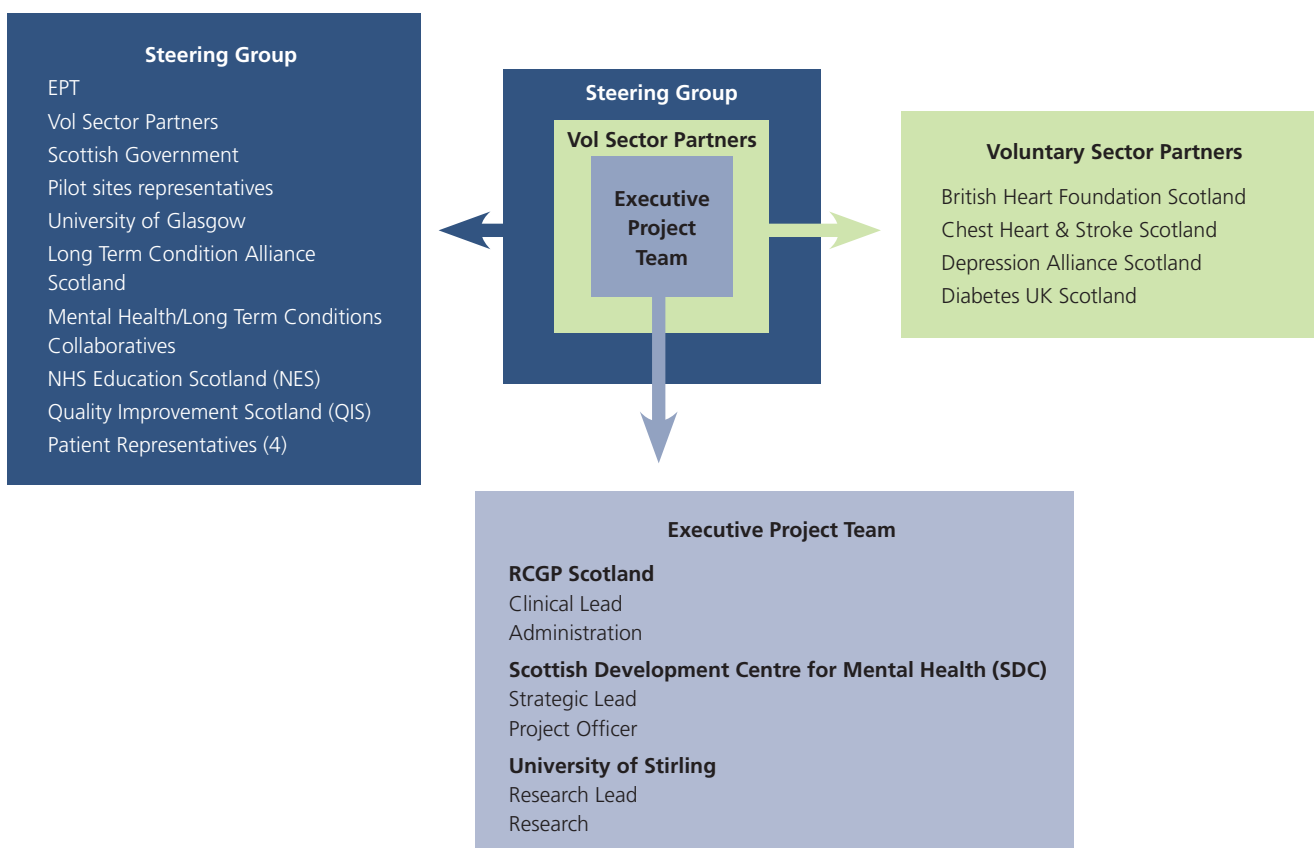
% = percent; mean = average.

## APPENDIX 2: THE GOVERNANCE OF LIVING BETTER LOCALLY AND NATIONALLY

### National Project Governance

The Living Better Project had a three tiered governance structure, with a core Executive Project team whose purpose was to manage and deliver the project within agreed budgets and timescales, a wider project partnership involving four key voluntary sector partners, and a National Steering Group who's remit was to oversee the successful implementation of the project (see Diagram 1a below).

*Diagram A2a: The Living Better Governance Structure*



## Living Better Partnership in Action: Patient leaflets

A working group consisting of the Living Better Project Officer and Administrator, voluntary sector links and patient representatives was convened from July 2008 to July 2009 to write and produce two patient information leaflets covering diabetes and mood and heart disease and mood. The work was led by Chest, Heart & Stroke Scotland and Depression Alliance Scotland, with input from other partners. Paper and electronic copies of the leaflets were produced and disseminated through pilot sites, voluntary sector networks and conferences and events. Electronic versions of the leaflets are available to download from [www.livingbetter-scotland.org.uk](http://www.livingbetter-scotland.org.uk)



## The Executive Project Team

The aim of the Executive Project Team (EPT) was to manage and deliver the project within agreed budgets and timescales. The EPT was made up of three core partners: the Royal College of General Practitioners (Scotland) (RCGP Scotland), the Scottish Development Centre for Mental Health (SDC) (latterly Mental Health Foundation) and the University of Stirling. Each of the three core partners was responsible for a different function within the project, with RCGP Scotland providing overall project governance, clinical input, administrative support and financial management, SDC providing project management and training and development input, and the University of Stirling responsible for the research components of the project. Good working relationships between the partners were fostered through regular meetings, communication and updates, joint working on set tasks, and office sharing.

Effort was made to integrate clinical, research and development activities where appropriate, to enable each project component to feed into the other. For example, the research findings were used to shape the developmental activities, and the development arm helped to support the set up of research focus groups.

## Voluntary Sector Partners

Recognising the considerable role of the voluntary sector in supporting people with *long-term conditions*, the Living Better project worked in partnership with four key voluntary sector agencies throughout the life of the project: British Heart Foundation Scotland, Chest Heart & Stroke Scotland, Depression Alliance Scotland and Diabetes UK Scotland. The voluntary sector partners provided support and input into the project in a number of ways:

- Providing guidance and support through membership of the steering group;
- Facilitating the recruitment of patient representatives to the steering group;
- Writing and production of two patient information leaflets: *Diabetes and Mood* and *Heart Disease and Mood*;
- Providing guidance, advice and input into patient education courses;

- Providing information, leaflets and materials for Living Better exhibitions, training sessions and events;
- Presenting and representing the Living Better project at national events and conferences.

The good will and commitment to the project shown by key voluntary sector links helped to ensure that the needs and priorities of people living with *long-term conditions* were kept at the heart of Living Better's activities and priorities. Time constraints prevented these relationships being fully exploited however, and additional activities such as the production of a COPD and Mood leaflet were unable to be progressed.

## National Steering Group

The National Steering Group was made up of 33 representatives from the project's funders, voluntary sector partners, pilot sites, patient representatives and other key stakeholders. The National Steering Group met twice yearly over the lifetime of the project with the following objectives:

- To oversee the successful implementation of the project.
- To review progress on the key outcomes of the project.
- To provide advice, support and direction to the Executive Project Team.
- To inform strategic decisions relating to the project and share responsibilities concerning these decisions, and feedback on anything that may impact on the project.

The Steering Group benefitted from a multi-disciplinary membership with active patient involvement. Given its considerable size however, there were limits to the extent to which members could get involved in active project planning, and local pilot site representatives were not as able to be involved within the steering group as was hoped. A full membership list of the national steering group is available in Appendix One.

## Local Pilot Site Governance

### Reference group structure

Each of the five pilot sites (Angus, East Dunbartonshire, North Lanarkshire, South East Glasgow and Western Isles) set up reference groups to steer local activities. Membership of the reference groups varied from site to site, but was broadly made up of the following perspectives:

- Long-term conditions leads
- Representatives from participating GP practices (GPs, practice managers, practice nurses)
- CHP clinical lead
- Patient representatives
- Primary care mental health leads / managers
- Diabetes and / or Heart Disease Managed Clinical Network (MCN) Co-ordinators / Managers
- Voluntary sector organisations
- Representatives from the national Executive Project Team, usually the Project Officer, with input from Researcher and Strategic Lead as appropriate.

Each reference group was asked to nominate one or two key links, to act as a main contact point between the reference group and Executive Project Team (EPT) and represent the pilot sites on the National Steering Group. The designation of these key links varied from site to site and included CHP *long-term conditions* leads, primary care mental health leads and primary care development managers. The key link role worked most effectively when the individual(s) identified were senior enough to have good links within the CHP and an overview of local priorities and activities. It also proved more effective to identify two key links rather than just one, to compensate for turnover of staff through the lifetime of the project.

The Living Better Executive Project worked with the pilot sites to ensure a two way flow of information and good communication. National and local information sharing took place through site reports to National Steering Group, EPT representation on local reference groups and regular contact between the Project Officer and key links.

## How the reference groups worked

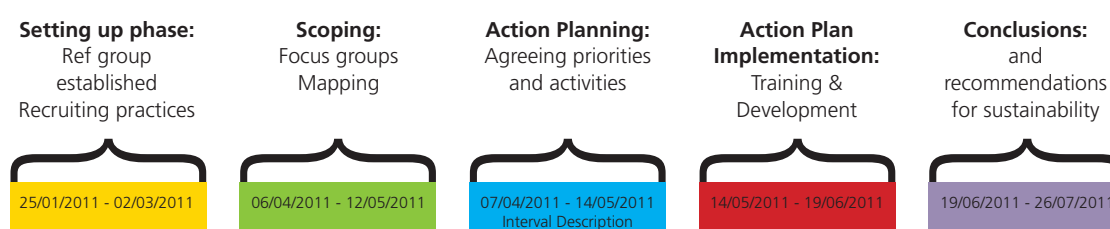
The role of the pilot site reference groups was to decide local pilot priorities, agree actions to address these priorities, review progress on implementing action plans and identify mechanisms for sustainability and roll out of learning from the pilots.

The reference groups generally met every two to three months throughout the pilot, supplemented by additional meetings with key links and / or sub group meetings as required.

To facilitate local ownership of the work, the reference groups were encouraged to agree their own frequency of meetings, set the agendas, chair meetings and where possible take their own minutes. The Project Officer provided input and support for these functions where required.

In responding to local needs and circumstances, the five Living Better pilots each developed individual activities and timescale, so that no two sites followed the same trajectory. However, all pilots consisted of the same five broad phases (see Diagram 2a below).

*Diagram 2a: Pilot site phases of activity*





Some pilots spent longer on particular phases than others, and details of each pilot site's activities are given in Chapter 2. To enable the reference groups to complete these phases, members of the EPT supported local pilot sites in a number of ways, including:

- Providing evidence about local needs.
- Supporting the development of action plans.
- Providing access to training and development.
- Helping to frame sustainability and roll out measures.

When reference groups worked well they showed:

- Good understanding and agreement of the needs to be addressed.
- Buy-in to the approaches agreed and commitment to implementing them.
- Active support from the GP practices involved.

When the reference groups worked less well this was due to:

- A lack of commitment at a suitably senior level to driving the work forward.
- Little local involvement in developing or delivering the proposed activities.
- Disagreements as to the best way forward.

It should be acknowledged however that no pilot site withdrew from the project, and all were able to complete the five pilot site phases.

### **Key Learning: Governance**

The Living Better project was governed at a national level by an Executive Project Team and supported by key voluntary sector partners and a wider National Steering Group. Five local reference groups steered the work of the pilot sites. Good relationships were maintained between the national and local structures via the key pilot site links in liaison with members of the EPT and through the National Steering Group meetings and local reference group meetings.

## APPENDIX 3: NATIONAL STEERING GROUP REMIT AND MEMBERSHIP

### Remit

The Project Steering Group will oversee the successful implementation of the project. It will receive update reports from the Project Officer/ Executive Project Team. It will review progress on the key outcomes of the project and provide advice, support and direction to the Executive Project Team. It will help to inform strategic decisions relating to the project and share responsibilities concerning these decisions, and feedback on anything that may impact on the project.

### Frequency of Meetings

Meetings will be chaired by the Chair of RCGP Scotland. Meetings will be held no less than every 6 months, more frequently if and when required. Meetings will be held in the offices of RCGP Scotland, 25 Queen Street, Edinburgh.

### Minutes of Meetings

Minutes sent to members within 14 days with actions highlighted. All members will provide an update of actions against their name no less than 14 days prior to next meeting.

### Membership

- I Dr Ken Lawton, Chair, RCGP Scotland
- I Professor Stewart Mercer, Project Clinical Lead, General Practice & Primary Care, Glasgow University
- I Ruth Wallace, Head of Devolved Councils, RCGP
- I Pippa Coutts, Scottish Development Centre for Mental Health, Project Strategic Lead
- I Professor Margaret Maxwell, University of Stirling, Project Research Lead
- I Amy Woodhouse, Scottish Development Centre for Mental Health, Project Officer
- I Dr Eddie Donaghy, Project Researcher, University of Stirling
- I Ilana Day, Depression Alliance Scotland
- I Andy Carver, British Heart Foundation Scotland
- I Anne Paris, Diabetes UK Scotland
- I Margaret Somerville, Director of Advice & Support, Chest, Heart & Stroke Scotland
- I Nigel Pacitti, Regional Manager (West), Mental Health Collaborative
- I Kevin Geddes, *Long-term conditions* Alliance Scotland
- I Professor Graham Watt, General Practice & Primary Care, Glasgow University
- I Shelley Gray, *Long-term conditions* Alliance Scotland
- I Elaine Hunter, Mental Health Division, Scottish Government

- I Kathleen Bessos, Scottish Government
- I Dr. Mini Mishra, Senior Medical Officer, Scottish Government Health Directorate
- I Patient Reps:
  - I Ross Kerr (Diabetes)
  - I Granville Solloway (CHD)
  - I Graham Bell (CHD)
  - I Irene MacDonald (Depression)
  - I Sue Kinsey, Chair, P3 (RCGP Scotland Patient Liaison Group)
  - I Sharlaine Walker, Planning Manager, Adult Mental Health, Angus
  - I Sylvia Verrecchia, Project Manager, Mild to Moderate Mental Health Project, NHS Lanarkshire
  - I Colin McCormack, Head of Mental Health Services, South East Glasgow CHP
  - I Peter Kaminski, Workstream Manager, NHS Greater Glasgow and Clyde
  - I Elaine Campbell, Western Isles CHP
  - I Pat Welsh, Western Isles CHP
  - I Gillian Notman, South East Dunbartonshire CHP
  - I Sean Doherty, Team Manager, Patient Safety and Performance Assessment Unit, NHS Quality Improvement Scotland
  - I Susanne Forrest, Programme Director: Mental Health, NHS Education for Scotland
  - I Euan Bailey, RCGP Scotland, Project Administrator

October 2010

## APPENDIX 4: LIVING BETTER DISSEMINATION EVENT

### Living Better Together: Learning from “The Living Better Project”

Living Better: Improving the mental health and wellbeing of people with *long-term conditions*

#### Programme

9:15	<b>Registration, Teas &amp; Coffees</b>
10:00	<b>Chair’s Welcome</b> <i>Dr Ken Lawton, Immediate Past Chair, RCGP Scotland (Chair)</i>
10:10	<b>The Scottish Context</b>
10:20	<b>Mental Health and Long-term conditions: The Evidence Base</b> <i>Professor Margaret Maxwell, University of Stirling</i> <i>Professor Stewart Mercer, University of Glasgow</i>
10:35	<b>A Patient Perspective</b> <i>Graham Bell, CHD Representative, Living Better Steering Group</i>
10:45	<b>Living Better—An Overview</b> <i>Amy Woodhouse, Living Better Project Officer, Mental Health Foundation</i>
11:00	<b>Break, Teas &amp; Coffees, Networking</b>
11:15	<b>Research and Evaluation Findings</b> <i>Dr Eddie Donaghy, Living Better Researcher, University of Stirling</i>
11:45	<b>Questions and Answer Session</b>
12:15	<b>Lunch &amp; Exhibitions</b>
13:15	<b>The Living Better Partnership: Sharing good practice</b> <i>British Heart Foundation Scotland, Chest Heart &amp; Stroke Scotland, Depression Alliance Scotland, Diabetes UK Scotland, LINKS Project</i>
14:00	<b>Workshops — Session 1 – Supporting Staff</b> <b>Culturally Sensitive Approaches for Primary Care</b> Exploring how to meet the mental health needs of people with long-term conditions from South Asian communities. <i>Dr Eddie Donaghy and Shazia Akhtar, Diabetes UK Patient Representative</i>

### **Signposting to Local Sources of Support**

Looking at the different social and community resources to support mental health and how to promote them to people with long-term conditions in primary care settings.

*Kevin O'Neill, Mental Health Needs Assessment and Service Development Manager, NHS Lanarkshire*

### **Effective Mental Health Screening and Assessment**

Exploring and overcoming barriers to discussions around mental health in primary care settings.

*Margaret Hart, Independent Trainer*

### **15:00 Break, Teas & Coffees, Networking**

### **15:15 Workshops — Session 2 – Supporting Patients**

#### **Self Management Approaches for Chronic Obtrusive Pulmonary Disease (COPD)**

Sharing experiences in setting up and delivering self management courses.

*Gillian Notman, Joint Occupational Therapy Lead Adviser, East Dunbartonshire CHP*

#### **Helping People Live Better with their Long-term conditions**

Exploring strategies to enhance emotional wellbeing.

*Margaret Hart, Independent Trainer, and Lynne Orrock, The Positive Pathways Project, Angus*

#### **The Potential for Social Networking**

Exploring the use of the internet to overcome stigma and geographical barriers.

*Chris O'Sullivan, Mental Health Foundation, and Elaine Campbell, Planning & Development Co-ordinator, NHS Western Isles*

### **16:15 Summing Up**

*Dr Ken Lawton, Immediate Past Chair, RCGP Scotland (Chair)*

### **16:30 Close**





# THE **LIVING BETTER** PROJECT

Improving the mental health and wellbeing of South Asian people with long-term conditions

## South East Glasgow Pilot Site Report

**March 2011**

# ACKNOWLEDGEMENTS

The Living Better Executive Project Team would like to thank members of the South East Glasgow Reference Group for their support to the project, in particular Colin McCormack and staff at the Keir Street practice for their support with and participation in the project's research and development activities. The Living Better project would like to thank the South Asian people who participated in and contributed to the focus groups. The Living Better project would also like to thank and acknowledge the support from Lee Knifton of the Mental Health Foundation (Scotland) and the valuable work of Ravina Naroo (Research Consultant for the Mental Health Foundation) in preparing and facilitating the South Asian focus groups. Living Better would also like to thank Dr Saima Ali from the University of Warwick for discussing her research on diabetes and depression in the Midlands involving the South Asian community and her advice on addressing depression in the South Asian community in the UK.

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## EXECUTIVE SUMMARY

Research internationally has established that depression occurs in about 20% of people with a *long-term condition* and is around 2 to 3 times more common in people with a *long-term condition* than in people who have good physical health (NICE, 2009).

The Living Better project was launched in 2008 as a three year, Scottish Government funded research and development initiative led by The Royal College of General Practitioners (Scotland) in partnership with The Scottish Development Centre for Mental Health / Mental Health Foundation and the Universities of Stirling, Edinburgh and Glasgow.

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 condition* across Scotland.

The Living Better project worked within 5 Community Health Partnerships (CHPs) and 7 General Practices across Scotland including Angus, East Dunbartonshire, North Lanarkshire, South East Glasgow and Western Isles. Each pilot site developed a **Reference Group** to steer the pilot and worked through a process of needs analysis, action planning, implementation and review to develop appropriate local responses to support the mental health needs of people with *long-term conditions*. In South East Glasgow Keir Street practice was recruited to support the implementation of the pilot. The South East Glasgow Living Better Reference Group decided to focus its activities on supporting the mental health needs of the local South Asian population because of the large South Asian community in the area and the higher rates of Diabetes and Coronary Heart Disease (CHD) found in this community.

**Focus groups** were undertaken with over 40 South Asian patients in South East Glasgow with a diagnosis of Diabetes and / or Coronary Heart Disease (CHD) and 12 Health Professionals. The following principle findings emerged from the focus groups:

- Living with diabetes and/or CHD can be both an acute and chronic stress for South Asian people
- The stigma of mental illness can make it difficult for many South Asian people to verbally express their emotional feelings regarding the stresses of living with diabetes and/or CHD
- South Asian people with a diabetes and/or CHD are, in the main, looking for support to help them live as socially active and fulfilling lives as possible.
- Many health professionals believed that addressing mental health and wellbeing in South Asians living with diabetes and/or CHD requires a wider strategic campaign linking with key South Asian community agencies to address the stigma of mental illness
- GPs, practice and specialist nurses lack the time to tease out emotional health issues with South Asian diabetes and/or CHD patients. The possibility of looking into South Asian, bilingual healthcare support workers providing empathetic support should be considered.
- The actual Quality and Outcomes Framework (QOF) questions and pre-questions are rather basic/crude and are seen by many, especially nurses as a 'tick box' exercise

**Quantitative patient surveys** were completed in person with 100 South Asian Diabetes / CHD patients registered at the participating practice. Survey responses indicated that:

- 45% of respondents had a HADS (Hospital Anxiety and Depression Scale) score which indicated depression and approximately half (49%) had a score registering anxiety
- Living with *long-term conditions* can affect peoples' outlook with only 22% feeling optimistic about the future and over half (62%) of South East Glasgow respondents feeling physically drained with no energy to spare.
- Half of South East Glasgow respondents replied that living with *long-term conditions* made them feel 'down' 'frustrated' and 'stressed' as a result of their condition.

In response to the issues raised in the focus groups and patient survey the South East Glasgow Living Better reference group developed an **action plan** which focused on improving access to mental health awareness and signposting information within the local South Asian community and developing the skills and knowledge of health professionals to undertake culturally sensitive mental health screening and assessments. The following activities were undertaken as part of the South East Glasgow action plan:

- A mapping of local culturally sensitive sources of support
- Mental health promotion at the Glasgow Mela
- Developing and delivering a half day culturally sensitive mental health training for health professionals who support South Asian patients with Diabetes

The following **recommendations** were made as a result of learning derived from pilot research and development activities:

- Promote positive mental health improvement messages within Glasgow's South Asian community with *long-term conditions* in appropriate and accessible ways
- Foster opportunities for peer support within the local South Asian community through health, social care and voluntary sectors
- Develop further links with UK academics, practitioners and patients to explore the means of undertaking culturally appropriate mental health assessments
- Improve signposting to local culturally appropriate sources of support

## 1. SOUTH ASIAN PEOPLE LIVING WITH DIABETES AND CORONARY HEART DISEASE

Ample evidence has been collected which shows that South Asians in the UK experience high rates of: (i) non-diabetic hyperglycaemia which carries a high risk of conversion to diabetes; (ii) Type 2 diabetes and its complications; and (iii) premature cardiovascular mortality and morbidity, at least partly as a consequence of diabetes (South Asian Health Foundation & Diabetes UK, 2009).

Numerous research studies have highlighted that South Asian people living in the UK experience higher rates of coronary heart disease (CHD) - between 40% and 60% higher compared with white indigenous UK communities. South Asians in the UK have a mortality rate from CHD approximately 40% greater than the UK general population (Kuppuswamy & Gupta, 2005; Bhopal et al, 2005).

Type 2 diabetes is up to four to six times more common in South Asian people than the general UK population. Whilst South Asian people make up just 4% of the total UK population, an estimated 8% of the UK population with diabetes is South Asian (Fischbacher et al, 2009; NRCEMH & SDG, 2004). In a recent Scottish study on diabetes in Tayside, 3% of white Scottish men had diabetes, compared with 10% of South Asian men. Among white Scottish based women, 2.4% had diabetes, compared with 9.8% for South Asian women. South Asians develop diabetes earlier in life, at lower levels of obesity, suffer longer with complications and have a subsequent higher mortality risk than their white UK counterparts (Department of Health, 2006; Chowdhury & Lasker, 2002). They are also more likely to have eye complications and higher blood sugar levels. It is not known why South Asians in Scotland may be more susceptible to diabetes but that genes, diet and lack of physical activity may play a role (Fischbacher et al, 2009).

In 2007 Diabetes UK Scotland and NHS Health Scotland published 'A guide to working with black and minority ethnic communities in Scotland living with long-term conditions'. The report noted that **'minority ethnic communities are among the most vulnerable to the impact of living with a long-term condition..... Scotland is now a multiracial society. Its increasing diversity provides a challenge for us all to deliver culturally appropriate and accessible services'** (Diabetes UK Scotland & NHS Health Scotland, 2007).

In the same vein Sheikh's BMJ editorial '*Ethnic minorities and their perceptions of the quality of primary care: Greater personalisation of care is needed*' noted that 'given the increased importance assigned to responsiveness and personalisation of care, the key practical message of this work (with ethnic minorities) is that practices need to identify and understand the priorities of their communities and tailor care accordingly' (Sheikh, 2009).

### Diabetes and Depression in UK South Asians

It is well established that depression is highly prevalent in people with *long-term conditions* and should be treated. Up to 33% of patients develop depression after a myocardial infarction [1] and meta-analysis has shown that depression is associated with a doubling of mortality in CHD

[2]. It is estimated that one in three patients with heart failure and one in five patients with CHD experience depression [3] Depression is also found in 30% of cases of diabetes [4]. Such 'co-morbidity' of physical and mental health problems are exacerbated by socio-economic deprivation such as exists in certain areas of Scotland [5,6].

In their recently published report earlier this year (2010) - *Emotional and Psychological Support and Care in Diabetes* - the Emotional and Psychological Support Working Group of NHS Diabetes and Diabetes UK reviewed research on inequalities in service provision experienced by BME communities in the UK. They reported that;

*Inequalities exist in access to healthcare and provision of emotional and psychological services, with some individuals and communities poorly served and seldom heard. Barriers to accessing services include experience of discrimination, inappropriate service delivery, inaccessible health information, low expectations (preventing or delaying access to healthcare), and a lack of cultural understanding among service providers.*

In research very relevant to the Living Better project, Ali et al (2009) recently published research aimed at determining the prevalence of depression in South Asian and White European people with type 2 diabetes and to assess the recognition of depression in Primary Care. A total of 862 adults with type 2 diabetes (562 South Asian and 300 White European) were screened for depression using the depression subscale of the Hospital Anxiety and Depression Scale. The researchers' concluded that depression is under-diagnosed in people with type 2 diabetes, most acutely in South Asians, suggesting a need to improve methods of detection.

The above research underlines the importance of improving communication between healthcare providers and patients when it comes to teasing out emotional and psychological issues, discussions regarding the aetiology and also the different treatment options for diverse populations with diabetes. It also raises important issues around the measurement of depression/anxiety disorders in the South Asian community.

The question of whether directly translated questionnaires summarise the same meaning as the English worded original has been the topic of much consideration and debate (Sartorius, 1994). As Birbilli (2000) notes, collecting data in one language and presenting the findings in another involves researchers taking translation-related decisions that have a direct influence on the validity of the research and the findings. Factors which affect the quality of translation in research of this kind include: the linguistic competence of the translator/s; the translator's knowledge of the culture of the people under study; the autobiography of those involved in the translation; and the circumstances in which the translation takes place. Consequently there is a need for social researchers who have to translate data from one language to another to be explicit in describing their choices and decisions, translation procedures and the resources used.

With this in mind, however, acceptable linguistic and conceptual equivalence has been demonstrated in the translation of the English version of the HADS into a South-Asian language, Urdu, by Mumford et al (19991), which was shown to be reliable and valid measure of depression and anxiety. When Lane et al (2007) conducted research study among Punjabi speaking CHD and diabetes patients in the Midlands to translate and validate the Hospital Anxiety and Depression Scale (HADS) into Punjabi, they concluded that the Punjabi HADS is an acceptable, reliable and valid measure of anxiety and depression among physically ill Punjabi speaking people in the United Kingdom.

### **Psychosocial Factors, CHD and UK South Asians**

Williams et al (2009) assessed psychosocial profiles of 1130 South Asian and 818 white European healthy men and women aged between 35 and 75 years, who had previously participated in a cardiovascular risk assessment programme in London. Using standardised questionnaires Williams et al assessed psychosocial factors potentially contributing to CHD risk and found that UK South Asians had

- (i) Considerably higher psychosocial hardship when compared with UK whites;
- (ii) South Asian men and women experienced greater chronic stress, in the form of financial strain, residential crowding, family conflict, social deprivation and discrimination, than white Europeans;
- (iii) Whilst South Asians had larger social networks, they reported lower social support and greater depression and hostility;
- (iv) These effects were in the main independent of socioeconomic status.

These findings are important in the context of the Living Better project given that the provision of emotional and psychological treatment and support has been found to reduce psychological distress and improve health related outcomes particularly in relation to *long-term conditions* such as CHD (Ethnicity and CHD: Race Equality Foundation, 2010).

### **CHD, Cardiac Rehabilitation, Equity of Access and South Asians**

People living with CHD require long-term support. Research has shown that cardiac rehabilitation can potentially improve health and is cost-effective, especially when integrated with other services provided in community and hospital settings. Programmes vary, but generally consist of education and supervised exercise to help people recover from CHD. According to the National Service Framework for CHD (DH, 2000), every eligible person admitted to hospital with CHD should be invited to attend cardiac rehabilitation before they go home. However, less than half the people entitled to cardiac rehabilitation receive it and the majority who do are 'white' males. This leaves minority ethnic groups such as South Asians under-represented in receiving cardiac rehabilitation (British Heart Foundation, 2009).

## Stigma and Mental Health in UK South Asians

The stigma around mental illness is seen as especially strong in South Asian communities. In 2008 Health Scotland initiated an extensive literature review and scoping exercise with Black and minority ethnic groups on perceptions of mental wellbeing in Scotland which noted;

*One conclusion that could be drawn from this scoping exercise is that mental wellbeing is being conceptualised in terms of the absence of mental illness. However it was clear that mental wellbeing means much more than this. The conceptualisation of mental wellbeing that has emerged from this initial analysis has three critical dimensions - **interconnection with physical health; interconnection with social and family wellbeing and interconnection with spiritual wellbeing.***

## 2. ABOUT LIVING BETTER

The Living Better project was funded by the Scottish Government in response to these issues. It was a three year initiative (2008-2011) led by the Royal College of General Practitioners (Scotland) in partnership with the Mental Health Foundation (incorporating the Scottish Development Centre for Mental Health) and the Universities of Stirling, Edinburgh and Glasgow.

The project had the following 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 (CHD), Diabetes or Chronic Obstructive Pulmonary Disease (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 Partnerships' responses in terms of flexibility, communication, and shared learning
- To strengthen partnership working within the CHPs
- To share the learning across Scotland

The Living Better project worked within 5 Community Health Partnerships (CHPs) and 7 General Practices across Scotland each addressing specific *long-term conditions*:

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

Each pilot site worked through a process of needs analysis, action planning, implementation and review to develop appropriate local responses to support the mental health needs of people with *long-term conditions*.



### 3. SOUTH EAST GLASGOW CHCP

For the majority of the life of the Living Better pilot local health services in Glasgow were managed by six Community Health and Care Partnerships. The Living Better pilot took place in South East Glasgow CHCP, which covers a diverse area of Glasgow City. Data from the 2001 census indicates that the area has a population of approximately 101,476 but the 2004 estimate gives a total of approximately 113,695 and it is acknowledged that there has been a significant incoming population over recent years both in terms of asylum seekers and refugees but also in respect of nationals from the new European accession states.

Whilst having areas of affluence, South East Glasgow also contains significant areas of deprivation. Over 29% of the local area within the CHCP falls within the 15% most deprived in the health domain on Scottish Index of Multiple deprivation (SIMD 2009). Certain postcode areas of South East Glasgow have as many as 66% of the population permanently sick/disabled, unemployed or low paid and with long-term illnesses such as diabetes and/or Coronary Heart Disease (CHD). South East Glasgow has the one of the lowest life expectancy rates in the West of Scotland, with both South East Glasgow and Greater Shawlands well below the Scottish average. Life expectancy is one of the key indicators of health status. There are currently 30,842 people (30%), within the area, who have registered with a *long-term condition*.

South East Glasgow also has the highest concentration of Black and Ethnic Minority (BME) communities in Glasgow with 11.6% of people in the South East coming from a Black and Minority Ethnic background, this is also the largest Black and Minority Ethnic community in the whole of Scotland.. The black and minority ethnic communities are found in high concentrated numbers within particular postcodes, notably; East Pollokshields which has 46% of its residents recorded as being from a black and ethnic minority background; 22.25% of Crosshill residents are from minority ethnic groups, with similarly high figures for Strathbungo (37.6% of the population), Dumbreck (28%) and Govanhill North (13.2%) (South East Glasgow CHCP Health Improvement Plan 2006-07).The majority of South East Glasgow's BME communities are South Asians, mainly Pakistani.

## 4. ABOUT THE SOUTH EAST GLASGOW PILOT

South East Glasgow was identified a possible Living Better pilot site by the then Head of Mental Health for South East Glasgow CHCP. It was recognised that the locality had some considerable resources to draw on, such as STEPS, the local primary care mental health team, but also had some particular challenges to face due to its high levels of deprivation. It was also recognised that more could be done to meet the mental health needs of the local South Asian community, particularly those who were living with *long-term conditions*.

The reference group convened for the first time in March 2009 and met regularly throughout 2009 and 2010. Prior to the change of structure to CHCPs in October 2010 the reference group was led locally by the Head of Mental Health for the CHCP with membership from the MCN Manager and co-ordinators for Greater Glasgow & Clyde, the Mental Health Collaborative, health inequalities pharmacist, primary care development, the CHCP clinical lead and patient reps. Identifying participating practices proved a particular challenge in South East Glasgow, and it was not until late spring 2009 that the Keir St practice came on board. It was agreed in early 2009 that the pilot would focus on supporting the needs of the South Asian community

Table 1: South East Glasgow overview

Phase	Activity	Date
1. Setting up	Reference group convened & GP practices recruited	September 2008 – Jun 2009
2. Scoping phase	Reference group development day Patient & Staff focus groups	November 2008 – March 2010
3. Action planning	Developing South East Glasgow Action Plan	December 2009 - March 2010
4. Action plan implementation	Mapping Staff training Awareness raising	March 2010 – October 2010
5. Quantitative Data Collection	Patient survey Clinical Audit	October 2010
6. Final report	Final report & dissemination meeting	March 2011

## 5. RESEARCH FINDINGS 1 – FOCUS GROUPS

### 5.1 Patient Focus Groups: Gathering information from South Asian People living with Diabetes and / or CHD

In South East Glasgow, given the high proportion of South Asians living in areas like Pollockshields and Govanhill, and the high rates of diabetes and CHD in this community the Living Better reference group made a decision to focus pilot activities solely on the needs of the South Asian community with *long-term conditions*.

Four separate focus groups were organised with Muslim males, Muslim females, Hindu/Sikh males, and Hindu/Sikh females and attended by 40 people with diabetes and/or CHD. These focus groups were facilitated by a multilingual South Asian researcher experienced in conducting research on mental health issues in the South Asian community.

**Key aims of the focus groups were to discuss:** (i) *What is it like to live with diabetes and/or CHD;* (ii) *how does it affect the person, their family & lifestyle;* (iii) *what is the impact of the condition on peoples' mental health & wellbeing and* (iv) *what type of support do they want to help live with the condition?*

A full report of the South East Glasgow focus group findings and discussion was completed last year is available at [www.livingbetter-scotland.org.uk](http://www.livingbetter-scotland.org.uk).

#### Summary of Key Focus Group Findings

Three principle findings emerged from the focus groups:

- Living with diabetes and/or CHD can be both an acute and chronic stress for South Asian people
- The stigma of mental illness can make it difficult for many South Asian people to verbally express their emotional feelings regarding the stresses of living with diabetes and/or CHD
- South Asian people with a diabetes and/or CHD are, in the main, looking for support to help them live as socially active and fulfilling lives as possible. As such they are looking for Level 1 and Level 2 social support to both prevent and alleviate the stresses of living with diabetes and/or CHD, although a significant number did want counselling.

#### Types of Support Most Commonly Discussed as Helpful in the Focus Groups were;

- **Emotional support:** people to show understanding and appreciation of the effects of living with a *long-term condition* - confiding
- **Informational support:** helping the person understand their illness better and in particular how to access available resources and coping strategies to help self-manage their condition
- **Assistance and Practical Support:** information about services that enable them to be socially active & pursue activities beneficial to their physical and emotional wellbeing
- **Peer support:** sharing experiences and information with people with the same condition – empathy.
- **Religious Support-** for many Sikhs, Hindus and Muslims – especially men- their religious beliefs were a source of strength and support in living with diabetes and/or CHD.

## Summary of Mental Health Issues highlighted in South Asian Patient Focus Groups

Living with diabetes and/or CHD is both an Acute & Chronic Stress and Impacted on South Asian Focus Group Participants in the following ways:

**Impact and Stigma of Diabetes:** Despite knowing the high risk of developing diabetes and knowing family and friends with the condition, the shock of being diagnosed with diabetes was often very profound.

A diagnosis of diabetes can occasionally be perceived as a source of individual and/or family shame and can be perceived as negatively affecting existing marriage or potential marriage arrangements. In the health professional focus groups GPs, Nurses and Community workers spoke of their occasional experiences of some South Asian people attempting to hide their diabetes from husbands, families and the wider communities. This could cause serious physical and emotional problems.

Living with diabetes and/or CHD puts a significant strain on family relationships, especially in the opinion of South Asian women who have diabetes and/or CHD.

Despite the widely held perception that the South Asian extended family provides unconditional and strong support in the face of life stresses, not all women participants stated that families were unconditionally supportive in living with the stresses of diabetes and/or CHD.

**Having diabetes and/or CHD can Increase Social Isolation:** For South Asian women in particular, living with diabetes and/or CHD can result in significant isolation in the home making it difficult to impart holistic, 'healthy lifestyle messages'.

Being socially isolated in their homes increased the risk of South Asian women in particular '*feeling down*' and negatively impacted self-managing their diabetes and/or CHD. Problems with accessing child care support increased social isolation of South Asian women.

**Stigma of Mental Illness:** Whilst the impact of COPD, diabetes and/or CHD caused emotional problems for South Asian participants, the stigma of mental illness was a barrier to talking about their distress and seeking help for emotional distress. In the Health professional focus groups 'masked' or 'hidden' depression in South Asians was often referred to.

### **The Need to Provide Services as Locally as Possible/The Importance of Transport:**

Unless services to help living with COPD, diabetes and/or CHD were provided in their local neighbourhood, South Asian women in particular were often unlikely to access such services, unless transport could be provided.

**Positive Patient Experiences:** These arose when (i) Health care professionals were bilingual, understood the patient's cultural, family and religious circumstances and provided health care advice with these factors in mind; (ii) Health care professionals provided medication when

requested, discussed the details of patient's should manage their medication and adapted treatment to the individual patient's cultural, religious and family's needs and circumstances.

**Negative Patient Experiences:** These arose when (i) Health care professionals could only speak English; (ii) Health care professionals showed a lack of cultural and religious awareness when discussing lifestyle change and patient self-management of diabetes and/or CHD.

**Language Problems** a lack of interpreting made it difficult for some patients to accurately articulate their physical/emotional/social problems, this negatively impacted on their ability to get appropriate guidance in managing their condition. Language problems negatively impacted on patients' abilities to access appropriate health care and comply with professional advice.

**The Importance of Social Support:** Older participants in all 4 focus groups spoke of the benefits of community support groups such as lunch clubs. South Asian men were far more likely to participate in exercise support groups which, they stated, were not only helpful to their physical health but equally important in that the twice weekly classes enabled them to strengthen their social networks and social bonds, providing opportunities to '*get out of the house*' and '*meet friends*' and '*just talk about life*'.

The participants in the 2 male patient focus groups were overwhelmingly older South Asians males aged 65 years and over and this should be borne in mind when interpreting these key findings.

South Asian women expressed a preference for more confidential one to one confiding support with a bilingual health care professional or confidant fluent in Urdu/Punjabi/Hindi to talk about emotional stresses of living with diabetes and/or CHD.

**The Importance of Providing Gender Appropriate Support Groups:** Some South Asian Health Professionals stated that based on their experiences South Asian women would attend support groups but they would (a) have to be easy to access, either very local or with transport provided; (b) be women only and facilitated by female South Asian bilingual support workers who understood cultural and religious norms and values.

**The Importance of Religious Faith in Living with Diabetes and/or CHD:** South Asian Muslim males in particular spoke positively of the benefits of their religious faith in living with diabetes and/or CHD. A number believed the prognosis of their illness was in 'God's hands'. South Asian Muslim males in particular expressed a desire for greater recognition of their religious faith within health services and improved opportunities to pray at all hours of the day when using health services.

Both men and women with diabetes and CHD spoke of the strain of having to take numerous medications which they believed had a negative impact on how they functioned socially and felt emotionally, visits back to Pakistan or India could result in disruption to medication intake.

## Types of Support South Asian People Wanted/Needed to Help Ease the Stresses of Living with diabetes and/or CHD

**The Importance of Gender, Religion and Culture in Influencing Support:** There was a gendered influence as regards the type of support people wanted in helping to ease the strains of living with diabetes and/or CHD

For South Asian males, no desire was expressed for services to address emotional wellbeing. Existing broad social support services – Levels 1 & 2, e.g., support classes (exercise class, general talking support group) to share experiences exchange information were seen as desirable.

For South Asian men these support groups such were good for mental wellbeing and mental health. They *'take our mind of thinking about the illness', 'get us out the house', 'help forget about the condition', 'provide opportunity to share experiences'*.

South Asian women had a preference for one to one confiding support from a health professional or, if in significant distress a counsellor. Ideally this would be bilingual so the person could express true emotional feelings in language they were most comfortable with.

A few women spoke privately (not in the full focus group) of the positive benefit of attending *Amina* a local community support group which helps women with social isolation, emotional problems and links with other culturally acceptable Islamic/South Asian organisations.

South Asian women who did express interest in support groups wanted them to be very local, women only, be held at appropriate times, have bilingual support workers and respect cultural norms. More support with childcare would help South Asian women's participation in support groups.

**More time with bilingual health professionals** with experience and knowledge of (i) gendered social roles; (ii) the importance of religion, family and culture in South Asian communities so that advice on medication regimes and lifestyle change was practical, culturally appropriate and therefore realistically achievable. Opportunity to confide in a bilingual culturally sensitive female health worker over the telephone

Some women spoke of the positive benefits of attending local dietary class facilitated by GGHB which provided advice and guidance on diet for people living with diabetes and/or CHD.

## 5.2 Health Professional Focus Groups

Two focus groups with health professionals working in *long-term conditions* across primary care were held in South East. These were attended by 12 health professionals including Practice nurses, Specialist nurses, *Long-term condition* planners, Mental Health planners, and Health Improvement staff.

## Key Findings from Health Professional and Reference Group Focus Groups

Health professionals believed there has been significant progress in addressing mental health and wellbeing in people with *long-term conditions* in South East Glasgow following the formation of the CHCP which has helped develop partnership working between health services and local authority services particularly through the work of STEPS.

Whilst a range of Health professionals described STEPS as 'outstanding', and 'doing a terrific job' some wondered if it was sufficiently culturally sensitive for South Asians, especially women.

### Limitations of QOF Screening Questions

Whilst the introduction of the two QOF questions asking patients about their emotional feelings were seen as a step forward, a number of health professionals believed they were quite inappropriate for addressing mental health issues in UK South Asians because (i) they were a bit like a 'tick box exercise'; (ii) the questions were too basic; (iii) they came too late into the consultation especially with diabetes patients who required a lot of physical checks and (iii) patients would often reply 'fine' because of the stigma of mental illness.

Some health professionals believed more work has to be done to raise awareness of concepts of emotional health and wellbeing in South Asians in health and social care professionals working with South Asian diabetes and/or CHD patients.

GPs, practice and specialist nurses lack the time to tease out emotional health issues with South Asian diabetes and/or CHD patients. The possibility of looking into South Asian, bilingual healthcare support workers providing empathetic support should be considered.

Not all primary care staff working with people with diabetes and/or CHD (and *Long-term conditions* generally) know about all of the services that exist in the community so sometimes patients are not referred.

Services have to be delivered as locally as possible as South Asian patients generally unwilling to travel out-with their own areas. More detailed mapping exercises required on appropriate ethnic minority services for people with diabetes and/or CHD in South East Glasgow CHCP.

More support services for people with diabetes and/or CHD should be provided out-with clinical settings to foster a more holistic environment.

A programme of South Asian mental health awareness raising is required to give health care staff, especially nursing staff, the confidence to address emotional issues in South Asian people with diabetes and/or CHD.

Nurses aren't being asked to providing counselling for these patients, any advanced mental health role should involve self-help coaching and be protocol driven but not counselling or therapy.

One to one telephone support and/or group support classes should be considered and/or made more widely available with input from health care support workers/paraprofessionals.

## Key Learning from Engagement with Health Professionals:

- **Strategic Need to Address Stigma of Mental Illness** – Many health professionals believed that addressing mental health and wellbeing in South Asians living with diabetes and/or CHD requires a wider strategic campaign linking with key South Asian community agencies to address the stigma of mental illness.
- **Need for Prepared, Informed, Proactive Primary Care Staff** – There is a need to proactively target South Asians living with diabetes and/or CHD and their carers and (i) on diagnosis explain the risks to their mental health and wellbeing that the stresses of living with diabetes and/or CHD can cause; (ii) how to prevent these stresses developing into serious risks to their mental health and wellbeing and (iii) what to do if these stresses begin to cause emotional distress and/or feelings of anxiety and depression
- **Concern over QOF Screening Questions** – for many staff, especially primary care nursing staff, the QOF screening questions were seen as (i) a ‘tick box’ exercise quickly asked at the end of the annual or 6 monthly review; (ii) because of time pressures many were concerned they may be ‘opening Pandora’s Box’ by asking these questions but don’t have the time to properly address the patient’s emotional issues; (iii) some nurses expressed lack of confidence in addressing mental health issues and would like training to improve their skills in this area.
- **Nurse Training** – There is a requirement to provide Primary Care Nursing Staff with skills knowledge and confidence to address mental health and wellbeing issues in South Asians with diabetes and CHD more effectively than simply asking the two QOF depression screening questions. Cultural and religious awareness training was seen as important.
- **Greater Enablement and Improved Signposting of Local South Asian Support Services for GPs and Nurses** – of local South Asian social support services to share data for appropriate services for South Asians living with diabetes and/or CHD to live as socially active lives as possible. Consequently, information on the following are important – Transport, Leisure, Exercise, Diet, Benefits/Financial advice, *Long-term conditions* Support Groups, access to Voluntary Sector agencies that provide guidance and information on self-management such as Diabetes UK, Chest Heart & Stroke and British Heart Foundation.
- **Improve Partnership Working** between CHPs, GP Practices, Local Authorities and Voluntary Sector Agencies to support an integrated system of care and support in local communities for South Asians living with diabetes and/or CHD.



## 6. RESEARCH FINDINGS 2 – PATIENT SURVEY

To quantify our focus group findings and assess mental health & wellbeing of people on Diabetes and CHD Registers the Living Better project undertook a structured patient survey across the 5 pilot sites. The survey collected data on the following

- Depression and Anxiety using Hospital and Anxiety Depression Scale
- Work & Social Adjustment using the Work and Social Adjustment Scale
- Mental Wellbeing using the Warwick-Edinburgh Mental Wellbeing Scale
- Data on DEPCAT, Multi-morbidity, Household Circumstances, Employment
- Piloting Complexity Tool (assessing social determinants health)
- Range of emotional feelings living with their particular illness
- Type of support people wanted to help live with their illness

In the other 4 pilot sites people on Diabetes and CHD Registers in 2 participating GP practices were randomly selected and received a joint letter from the GP practice and Living Better inviting them to take part in the a postal structured questionnaire survey.

A review of recently published research on addressing depression in the south Asian community (Ali, 2009) and discussions and correspondence with researchers in England currently conducting research on mental health and wellbeing in South Asians with diabetes indicated that response rates to postal structured questionnaires would be poor if we adopted this approach in South East Glasgow. Following the research in England Living Better decided to conduct the patient survey face to face using a bilingual researcher experienced in conducting research on mental health issues in the South Asian community. The same person who facilitated our focus groups conducted the face to face patient survey in Urdu, Punjabi and Kashmiri.

There are clearly methodological issues that have to be addressed in adopting this approach, not least the possibility of bias, (time precludes addressing all the issues in this report) but after discussions with researchers in England we decided this approach would be more favourable than using a postal survey to gather data from South Asian people with diabetes and/or CHD.

A target of 100 patients in total from the diabetes and CHD registers was set, 50 from each register. These patients were randomly selected from the register and phoned from the participating GP practice asking if they would be prepared to participate in the survey. A total of 160 separate individuals were contacted and 100 agreed to participate, giving a very high **response rate of 62%**.

The questionnaire was completed face to face in Urdu, Punjabi or Kashmiri by a trained mental health researcher. We used a Punjabi and Urdu translated version which has been validated in other depression/anxiety studies involving South Asians (Ali et al, 2009). Recent research by Ali compared the prevalence of depression in South Asians with diabetes with White European people with the same condition. She conducted her study in 14 general practices in the U.K. and used the

Hospital Anxiety and Depression Scale (HADS) to measure symptoms of depression. Dr Ali reported significantly higher rates of mild levels of depressive symptoms in South Asians compared with White Europeans. A number of factors may influence whether South Asian people are diagnosed with depression, including culture and the somatic presentation of symptoms.

One of the most interesting findings from Ali's research was the extraordinarily high rates of unrecognised depression. Overall 83% of those taking part in her study who had moderately severe (and therefore clinically significant) levels of depression had not been diagnosed or treated by their G.P. These rates were much higher in South Asians (90% unrecognised) with diabetes compared to their White European counterparts (63% unrecognised). As Dr Ali commented, these findings have serious implications for practice and for the care of South Asian people with diabetes. These disparities in identification and treatment need further investigation.

#### ***Key patient survey findings:***

##### **Age Range**

The age range was as follows **54 years and under (29%); 55 – 64 years (30%); 65-74 years (28%) 75-84 years (13%). South Asians develop diabetes and heart problems at a younger age than White people in the UK.**

##### **Multi-Morbidity**

Levels of multi-morbidity were high in the South Asian respondents with more than half, **52%, living with two or more long-term conditions.** A significant proportion of people with diabetes also had CHD and vice versa and for this reason we have combined the scores for diabetes and CHD.

##### **Screening Levels of Depression and Anxiety by HADS**

The Hospital Anxiety Depression Scale is a validated, commonly used screening tool often used by doctors, nurses and a range of therapists to assess levels of anxiety and depression. It should be emphasised that self-assessment scales such as HADS are only valid for screening purposes and confirmation of depression and or anxiety must rest on the process of clinical examination (Snaith, 2003). The HADS comprises statements from a list of four options which the patient is asked to assess based on their experience of the past week. There are 14 statements; 7 relevant to feelings associated with anxiety and 7 to feelings linked with depression. Responses are scored from 3 to 0. There are 4 ranges; normal 0-7; mild (8-10); moderate 11-15; and severe 16-21 (Zigmond & Snaith, 1983). We used an Urdu/Punjabi version which has been validated in research studies involving South Asians.

##### **HADS Screening Scores for Depression and Anxiety**

The HAD scores for people who responded to our postal questionnaire indicated that **45% of respondents had feelings associated with depression, and almost half (49%) with a score registering anxiety.** This is at the levels associated with depression/anxiety and *long-term conditions* as outlined by NICE in their 2009 guidelines. A majority of people who did register

as being at risk tended to score on the mild scale. Research indicates that even feelings of mild depression when unaddressed, especially in people with *long-term conditions*, can lead to the development of moderate to severe depression (Haddad, 2009). Twelve month prevalence rates of depression in society in general are between 3% and 10%. In people with a *long-term condition* these rates are rates 2-3X higher (NICE Guideline Depression in adults with a Chronic Physical Health Problem: Treatment and Management, 2009).

Scores for depression amongst South Asian respondents were significantly higher when compared with White Scots in the other 4 CHPs.

Table 2: HADS Depression Scores

Depression Score	None	Mild	Moderate	Severe
South East Glasgow	55%	21%	15%	9%
All 5 CHP Sites	68%	17%	11%	4%

Table 3: HADS Anxiety Scores

Anxiety Score	None	Mild	Moderate	Severe
South East Glasgow	51%	22%	20%	7%
All 5 CHP Sites	58%	22%	14%	6%

## WEMWBS

WEMWBS (Warwick-Edinburgh Mental Wellbeing Scale) is a 14 item reliable and validated scale of mental wellbeing covering subjective wellbeing and psychological functioning, in which all items are worded positively and address aspects of positive mental health. The scale is scored by summing responses to each item answered on a 1 to 5 Likert scale. Responses are made on a 5-point scale ranging from 'none of the time' to 'all of the time'. The minimum scale score is 14 and the maximum is 70 (Stuart-Brown & Janmohamed, 2008).

Once again WEMWBS scores are important in the context of Living Better as they give a general picture of that's individual person's general mental wellbeing. WEMWBS aims to measure mental wellbeing itself and not the determinants of mental wellbeing. It is not designed to identify people who have or probably have a mental illness. We present two responses which indicate how living with a long-term condition impacts on people's mental wellbeing. One is asking people to grade their responses to the statements 'I've been feeling optimistic about the future' and 'I've had energy to spare'.

Responding to the statement '*I've been feeling optimistic about the future*' one quarter selected the options 'none of the time and rarely'. Approximately half of respondents replied none of the time/rarely to the statement 'I've had energy to spare'.

Optimism and energy are two important factors to a person's mental wellbeing. That such high numbers responded this way indicates how living with a long-term condition is linked with negative mental wellbeing.

Table 4: WEMWBS Score- Question 1 – 'I have been feeling Optimistic about the Future'

Score	None of the Time/Rarely	Some of the Time	Often/All the Time
South East Glasgow	22%	29%	41%
All 5 CHP Sites	25%	36%	39%

Table 5: WEMWBS Score- Question 5 – 'I Have Energy to Spare'

Score	None of the Time/Rarely	Some of the Time	Often/All the Time
South East Glasgow	62%	21%	18%
All 5 CHP Sites	51%	29%	20%

## Measuring the Impact of Long-term conditions on Work and Social Functioning: The Work and Social Adjustment Scale

Collecting data on patients' perspectives concerning impaired social functioning provided important data in attempting to understand the impact that living with *long-term conditions* has peoples' mental health and wellbeing. The Work and Social Adjustment Scale (WASAS) – see appendix- is a simple, reliable and validated assessment of impaired functioning and can provide valuable insight into how in the impact of living with *long-term conditions* (Mundt et al, 2002). People are asked to score work and social activities and how their illness affects them on a score from 0 (no affect) to 9 (very severely affected). A WASAS score below 10 indicates little effect on work and social functioning or as it is often referred to 'sub-clinical') a score between 10 and 20 indicates that that person's work and social functioning are significantly affected (or as often referred 'significant functional impairment'); a score above can 20 indicate an association for increased risk of mental health problems such as depression and anxiety.

The scale is not a mental health assessment tool in and of itself but it is commonly used in mental health studies to help understand people's immediate social situation re: their work, home life and social activities. A majority of our respondent's were retired and therefore the impact on their formal employment would be limited. This scale is a good indicator of providing data on what was discussed earlier, the impact of *long-term conditions* to people's lifestyles and personal relationships which in and of themselves can be stresses linked with depression and anxiety. As noted below scores for the WASAS scores for the impact on peoples' social and leisure activities were especially high.

Based on the Work and Social Adjustment Scale, in South East Glasgow almost one quarter of respondents were scored as having an association for increased risk of mental health problems such as depression and anxiety, whilst nearly half scored as having their social functioning significantly affected.

Table 6: Work and Social Adjustment Scale

WEMWEB Scores	Little Effect on Work or Social Functioning	Work and Social Functioning Significantly Affected	Association for Increased Risk of Mental Health Problems such as Depression and Anxiety
South East Glasgow	28%	26%	48%
All 5 CHP Sites	42%	23%	35%

## Everyday Feelings Experienced as a Result of Living with Main Condition

In the thematic analysis of focus group data, a number of common descriptions emerged that people used to describe what it was like to live with a *long-term condition*. People very rarely if at all used words like depression or to a lesser extent anxious. People with a *long-term condition* who attended the focus groups used a range of everyday terms. In a section of the structured questionnaire used to collect demographic data on age, multi-morbidity and type of supports wanted to live with these conditions, respondents were asked to select from a range of these everyday descriptions to reflect how living with a *long-term condition* affected how they felt emotionally. They could choose from a list of 10 options and select one or more or none. The most common selected are shown below.

Of those responding more than half found living with their *long-term condition* made them frustrated, 'feeling down' and stressed.

Table 7: Main Feelings as a Result of Living with COPD

Main Feeling	Frustrated	Feeling Down	Stressed	Socially Isolated	Frightened	Family Tension
South East Glasgow	52%	51%	54%	32%	31%	19%

Respondents were asked to select from a list of 12 support options that featured most prominently in the focus groups when we asked people with long-term conditions what type of supports they would like to help them live with their condition (see Table 7).

Table 8: Type of Support Wanted to Help Live with Main Condition

Type of Support Wanted	Exercise Class	Help with transport to Get Out More	More Time with Nurse	Regular Access to Friends	Counselling
South East Glasgow CHCP	31%	38%	12%	23%	17%

### Key Observations from Patient Survey

- South Asian people in South East Glasgow who participated in the Living Better patient survey had worse mental health and wellbeing than the other 4 Living Better CHP sites
- The patient survey did identify that a significant proportion of the South Asian participants screened positively for mental health and wellbeing problems commonly linked to living with *long-term conditions*.
- Whilst the HADS scores of Mild/Moderate/Severe are not a clinical diagnosis of depression and anxiety rather they are indicators, nonetheless the scores in South East Glasgow suggests that a high proportion of respondents experience feelings strongly associated with depression and anxiety.
- 45% of South East Glasgow South Asian respondents scored Mild/Moderate for Depression on HADS
- 49% of South East Glasgow South Asian respondents scored Mild/Moderate for Anxiety on HADS
- Living with *long-term conditions* can affect peoples' outlook with one quarter of South East Glasgow South Asian respondents rarely feeling optimistic about the future and over one half feeling physically drained with no energy to spare.
- Over one half of South East Glasgow South Asian respondents replied that living with *long-term conditions* made them feel 'down' and 'frustrated' and 'stressed' as a result of their condition.
- It would appear that South Asian people are more prepared to record feelings of emotional distress linked with their *long-term condition* anonymously or privately than publicly in an open forum such as a focus group.

### Key Observations on Support Wanted

- As with the focus group findings, the patient survey findings indicate that of South East Glasgow South Asian respondents were looking for support to help them maintain as active a social life as possible and help with self-management of their condition rather than seek extra support from formal NHS services.
- Especially popular were light exercise and breathing classes to help peoples' physical conditioning, pulmonary rehabilitation and COPD general support group to help provide empathy and informational support about the best ways of living with COPD

## Key Learning from Patient Engagement

People Living with *Long-term conditions*:

- (i) Find it stressful physically, socially, and emotionally but can find it difficult to talk openly about their emotional distress other than with a GP if they have the time or with a Nurse if they know them well.
- (ii) Can find it difficult to talk openly about the impact it has on their mental health & wellbeing –but in private are more prepared to register feelings that indicate negative mental wellbeing e.g., ‘*feeling down*’ or more stress related feelings such as ‘*frustrated*’ or simply ‘*stressed*’.
- (iii) Are looking for services to empower them with knowledge about their illness & information to help them be socially active citizens and to help with self-management of their condition.
- (iv) Both the patient focus group and patient survey data indicate that people living with a *long-term condition* find levels 1 and 2 social support important both in the context of buffering the stresses associated with living with *long-term conditions* but also in terms of helping to alleviate these stresses and negative emotional feelings as they occur.

## Depression in South Asian Communities in the UK

Given the cultural and religious differences within UK South Asians compared with UK whites it has been widely argued that the presentation of mental illnesses such as depression will differ from white indigenous communities (Krause, 1989). Bowl and Barnes (1991), on the basis of growing numbers of second generation South Asians being born, acculturated and socialized in the UK, argued that the recognition and presentation of mental illnesses like depression could in time become similar to the white indigenous population. Evidence for this standpoint was suggested by Howlett et al (1992) in their investigation of white, South Asian and Afro-Caribbean peoples’ concepts of health and illness causation. They found that South Asians gave similar responses to the other groups to questions as to whether worry, stress and tension were causes of depression (54% South Asian, 51% white, 58% Afro-Caribbean). Other studies have also reported that South Asians acknowledge worry and stress to be significant factors in mental illness (Donovan, 1984). A commonly held view across a range of health and social care services suggests that a reluctance of older, first generation South Asians to access UK services mental health services reflects beliefs and cultural traditions more attuned to non- westernized traditional beliefs of their country of origin.

When Bhui et al (2006) assessed the prevalence of depression in Punjabi primary care attenders in England by examining the role of culture, physical illness and somatic symptoms they noted that previous studies exploring the prevalence of depression among South Asians reported inconsistent findings. They argued that research arte-facts due to sampling bias, measurement errors and a failure to include ethnographic methods may all explain this. They estimated the prevalence of depression, and variations of prevalence with culture, cultural adaptation, somatic symptoms and physical disability in a cross-sectional primary care survey of Punjabi and English attendees. They

found that, compared with their English counterparts, depressive diagnoses were more common among Punjabis, Punjabi women, Punjabis with physical complaints and, contrary to expectation, even Punjabis with low scores for somatic symptoms.

Bhui et al then posed the following question *'How do culturally defined expressions of distress reduce the recognition of depression in surveys'*? They answered it by drawing on previous research which reported subjects' causal explanations for distress to two vignettes (Bhui et al., 2002). This found that, among Punjabis only, psychosocial explanations were less frequent if medical/somatic or religious explanations were expressed. Bhui et al concluded that competitive expression of psychosocial and somatic expressions of distress among Punjabis, if prominent in both clinical situations and in research settings, may militate against recognition of mental health problems. Such a process may be relevant for the mental health care of other South Asian groups.

Bhui et al (2006) argue that social and economic contexts may contribute to divergent conclusions of studies that recruited different South Asian subcultures in different countries. However they highlight that (i) the Indian diaspora throughout the world have higher rates of suicide than host nationals (Patel & Gaw, 1996); (ii) In the UK, young Indian women have higher rates of self-harm than white British people (Bhugra et al, 1999). These findings they suggest are *'difficult to reconcile with the studies showing that Indians and Pakistanis have lower rates of depressive presentations in primary care and lower rates of mental health problems in the community'*. One possible explanation for lower recorded rates of depression may be the pluralistic help-seeking traditions of South Asians which promote help seeking from non-health agencies such as traditional healers, as well as the use of self-help through religious prayer and ritual, and folk remedies for addressing their misfortune (Dein & Sembhi, 2001).

Other studies on depression in UK South Asians indicate frequent and comparatively high rates of physical complaints among South Asians visiting their GPs (Balarajan et al., 1989; Gillam et al, 1989; Wilson & MacCarthy, 1994). These factors perhaps reflect more common use of physical idioms for emotional distress, e.g., as Krause (1989) highlighted 'sinking heart' is a common phrase of social and emotional distress among Punjabis. This has led some, e.g., Bhui et al, 2002; Kirmayer & Robbins, 1996 to argue that the existence of such physical phrases and complaints of physical health problems may diminish the recognition of mental health problems in South Asians.

### **Diet, Diabetes and South Asians in the UK**

Lawton et al (2008) conducted 32 qualitative interviews with Pakistanis (23) and Indians (9) with diabetes in Lothian to investigate their food and eating practices, their perceptions of the barriers and facilitators to dietary change, and the social and cultural factors informing their accounts. The authors have sought to illuminate the social and cultural processes informing the food and eating practices of Pakistanis and Indians living in the UK, by focusing on those with type 2 diabetes, for whom dietary management is a key recommendation. Despite significant differences in the dietary advice received, respondents offered similar accounts of their food and eating practices after being diagnosed with diabetes. A majority continued to consume South Asian foods, especially



in the evenings, despite their perceived concerns that these foods could be 'dangerous' and detrimental to controlling their diabetes. Respondents described such foods as 'strength-giving', and highlighted a cultural expectation to participate in community based activities with family/ community members. Male respondents often reported limited input into food preparation. Many respondents attempted to balance the perceived risks of eating South Asian foodstuffs against those of alienating themselves from their culture and community by eating such foods in smaller amounts. This strategy could sometimes lead to a lack of satiation, something not recommended in current dietary guidelines.

Despite their perceptions and concerns that South Asian foodstuffs, such as roti, could be detrimental to their blood glucose control, most respondents reported limited changes to their consumption of such foods following diagnosis of diabetes. Hence, while health was a consideration to them, it was one which was interwoven with other issues and concerns notably communal and family activities and duties. A central concern for these South Asian diabetics was forging and maintaining their identity as family and community members living in the UK. Given that the consumption of South Asian foodstuffs played a central role in this process, respondents often attempted to manage their identity and diabetes simultaneously by reducing the quantity they ate.

Virtually all respondents, for instance, highlighted the seemingly obligatory role that the consumption of South Asian foods played within their families and communities, particularly once settlement in the UK became more permanent. Respondents, for instance, described how they could cause offence and/or risk alienation if they did not partake in the acts of commensality with family and community members. These included the giving and receiving of South Asian sweets and dinner/meal invitations which Lawton and others have noted perform a vital function amongst South Asians who live in Britain. Not only do they serve as a means by which honour, status and prestige are generated and expressed (as in highly visible, and often ostentatious, events such as wedding meals and more crucially, as Shaw (2000) has observed, this system of gift-exchange has enabled those separated from their extended families on the Indian subcontinent to create social networks, which may include neighbours and other fictive kin as well as 'real' kin. In addition to providing a system of mutual support, these networks have enabled South Asian settlers 'to rebuild almost every aspect of their social and cultural traditions' and Britain to become 'a home from home' (Ballard 1994).

Lawton et al argue their findings indicate the importance of promoting dietary changes which work with the kinds of foods Indians and Pakistanis are eating already. In particular, they underscore the need for strategies for fat and energy reduction which focus on traditional cooking practices and, more specifically, through the promotion of lower fat authentic versions of recipes for commonly consumed dishes (Lawton et al, 2008). Equally important in the case of South Asian Muslims are dietary considerations for diabetics during Ramadan as highlighted by Seikh & Wallia (2007) in their guidance in this area.

## **The Need for Practical and Culturally Appropriate Dietary Advice**

Lawton et al's Lothian study concluded that to achieve sustainable and appropriate dietary change, it is vital that education and advice tackle the potentially erroneous perception that South Asian foods are necessarily an 'unhealthy' or 'risky' options since, as indicated earlier, the pre-migration diet is considered, from a biomedical perspective, to be a healthy one, which is appropriately suited to the prominent use of foodstuffs such as vegetables and dhal. Education should also emphasise that 'healthy' food options do not have to be bland and tasteless (in other words, spices can be used) and the consumption of what are perceived as 'strength-giving' foods is acceptable, provided, as indicated above, these are cooked in 'healthy' ways, and eaten alongside high-fibre foodstuffs, such as fruit and vegetables. Therefore when delivering this kind of dietary advice, it is important that health professionals avoid stereotyping the diets of South Asians (Lawton et al, 2008).

These sentiments were echoed by Pieroni et al (2007) following their research in Bradford with 150 South Asian women which investigated their perceptions of the medicinal qualities of traditional vegetables in the context of high diabetes rates in UK South Asians. Following their research they recommended that strategies to address diabetes in South Asians must take into account socio-cultural components and cultural health beliefs as well as patients' views on dietary ingredients.

## **The Importance of Group and Community Based Dietary Initiatives**

Pieroni et al (2007) finish by noting their findings underline the importance of delivering education, advice and support to the whole family and not just the person with diabetes, since responsibility for food purchase and preparation may be devolved to several household members. Given (i) the broader role that the shared consumption of South Asian foods plays in community life; (ii) respondents' concerns about causing offence if they did not participate in such activities, it may be wise to invest energy and resources in raising general awareness about healthy eating through group and community-based initiatives.

## **Promoting Exercise South Asians in the UK**

South Asians are identified as less physically active than Europeans, with studies reporting far less participation in recreational physical activity (Johnson, 2000; Hayes et al, 2002). Bhopal (2002) points out that '*lack of physical exercise (in South Asians) poses a huge challenge*'. The case to promote physical activity in South Asian communities for primary and secondary prevention of CHD and diabetes has been made for over fifteen years. For those with existing cardiovascular disease or diabetes, physical activity reduces both mortality and symptoms, and improves disease control and quality of life. Yet there remains little evidence of successful interventions among South Asian groups (Hayes et al, 2002; Carrol & Azam, 2002).

## **Promoting Exercise South Asian Women in the UK**

As Johnson (2000) and Lip et al (1996) note, promoting physical activity among South Asian women may pose particular challenges, with cultural differences typically identified as contributing. Research suggests that they undertake less physical activity or recreational exercise than others and that cultural barriers, such as religious modesty or avoidance of mixed-sex activity, and fear of going out alone mitigate against participating in recreational physical exercise.

It is possible however to encourage physical activity in South Asian women as demonstrated by Sriskantharaj and Kai (2006) following their research involving South Asian women with diabetes and/or CHD in England which led them to conclude that the potential to enhance levels of physical activity in South Asian women and address CHD and diabetes was high.

As Rankin & Bhopal (2001) and Farooqi & Bhavsar (2001) argue, innovative messages around physical exercise in South Asian women should be developed, given that basic advice from health care professionals to 'just do exercise' is inadequate. More effective guidance for targeted secondary prevention is needed at community and individual levels, reinforcing primary prevention and awareness raising. Specific reassurance and advice on appropriate physical activity in health encounters should be emphasized and regularly reviewed, as typically occurs with nutrition and weight. There may be potential for greater use of community peer educators, staff working in cardiac rehabilitation, physiotherapy or exercise on prescription.

Following their research described above, Sriskantharaj and Kai (2006) argued that further work should develop and evaluate physical activity promotion interventions in South Asian women and that measures to improve access and reduce barriers to exercise and leisure activity, including exercise on prescription schemes, should not be ignored. This menu should include, for example, increased provision of women-only activity and greater availability of bilingual staff. They also warn against barriers of cultural 'difference' being overemphasized as these can induce a defeatist attitude among health promoters, at the expense of recognizing much that is shared with the challenges of promoting physical activity in the majority population. Similar to growing experience with the majority population Sriskantharaj and Kai (2006) suggest strategies that do not require attendance at a special facility and which promote both 'active' living and regular brisk walking for its specific health benefits and socially enjoyable outcomes may also chime with South Asian women. Approaches might build, for example, upon the potential of 'lay-led' walking schemes.

## **Exercise Programmes help Build Social Support – Strongly Associated with Positive Mental Health and Wellbeing**

Such exercise initiatives would also address social isolation, which increases the risk of developing depression and anxiety and as the *Mosaics of Meaning* report (2007) noted, can be more common in South Asians when compared with white indigenous communities in Glasgow (Mosaics of Meaning, 2007). Such initiatives would also facilitate the opportunity to share illness experiences which has been seen as a very helpful source of social support for people with *long-term conditions* both in white indigenous communities and among South Asian men and women who participated in the four Living Better focus groups. ‘*Getting out of the house*’ twice a week to attend exercise classes were especially valued by Muslim men who attended the Dixon Centre exercise classes, not just because of the physical benefits of the exercise programmes but also in providing them with an opportunity to talk with friends and share a meal together. Numerous research studies, including cross-cultural ones involving the South Asian community, have shown the positive benefits to mental health and wellbeing, both in promoting positive mental health and wellbeing but also in acting as a buffer to chronic and acute stresses (associated with living with diabetes and/or CHD) that can increase the risk of developing anxiety and depressive disorders.

## 7. SOUTH EAST GLASGOW ACTION PLAN

In response to the issues identified in the focus groups the following priority areas were agreed by the South East Glasgow reference group (see Action Plan below). It was not feasible for the South East Glasgow pilot to address all the issues raised by patients and professionals in the focus groups within the timescale of the project, and some issues of the issues raised required other avenues for implementation, e.g. supporting South Asian carers and Equality and Diversity Impact Assessments of mainstream services.

Issues	Actions	Outcomes
<b>A. INFORMATION</b> <ul style="list-style-type: none"> <li>Certain groups within the community are less likely to access support, e.g. BME communities, Older people, Younger people</li> <li>Stigma deters South Asian community from seeking help for mental health problems and / or LONG-TERM CONDITION</li> </ul>	1. Develop mental health awareness information for people in South Asian community with long-term conditions	<ul style="list-style-type: none"> <li>Awareness raising day held at Glasgow Mela.</li> <li>Translated STEPS leaflets disseminated</li> </ul>
<b>B. SCREENING AND ASSESSMENT</b> <ul style="list-style-type: none"> <li>Staff can find it difficult to raise mental health issues with patients in consultations (Nurses, trainee GPs, podiatrists, dieticians etc)</li> <li>QOF screening can be a tick box exercise</li> <li>Screening tools (HADS/ PHQ9) may not be appropriate for BME communities</li> <li>Translation issues / confidentiality</li> <li>Stigma of mental health deters patients from opening up</li> </ul>	2. Training for health professionals on: <ul style="list-style-type: none"> <li>Mental health awareness incl. different cultural manifestations of</li> <li>different ways of assessing mental health needs (holistic approaches)</li> <li>Local sources of support</li> </ul>	<ul style="list-style-type: none"> <li>Culturally sensitive mental health screening and assessment training for health professionals' half day workshop developed and delivered</li> </ul>
<b>C. REFERRAL OPTIONS</b> <ul style="list-style-type: none"> <li>Patients and professionals don't always know what help exists</li> <li>Patients prefer local support options and are unlikely to cross boundaries (7 communities)</li> <li>Information required about low level social support options, e.g. buddying, exercise classes, alternative therapies, financial advice etc.</li> </ul>	3. Identify culturally appropriate local and national sources of support	<ul style="list-style-type: none"> <li>South East Glasgow service mapping exercise undertaken and distributed</li> </ul>
<b>D. WHOLE SYSTEM</b> <ul style="list-style-type: none"> <li>Need to ensure LB fits in with other local policies and priorities</li> <li>Limited capacity within services</li> <li>Linking with East Dunbartonshire Living Better pilot</li> </ul>	4. Promote project activities at CHCP and Health Board levels to ensure sustainability and roll out  5. Disseminate learning from pilot through event for key stakeholders	<ul style="list-style-type: none"> <li>Living Better findings shared through GG&amp;C Race, Culture and Religion conference</li> </ul>

## 8. TRAINING AND DEVELOPMENT ACTIVITIES

The training and development activities prioritise through the action planning process were undertaken and delivered between March and October 2010.

### Mapping local culturally sensitive sources of support

The mapping exercise was undertaken by an independent researcher in early summer 2010 and placed a particular focus on gathering information about services in neighbourhoods with a high South Asian population, such as Govanhill and Pollockshields. The exercise used reference group contacts, web based searches, and a snowball approach to gather information about 27 services available across South East Glasgow, including information about ways in which they promoted accessibility to people with a South Asian background. The results of the mapping exercise were also shared with the Positive Action in Housing who maintain the Scottish Ethnic Minorities Directory. A copy of this mapping report is available in Appendix One.

### Mental Health Awareness Information for the South Asian Community

At a suggestion of the reference group the Living Better Project arranged a stand at the Glasgow Mela in June 2010, an annual multicultural arts festival attracting approximately 40,000 visitors. The primary aim of the stand was to give out information about mental health and sources of support to the local South Asian community, but also to gather information about self help strategies and things that people do to improve their mood. Outcomes from the day included:

- 176 tips and suggestions gathered
- Mental health information in English and Urdu distributed
- New referrals to MELTS service achieved
- Awareness raised amongst health professionals as well as members of the public, e.g. South East Glasgow GP made aware of translated leaflets.

More importantly perhaps, the activity proved to be a successful way of reaching the South Asian population in Glasgow and beyond for very little financial outlay, and raised expectations amongst reference group members about how the event could be used for health improvement activities in future years. A copy of the Mela report is available in Appendix Two.

### Culturally Sensitive Mental Health Screening and Assessment Training for Health Professionals

Living Better commissioned Dr Saima Ali, Researcher from Southampton University to write and deliver a half day training course designed to raise awareness of the prevalence of depression and diabetes in the South Asian community, explore cultural understandings of depression and diabetes, discuss methods of diagnosing depression in the South Asian community and provide information about available culturally appropriate sources of help and support.

The course, the first of its kind in Scotland, was delivered on a one off basis in October 2010. Nine local health care professionals attended – GP's, Practice Nurses, Community Pharmacists and Specialist Nurses, the majority of whom were South Asians.

Because culturally sensitive mental health support for people with *long-term conditions* is still an emerging area of work, and transferrable good practice is not readily available, the workshop was largely exploratory and discursive rather than skills based. However, one positive outcome of this training was the forging of good links between the reference group and Dr Ali, one of a very few researchers in the UK researching this area

## 9. KEY LEARNING AND RECOMMENDATIONS

### Key Learning from Engagement with South Asian People Living with Diabetes and/or CHD and their Carers

- **Informational Support to Assist in Self-management:** South Asian people with diabetes and/or CHD wanted information on improving self-management of their condition. This was especially the case in addressing potential acute medical effects of their condition but also in preventing such potential acute effects. There is also a need to promote positive mental health improvement messages within the South Asian community in appropriate and accessible ways. Multicultural events such as the Glasgow Mela offer one such opportunity to do this.
- **Assistance and Practical Support:** South Asian people with diabetes and/or CHD wanted information about services to enable them to be socially active & pursue activities beneficial to what many called '*getting on with life*'. This was especially the case with maintaining and fulfilling family obligations/goals, employment requirements/opportunities, and lifestyle goals. The South East Glasgow mapping report provides information about some of the local services which might help individuals to with their goals, but this information needs to be regularly updated and promoted widely to ensure that people know about services which exist in their neighbourhoods.
- **Peer Support:** sharing experiences and exchanging information on improving self-management with people with the same condition was seen as beneficial by many. This was especially the case with South Asian people who had experienced surgery and/or acute illness relating to heart disease. Opportunities for peer support should be fostered by local health, social care and voluntary sectors.
- **The Importance of Understanding and Confiding in Immediate Family/Close Friends:** South Asian people with diabetes and/or CHD wanted people close to them to understand and appreciate the effects of living with *long-term conditions*. In the same vein confiding in people close to them about the strains of their condition was seen as an important source of support in addressing the acute and chronic stresses of living with diabetes and/or CHD. Carers and family members also require mental health information and support to help them cope with the emotional impact of their caring roles.



## Key Learning from Engagement with Health Professionals:

- **Nurse Training** – There is a requirement to provide Primary Care Nursing Staff with skills knowledge and confidence to address mental health and wellbeing issues in South Asian people with diabetes and/or CHD more effectively than simply asking the two QOF depression screening questions. The culturally sensitive mental health awareness training developed through the Living Better project provides one mechanism for meeting this objective, but culturally appropriate mental health screening and assessment is still an area where best practice is yet to emerge. There is therefore a need to further develop links with other academics and practitioners exploring this field.
- **Need for Prepared, Informed, Proactive Primary Care Staff** – There is a need to proactively target South Asian people with diabetes and/or CHD and their carers and (i) on diagnosis explain the risks to their mental health and wellbeing that the stresses of living with diabetes and/or CHD can cause; (ii) how to prevent these stresses developing into serious risks to their mental health and wellbeing and (iii) what to do if these stresses begin to cause emotional distress and/or feelings of anxiety and depression
- **Improved Signposting and Greater Enablement** of local social support services to share data for appropriate services for people living with *long-term conditions* to live as socially active lives as possible. Consequently, information on the following are important – Transport, Leisure, Exercise, Diet, Benefits/Financial advice, *Long-term condition* Support Groups, access to Voluntary Sector agencies that provide guidance and information on self-management such as Diabetes UK, Chest Heart & Stroke and British Heart Foundation. The South East Glasgow mapping report and Positive Action in Housing Directory may help with this.
- **Improve Partnership Working** between CHPs, GP Practices, Local Authorities and Voluntary Sector Agencies to support an integrated system of care and support in local communities.
- **Strategic Need to Address Stigma of Mental Illness in South Asian People with Diabetes and/or CHD** – Many health professionals believed that their task in addressing mental health and wellbeing in people with diabetes and/or CHD requires a wider strategic campaign linking with key agencies that address stigma of mental illness such as the 'See Me' campaign.

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