



The Living Better Project

Addressing Mental Health and Mental Well-being in People Living with Diabetes and/or CHD

Feedback from Western Isles Focus Groups (1)

October 2009

Index

Summary.....	3
The Living Better Project: General Background.....	4
Emotional Consequences of Living with Long Term Conditions.....	4
Addressing the Challenge Of Long Term Conditions: The Policy Context.....	6
The Living Better Research Component.....	8
The Evidence Base - Shaping Policy – Shaping the Living Better Project’s Actions	8
The Living Better Project’s Basic Goal.....	8
What Patients said in Focus Groups’ About Living with Diabetes and/or CHD.....	8
Summary of Health Professionals’ Comments from Focus Groups.....	12
Similar Themes to Emerge From Patient & Professional Focus Groups.....	13
Analysis of Focus Group Data.....	14
Some Observations and Preliminary Conclusions.....	18
Bibliography.....	20
Appendices.....	24

(i) Executive Summary

General Background

The World Health Organisation has stated that managing long-term conditions (LTCs) is the biggest challenge facing healthcare systems worldwide, given that over 60% of all deaths are attributable to them, and that in those who have them, they can limit a person's lifestyle, opportunities, outlook and potential. Scotland is no exception to this challenge given the actual and projected numbers of people living with at least one long term condition.

In Scotland, diabetes and Coronary Heart Disease, (commonly referred to as CHD and generally defined as group of conditions that includes acute myocardial infarction, angina and heart failure) are two of the most common LTCs many patients in Scotland live with both conditions. Because of the acute and chronic stresses associated with living with these and other long term conditions, mental health problems, notably depression and/or anxiety, are increasingly common in these patients. Being depressed and/or anxious can have a detrimental impact on how these patients manage their condition/s, and consequently, the physical outcomes of diabetes and/or CHD, making their general health status poorer. The combined effects of living with diabetes and/or CHD are detrimental to the person, their family and society generally (1, 2, 3, 4, 5, 39, 45).

The challenge to prevent long term conditions occurring in the first place is a central part of health and social care policy in Scotland. At the same time, government and various health, social care and voluntary sector organisations are increasingly identifying and addressing mental health and wellbeing as vital components in the management of long term conditions in general, and diabetes and/or CHD in particular.

The Living Better Project

The Living Better project is a Scottish Government funded initiative which is working with 5 Community Health Partnerships and 10 GP practices across Scotland to address mental health and wellbeing in people with long term conditions. In 4 CHP sites we are focusing on diabetes and/or CHD and in 1 CHP site Chronic Obstructive Pulmonary Disease (COPD).

Western Isles CHP is one of the Living Better Projects 5 CHP sites and patients with diabetes and/or CHD were randomly selected from the computerised Quality & Outcomes Framework (QOF) management system registers in two GP practices in the CHP. Patients were invited to attend focus groups in their areas.

The focus groups involving these patients and primary care staff working with them were discussed; (i) what it was like to live with diabetes and/or CHD; (ii) the emotional strains and mental health issues that arise and how they manifest themselves; (iii) the type of support systems these patients would like to see available to help them live with their condition and reduce the associated stresses (iii) whether health, social care and voluntary sector professionals were aware of mental health and well-being issues in these patients and how confident they were in addressing these issues; (iv) whether health, social care and voluntary sector professionals believed services at CHP level were equipped to address these issues; and (v) what changes should occur locally to address mental health and wellbeing in this people with these conditions. The same approach and methods were used across all 5 participating CHP sites.

Summary of General Findings

Summary of Findings from Patient Focus Groups

Data analysis from focus groups with people with diabetes and/or CHD and health professionals working with them in Western Isles CHP suggests the impact of illness differs across these two conditions. Living with diabetes and/or CHD was both an acute and

chronic stress. The condition/s had significant impact/s on people's lifestyles and the lifestyles of those around them. Living with the condition/s were associated with the following negative life events;

- Shock of being diagnosed with diabetes and/or acute event around CHD
- A feeling that some family and friends do not understand the strain of living with a diabetes and/or CHD Frustration over lifestyle changes
- Loss of confidence
- Strain on family and wider personal relationships
- Frustration
- Anger
- Stress in lead up to and after the annual or 6 monthly review
- Fear
- Financial concerns
- Feeling isolated

For both conditions, however, social support was an important buffer to the stresses of living with diabetes and/or CHD. In addition, a lack of or weak social support was identified by patients and health professionals as increasing the risk of psychological distress in patients with diabetes and/or CHD.

Summary of Type/s of Support People Living with Diabetes and/or CHD Patients Would to Access to Help them Address Emotional Stresses of Living with the Condition

- More time with health professionals particularly nurses given time constraints on GPs
- More time to discuss emotional feelings
- Access to group support classes for CHP patients
- Longer term access to exercise classes for CHD patients
- Greater opportunity to confide emotional feelings on a one to one basis
- Opportunity to share experiences with someone with same/similar condition/s
- More information regarding locally appropriate support services
- Informational support to address financial issues especially when advice is needed quickly, e.g., during disability allowance review
- For people feeling 'very down' or 'feeling depressed' more rapid access to local counselling services
- Easily accessible information regarding concerns over physical condition/s
- Longer lasting follow up support services
- For people with diabetes more information about accessing appropriate food/s on the Island and elsewhere

Summary of Findings from Health Professional Focus Groups

- The stigma of mental ill-health remains a problem. Patients see mental well-being equated with mental illness
- Preparatory work around the introduction of QOF and the depression screening questions was poor with no adequate training
- Nursing staff lacked confidence in addressing mental health issues in patients with LTCs that they did not know well
- The QOF questions relating to mental health and wellbeing were seen as rather basic/crude.

- A feeling that QOF issues around mental health and wellbeing were seen as a 'numbers' exercise
- A feeling of 'what do we do next'? after QOF questions or using HADS/PHQ9
- Need for improvement in rapid access to information on community support services for people with diabetes and/or CHD
- Difficulties of speaking about mental health issues in people with diabetes and/or CHD in W. Isles
- Support group work is more difficult in an Island community with a small population, especially around diabetes. It was felt that the complications related to insurance/s, driving licence, employment issues meant people wanted to keep their diabetes as private as possible, although the benefit of one to one confiding was seen as a source of support. Someone on the Island having a heart attack or major heart surgery meant most people on the island would find out about this.
- Belief that mental health issues surrounding diabetes and/or CHD lag way behind the 'big strides' made in the physical management of diabetes and/or CHD in the last decade, although some excellent training around counselling support for people with diabetes had taken place on the Island of Stornoway.
- For GPs and Nurses, its fine to talk about holistic assessment '*but we don't have the time, even in the annual review*'
- The waiting list for Psychological therapies in primary care doesn't help address emotional issues of living with diabetes and/or CHD
- Support has to be client centred and tailored to individual needs and circumstances to be successful
- There was a lack of alternatives to anti-depressant medication which was a dilemma given HEAT targets on anti-depressant prescribing.

General Conclusions

Recognition of psychological distress is an important function of General Practice, yet approximately 50% of patients experiencing mental health problems can remain undiagnosed and untreated. Social support is a non-complex, low cost intervention. It has a number of forms and can involve individual one to one confiding with a health professional or an individual or individuals who may have the same chronic illness and provide shared understanding. It can also take the form of group classes such as exercise/dietary classes or general support groups not related to health per se. It has the potential to bring significant benefit to these patients. Greater consideration of this important aspect of mental health and well-being, during screening, assessment and treatment must be increasingly considered in people with diabetes and/or CHD.

If future systems of primary care are to be effectively equipped and effectively operational in addressing the mental health needs and mental well-being of people with diabetes and/or CHD in the Western Isles and across Scotland generally, greater consideration around how to improve the mental health awareness, knowledge and skills of primary care nurses and primary care staff across general practice is essential.

This report contains the findings from 5 focus groups in Western Isles and relates them to existing research in this area, locates these findings in the context of Scottish health and social care policy around long term conditions in general and diabetes and/or CHD in particular, to help Western Isles Living Better reference group address how to improve relevant services in general and the mental health and wellbeing of these patients in particular.

As the conclusion section notes, more and more consultations in primary care involving people with CHD and/or diabetes are with practice and specialist nurses. Greater mental

health and mental well-being awareness training should be provided to these nurses. This would improve the prevention, assessment, and treatment of depression and/or anxiety as well as promote mental well-being in people living with diabetes and/or CHD. The challenge is (a) how to provide this training innovatively and (ii) how to give nursing care staff in particular and primary care staff in general, more time to address mental health and wellbeing in patients with diabetes and/or CHD and long term conditions generally.

Living Better and Learning from other Scottish Wide Initiatives

It is important to note that given existent time pressures on GP and nursing staff already, consideration for such training to be rolled out to other primary care healthcare staff as is the case with the Scottish Government's '**Keep Well**' initiated being led by Health Scotland should be considered. This initiative is developing the role of Health care support workers (HCSWs) for delivery of anticipatory care. Health Care Support workers have been an integral part of Keep Well anticipatory care delivery undertaking a range of roles and responsibilities which were traditionally undertaken by the qualified nursing staff within Keep Well anticipatory care settings. It has been generally believed that there is a need to develop the role of healthcare support workers, to confidently deal with the enhanced expectations of their roles and to provide safe and effective services to patients in primary care (57). The role of anticipatory care is central to both the prevention and management of long term conditions and is therefore an important area for Living Better. Changing service provision does not automatically result in corresponding changes in health seeking behaviours by patients and as research around this area has suggested patient preferences for care delivery may be in conflict with the current reform agenda focussing on anticipatory care provision. Efforts to reform chronic illness care may falter unless this is addressed (58).

1.0 The Living Better Project: General Background

The Living Better project is a three year partnership initiative involving the Royal College of General Practitioners (Scotland), the University of Stirling, the Scottish Development Centre for Mental Health, Depression Alliance Scotland, the British Heart Foundation (Scotland), Chest Heart and Stroke (Scotland) and Diabetes UK (Scotland). The project aims to lead the development of improved care for people with diabetes and/or Coronary Heart Disease (CHD) who because of the acute and chronic strains of living with these conditions also have mental health needs which, can often go unmet. The project will work with 6 Community Health Partnerships (CHPs) across Scotland to identify current service provision and consider and attempt to deliver new ways to improve care. In each of the 6 participating CHPs a Living Better Reference Group will be established, consisting of service users, key health and social care professionals working in diabetes and/or CHD, and key strategic planners. This Reference Group will be a vehicle for assessing existing service provision for this population of patients, and developing and implementing new stepped care pathways to address mental health issues in people with diabetes and/or CHD. Two GP practices in each participating CHP will work closely with the Living Better project to identify appropriate patients who will be involved in the Living Better project itself and also in the evaluation of the Living Better project.

The principal goals of the Living Better project are;

1. To improve the detection and diagnosis of mental health problems and promote mental well-being among people with long term physical conditions, specifically Chronic Heart Disease and/or diabetes in primary care
2. To improve the provision of appropriate interventions and treatment including medical and non-medical options to improve mental well-being and general mental health in people with diabetes and/or CHD
3. To ensure that responses reflect patient choice
4. To improve the Community Health Partnership's responses towards addressing mental health and well-being and mental illness in people with long term conditions in terms of flexibility, communication, and shared learning
5. To strength partnership working within these CHPs
6. To share the learning across Scotland

Community Health Partnerships are key structures for developing greater joined up care in the community. Living Better aims to lead and develop an approach that CHPs could implement to meet the mental health needs of this population; identifying transferable learning as we identify what needs to be in place at a local level to deliver stepped care pathways (such as training and skills development, or service developments, or establishing partnerships with other sectors etc.). The project aims also to learn how well equipped CHPs are to support and develop this type of initiative in primary care.

2.0 Emotional Consequences of Living with Chronic Physical Illness

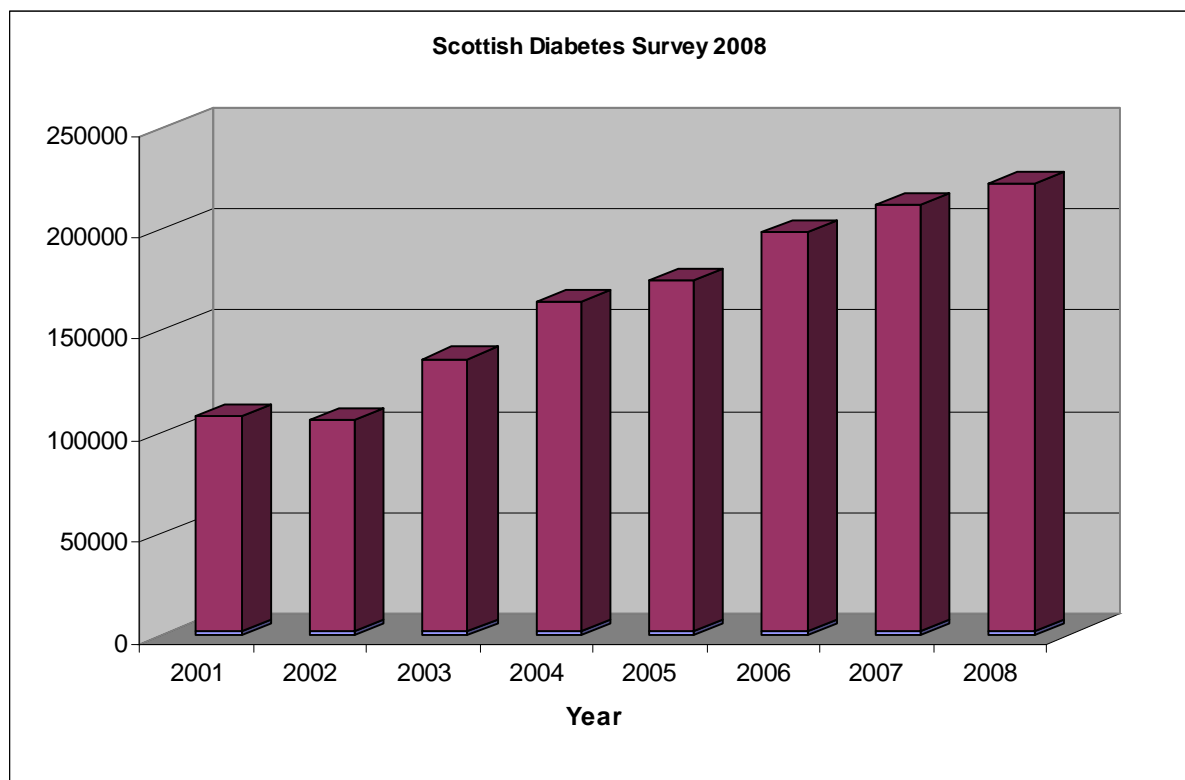
It is well established that depression is highly prevalent in people with chronic physical illness, and should be treated. Up to 33% of patients develop depression after a myocardial infarction [1] and meta-analysis has shown that depression is associated with a doubling of mortality in CHD [2]. It is 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]. A result of this recognised prevalence is that the revised Quality and Outcomes Framework (QOF) of the GMS contract incorporates case finding for these groups [7]. Screening for depression in patients with diabetes and Chronic Heart Disease was added to the QOF in 2006.

Recognition of significant psychological distress is an important function of general practice, and depression and anxiety together form the most common reason for patients consulting a GP in Scotland. Approximately 50% of patients with such mental health problems remain undiagnosed and un-treated [8-10]. In deprived areas, the prevalence of mental illness is higher, and the detection rate lower than in more affluent areas [11]. A recent study on depression in Scotland found that around half of patients with significant symptoms were not identified by their GP as suffering from a depressive disorder (11b). Given the higher demands placed on GPs by patients with chronic physical illness together with the significant time constraints GPs face, it seems likely that depression in patients with chronic illness is massively under-diagnosed (hence the rationale for the QOF points), and this is likely to be exacerbated by deprivation.

Diabetes Prevalence in Scotland

There were 219,963 people with known diabetes in Scotland recorded on local diabetes registers at the end of 2008, which represents 4.3% of the population. In the 2007 diabetes survey, 209,706 people (4.1%) were reported. It is estimated that there may be as many as half a million people in Scotland with diabetes within the next ten years [12a]. Diabetes UK estimates that 620,000 people in Scotland - about one in 10 of the population - could have pre-diabetes but are undiagnosed.

As the chart below indicates, the reported prevalence of diabetes has increased in Scotland. People with diabetes not only have to live with the physical issues of being diabetic, they have higher risk of eye disease, renal failure and cardiovascular disease than people without diabetes. They are also at greater risk of developing depression and/or anxiety.



The increase in reported prevalence is thought to depend on a number of factors, which include:

- an increase in the rate of type 2 diabetes, associated with rising levels of people being overweight and obese

- demographic change – the risk of developing diabetes increases with age and growing numbers of older people in Scotland’s population results in higher numbers of people with diabetes
- changes in the definition of diabetes, with the diagnosis made at a lower level of fasting plasma glucose
- better survival of people with diabetes because of improved control of blood glucose, blood pressure and cholesterol level
- improved recording of diabetes on GP computer systems
- improved detection of diabetes in people with type 2 diabetes, many of whom have no symptoms

(Scottish Diabetes Survey, 2008)

As the table below shows, nearly 30% of people diagnosed as having diabetes have lived with the condition for 10 years or more.

Duration of diabetes (years since diagnosis)		
<i>Less than 1</i>	18,727	8.6%
1-4	69,412	31.8%
5-9	65,921	30.2%
10-14	30,073	13.8%
15-19	15,905	7.3%
20-24	7,738	3.5%
25-29	4,325	2.0%
30-34	2,409	1.1%
35-39	1,600	0.7%
40-44	888	0.4%
45-49	539	0.2%
<i>More than 50</i>	572	0.3%

Source: Scottish Diabetes Survey, 2008

The Diabetes Action Plan for the Scottish Diabetes Framework [12b] included aims to “*improve access to psychological and emotional support for people with diabetes in all parts of Scotland*” within its 9 key promises. This includes aims to improve the identification of depression and anxiety among those who care for people with diabetes. The inclusion of aims around psychological support has been welcomed by Diabetes UK as consultation with their members has highlighted psychological needs as is a key concern due to a perceived lack of in-put from health services in relation to psychological needs. One review indicated that treating depression can improve glycemic control [16]. Collaborative stepped care, including the use of enhanced education and support, antidepressants or problem solving delivered in primary care for patients with diabetes and depression was shown to reduce depression severity, increase patient rated improvement and increase patient satisfaction with care [17, 18].

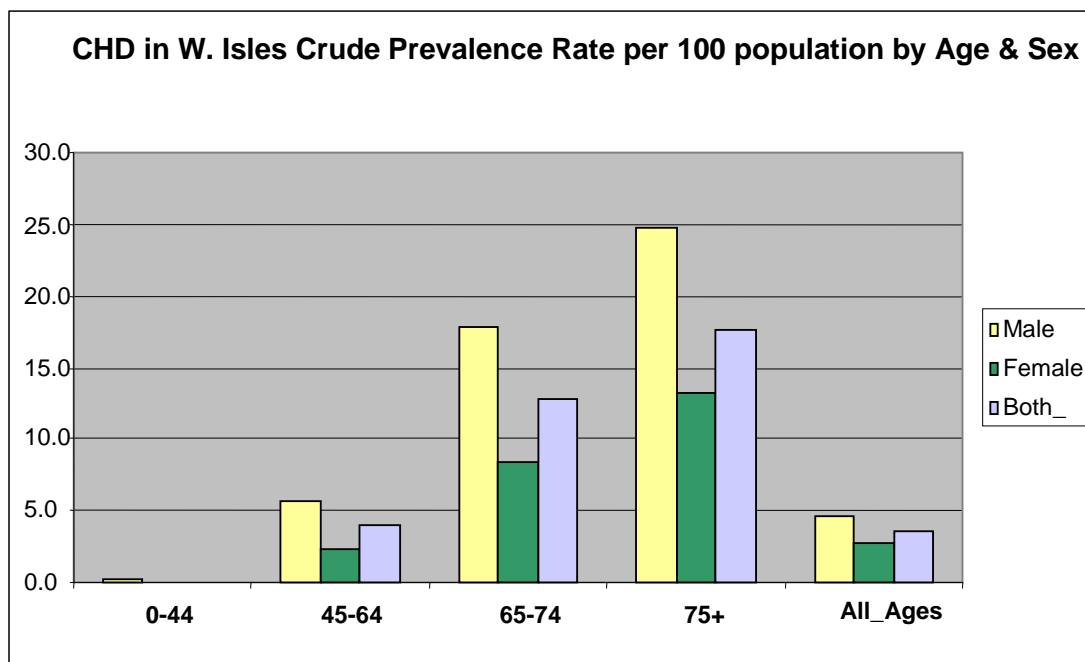
Diabetes in Western Isles

In 2008 the Scottish Diabetes survey estimated that there were 1,067 people in the Western Isles who had diabetes. This represents 4.1% of the population, slightly less than the all Scotland rate of 4.3%. The vast majority, 83% had Type 2 diabetes with 17% having Type 1 diabetes.

CHD Prevalence in Scotland

Whilst mortality rates for CHD in Scotland have declined in recent years, Coronary Heart Disease remains the leading causes of death in Scotland. Around one fifth (19%) of premature deaths in men and more than one fifth of premature deaths in women are caused by CHD. Approximately 140,000 people in Scotland have had a heart attack; 260,000 people are suffering or have suffered from Angina (the commonest form of CHD). Scotland has one of the highest death rates from CHD in the western world. This has been attributed to high rates of smoking, poor diet and deprivation. It is estimated that 14.9% of Scottish men and 14.5% of Scottish women are living with some kind of cardiovascular disorder. It is estimated that 82,000 patients with CHD and 24,700 patients with stroke or transient heart attack visit their GP each year. The prevalence of all conditions increases markedly with age. [13a, 13b]. The estimated prevalence of CHD based on admission to hospital is 3.6% of the Scottish population. CHD prevalence is higher in males (4.6%) than in females (2.7%) and is strongly associated to age. It is estimated that 16% of the Scottish population aged 75 years and over are living with CHD (14a) In some Scottish CHPs over a quarter of men aged 75 years and over have CHD. The effect of deprivation on prevalence amongst the younger population can be seen in the 45-64 age group. The prevalence rate in males aged 45-64 in East Glasgow (9.1%) is almost twice that of the rate in Aberdeenshire CHP (4.7%). For females aged 45-64 the prevalence rate in North Glasgow CHP (4.4%) is almost three times that in Shetland CHP (1.5%) [14a].

CHD Prevalence in the Western Isles



As the above chart shows, the prevalence of CHD among people in the Western Isles is in the older peoples' age ranges of 65-74 years and 75 years and over. It is estimated that the CHD morbidity in Western Isles is 4.2%, slightly higher than the Scottish estimated rate of 3.6%, which means just over 1,000 people in the health board area are affected by heart disorder/s (14a).

There is emerging evidence that treating depression improves morbidity and mortality in relation to CHD, which may be due to improved compliance for cardiac medication [14b]. Pharmacological treatment for people with CHD and depression can be complicated as some antidepressants have cardiac side effects, and herbal supplements (such as St.

John's Wort) can interact dangerously with cardiac drugs [15]. Hence it is recognised that management can be clinically complicated and that there is a gap in best practice for treating depression in CHD patients, and in general studies support the use of multidisciplinary approaches in providing care [14, 15].

3.0 Addressing the Challenge of Long Term Conditions: The Policy Context

The way health and social care is being planned and delivered in Scotland is changing. To address the challenge of growing numbers of people with chronic illnesses, health and social care organisations have been directed by the Scottish Government to work together in partnership with each other, with the voluntary sector and with patients and carers (19). On a wider level, under current Scottish Government health policy, Health Boards and Local Authorities are assessed on their levels of partnership working and are seen to be progressive if they deliver community partnership working; fair, equitable and accessible services for service users; put patients and carers at the centre; provide services that are as local as possible; and test out new ways of delivering integrated services in the community (19).

Alongside the recent progress and improvements made with managing long term conditions, greater responsibility for self-care and supportive care is now on people living with diabetes and/or CHD and their families and carers. Increasing responsibility is also being placed on community based health and social care organisations and the voluntary sector to provide and facilitate community based treatments and support for people with diabetes and/or CHD.

In light of this, meeting the challenges of living with long term conditions has become a major policy priority for NHS Scotland and its partnership agencies. Following the publication of the Kerr Report in 2005, *'Building a Health Service Fit for the Future'*, the Scottish Executive responded by producing *'Delivering for Health'*, a statement on the future plans for healthcare in Scotland. The model of care proposed within *'Delivering for Health'* (21) was based on the principle of integration, with patients and carers playing a central role in decisions about their care. Both policy documents underlined the need, if services are to be improved, of developing partnership working between the NHS, other public sector and voluntary organisations. This requires; (i) developing efficient partnership working between health, social care and voluntary sector organisations, with patients and carers at the centre of such partnerships and (ii) the need for a 'whole systems' approach to providing services, with each partner linking together to form one 'whole system' of care, again with patients and carers at the centre.

In October 2007, the new Scottish government launched their health policy action plan *'Better Health, Better Care'*. The proposals focused on the evolution of existing health policy as opposed to any radical departure from fundamentals contained in the Kerr report and *'Delivering for Health'*. The new and developing model of healthcare delivery in the NHS is through multi-professional teams crossing traditional professional, geographical and organisational boundaries. One example of this is the development of Managed Clinical Networks (MCNs) where the emphasis is on cross-boundary working to ensure equality of care and outcomes. Managed Clinical Networks deliver diabetes and CHD services across different sections of Scotland. They are important in the context of delivering information to people affected by diabetes and/or CHD as *'they lead to clearer information for patients and carers'* (19). Strongly linked with the Managed Clinical Networks of care is the centrality of the patient journey. This concept sees patient care as a combination of services involving health promotion, preventative care and follow-up care and support in the community from a range of health, social care and voluntary sector organisations working together. To address the challenge of managing long term conditions in Scotland requires a culture of trust and co-operation between different organisations. An important driver for achieving greater

partnership working, greater patient and carer involvement, and ensuring effective delivery of quality healthcare are the Community Health Partnerships that operate in every Health Board area of Scotland. A key role of CHP's is in developing systems of care for the management of chronic illnesses in the community, and supporting the increasing number of patients with more than one long term condition at home and in community settings (19).

It is becoming increasingly recognised therefore that peoples' physical and mental health and well being are not separate entities and must be intrinsically linked. Living with a long term condition and experiencing mental ill-health can be costly to the individual, their family and community and can result in a considerable loss of human potential and resources. It doesn't have to continue like this. Research on diabetes and depression, for example, has shown that social support (an important aspect of positive mental well being) can have a helpful affect on patient self-care and diabetes outcomes (39); and in people with coronary heart disease, effective treatment for depression has been shown to enhance quality of life and to improve physical, social and emotional functioning (43).

Yet, in autumn 2007, after reviewing the management of long term conditions across Scotland, Audit Scotland published a report in which they stated '*people with more than one long-term condition are less likely to be receiving joined-up care across all the services they receive*' (p.40). Their report recommended improved partnership working at primary care level between health, social and voluntary care providers in order to integrate services for people with LTCs. The report also recommended that Community Health Partnerships (CHPs) should have a key role in co-ordinating this.

3.1 The Evidence - Shaping Policy – Shaping the Living Better Project's Goals

Overall the evidence from numerous studies on people with diabetes and/or CHD and people with long term conditions generally, points to these conditions having a negative impact on mental health and wellbeing and demonstrates the increased likelihood of them experiencing depression and/or anxiety. The evidence also indicates there can be significant benefits obtained by improving best mental health practice in relation to these patient groups and that holistic, collaborative and integrated approaches in primary care offer the most promising mechanism for quality improvement for these patients. In this project we aim to draw on best practice in depression management as outlined in NICE guidelines and on evidence-based guidelines developed by the Scottish Executive Health Department as part of the national Mental Health Delivery Plan (2006). The Living Better project will also draw on policy developments as outlined in '*Towards a Mentally Flourishing Scotland*', (2009) which recognises importance of physical health to mental health, '*Better Health, Better Care*' (2007) which identified the need to make holistic care for long term conditions more consistent and widespread across Scotland and '*Gaun Yersel: The Self Management Strategy for Long Term Conditions in Scotland*' (2008) which identified emotional wellbeing as a key component of self management for long term conditions.

3.2 The Living Better Project – Basic Goal

The basic goal of the Living Better project is to build on the existing research evidence outlined above through focus groups with people with diabetes and/or CHD and health, social care and voluntary sector staff working with these patients. We will then link this evidence base to recent Scottish health policy in general and policy on mental health and wellbeing and long term conditions in particular. We will then sit down with key stakeholders in the 5 CHP sites and develop specific proposals and plans to improve the way in which local health, social and voluntary care services address the mental health and wellbeing of people living with diabetes and/or CHD.

4.0 The Living Better Project: Research Component: Findings from the Focus Group Meetings

For the initial research phase of the Living Better project a series of focus group discussions with people in Western Isles who have diabetes and/or CHD and health professionals who work with these patients was organised. A total of 5 focus groups were held, three involving patients (attended by over 40 people) and two with health professionals (attended by 14 people).

The findings from the focus group data will be used to inform the Living Better reference group meetings in the participating CHPs. Section 5 of this report contains the main findings from both the patient and professional focus groups.

4.1 The Patient and Health Professional Sample

The patient sample was a random selection of patients on the diabetes and CHD registrars of the two participating GP practices in Western Isles CHP. Health, social care and voluntary sector professionals were identified through discussions with Western Isles CHP staff working in long term conditions, diabetes and/or CHD.

4.2 Analysis of Focus Group Data

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 (20).

5.0 Summary of Key Findings from Patient and Professional Focus Groups

The following tables 1-4 summarise the key findings from the focus groups whilst table 5 summarises the key themes and sub-themes from both the patient and health professional focus groups.

Table 1: Summary of what Patients said about the Emotional Consequences of Living with Diabetes and/or CHD

- **Shock of being diagnosed with diabetes and/or acute event around CHD**
- **Acute and chronic stress due to lifestyle disruption**
- **A feeling that some family and friends do not understand the strain of living with a diabetes and/or CHD**
- **Frustration over lifestyle changes**
- **Loss of confidence**
- **Strain on family and wider personal relationships**
- **Frustration in general**
- **Anger**
- **Stress in lead up to and after the annual or 6 monthly review**
- **Fear of future complications due to illness**
- **Financial concerns**
- **Feeling isolated**
- **Lack of opportunity to 'talk openly about true feelings'**

Table 2: Summary of what Patients said about the type of support they would find helpful to address the emotional consequences of living with Diabetes and/or CHD

- More time with health professionals particularly nurses given time constraints on GPs
- More time to discuss emotional feelings
- Access to group support classes for CHP patients
- Longer term access to exercise classes for CHD patients
- Greater opportunity to confide emotional feelings on a one to one basis
- Opportunity to share experiences with someone with same/similar condition/s
- More information regarding locally appropriate support services
- Informational support to address financial issues especially when advice is needed quickly, e.g., during disability allowance review
- For people feeling 'very down' or 'feeling depressed' more rapid access to local counselling services
- Easily accessible information regarding concerns over physical condition/s
- Longer lasting follow up support services
- For people with diabetes more information about accessing appropriate food/s on the Island and elsewhere

6.0 Summary of Typical Patient Comments about living with CHD and/or diabetes and the impact on their mental health and well-being

6.1 CHD Patients: Shock of experiencing cardiac event and/or having surgery

***CHD Patient 1:** The heart attack, I was absolutely amazed because I didn't have any high blood pressure, I didn't have any weight... and I also took exercise and it just... it just happened very suddenly.*

***CHD Patient 2:** Prior to that you think it can't happen to you, you're indestructible. My circumstances... mine were mainly work induced.... I was relatively young when it happened. I worked for an international company, the hours got longer and longer. In the early nineties I suffered from hypertension, which was par for the course in the circumstances..... later I had TIA as the start of a stroke and a year or two later I had damaged my heart...it was all too much.*

***CHD Patient 3:** Well at the age I was at 52 it was quite a shock at the time. I don't know, you think about a lot of things when you have a condition and going for four by-passes, well I did anyway. Quite a lot of things go through your mind. My father died at 62 with a coronary, so that was one of the things that was on my mind. I was married at the time with a family and that was one of the things that was kind of bothering you.*

6.2 Diabetes Patients: Shock of being diagnosed as having diabetes

Diabetes Patient 3: *Well it was just I didn't think I had any symptoms, that was the shock. But the doctor decided to run a test and it was all high. So she said 'I'm afraid you've got diabetes and I'll put you on the register' 'oh' I said 'hold on, maybe the next blood test could be alright'. And she said 'no way'.*

Diabetes Patient 4: *I was pretty geared up into thinking I was going to be diabetic because both my parents were diabetic and both sets of grandparents were diabetic; and I was pretty certain it was going to come to me. I wasn't really keen on stabbing the finger but they did and the reading came up at 37.2 and I thought 'a little bit high!' But it was a bit of a shock when it came up at that. I was sent to a diabetic research unit just, there the attitude was 'you are diabetic, you will live as a diabetic'; here the attitude is 'you are diabetic, carry on and live and we'll treat the illness'. There's always that thing 'be sensible' which is probably the worst word that we have!*

6.3 CHD Patients: Loss of confidence following heart attack or major heart surgery

CHD Patient 6: *About two years ago I landed in hospital, then it was supposed to be... I was put on a potassium drip and I went home and I'd never been in hospital in my life before, but by golly I was in and out of hospital almost every second week... in the high dependency unit, and I think it was the last time I was told I had a heart condition of angina... after hypertension angina an atrial fibrillation. Lost all my confidence and before that I would be accused of being too confident altogether! I won't go anywhere because I think I'm going to drop dead.*

CHD Patient 8: *After I had my by-passes I was a different man when I came round... Suffering from depression and got over that and then fine for four years or to last February when I had an attack and since then I took one in June, and since then it's been downhill all the way. I had to get medically retired from my work.*

CHD Patient 15: *I don't know, I just... I just don't want to go anywhere and I won't go anywhere on my own. I have to have somebody, even going to the health centre. If I go out... well I say to some people, if I go out my own gate I'd be lost nowadays. I've really lost all my confidence.*

6.4 Diabetes and CHD Patients: Disruption to lifestyle

Diabetes Patient 1: *For a long time before that I'd been feeling very tired and I put it down to ageing, you know, 'I'm nearly 60 what do you expect?' Then I recovered and I coped pretty well for two or three years and then my sight began to go, I have diabetic retinopathy. So I sit on the couch and I can't even gaze into space. My hobbies were sewing and reading and they're two things that I can't do anymore. And there's not much in the way of services for handicapped people up here. It's a very religious place and everybody traipse off to church, nobody will knock the door and say 'do you want a couple of messages?'*

CHD Patient 3 : *As far as effect on my life is concerned, certainly the angina has slowed me down an awful lot. There's a lot more I would like to do around the house, certainly as far as gardening's concerned*

6.5 Fear

CHD Patient 10: *But then after the first one I felt 'well, what if this happens during the night and I don't waken?' you know, but after the first one you sort of say 'well then another one and another one' you know.*

CHD Patient 6: *I won't go anywhere because I think I'm going to drop dead.*

CHD Patient 3: *It does worry me, yeah, it does worry me, especially when I hear... for example, I heard last week a friend of mine who died a couple of weeks ago and he had by-passes two or three years ago, and I'm saying 'is this going to affect me?'*

CHD Patient 9: *I suppose it's frightened that you're going to have the same experience again, that it's going to start all over again.*

Diabetes Patient 6: *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. So that's the only thing that worries me.*

6.6 Strain on Personal Relationships & Disruption to Lifestyle

CHD Patient 8: *It can be difficult to talk about it at times. Well I sort of can and can't, you know what I mean? There are times we all need space.*

CHD Patient 10: *It was very difficult; in fact I still now find it... I've been out of art 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 a lot of 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, I don't think it's been easy for me or my partner.*

Diabetes Patient 14: *I resent having to take tablets and inject myself four times a day and quite frankly she (wife) said to me the other day 'I'm worried about your diabetes?' and I said 'well no I'm not'.*

6.7 Financial Concerns

Diabetes Patient 5: *I was put on sickness pay, and after that I forget what period of time it was, but I was called up to the MNI... I had to get assessed for my disability allowance by this independent GP, he asked all these questions and I was made to feel very awkward, I've worked all my life on the boats and it's hard work I just couldn't do it anymore I'd be no use to anybody but for a while there I thought I'd lose my money and that was a real worry.*

6.8 What type of Support People with Diabetes and/or CHD wanted and why?

6.8.1 The Importance of Shared Experience in addressing Emotional Wellbeing

CHD Patient 11: *I think trained counsellors, with all due respect, don't necessarily appreciate the problems or possibly the nervousness of talking about a problem. What's worrying me sitting here is I had this done four/five years ago (heart surgery) and now I've got depression, I didn't have that before. Now my wife is understanding or partner whatever*

else, but she hasn't been where I am and she possibly can't see the problem. In my work environment I was in the situation where I was obliged to see a counsellor, and I said to one of them 'have you ever seen blood running down the gutter?' 'no', I said 'until you have, you can't help me at all.' And we did our own inner group, the lads I worked with, sorted out our problems.

CHD Patient 16: *My own circumstances, my wife has never been ill in her life so I'm a wimp if I've got a sniffle! And you go and you can say 'yeah, I've got a pain' or whatever, and she'll say 'well yeah, alright' and that's it. But 'I **have** got a pain' that means something to everybody sitting here because they've had that pain and they can say 'well, is it like it was before or is it nothing?'...*

6.8.2. More Time with Health Professionals and Greater Sensitivity when asking Patients how they are feeling emotionally.

Diabetes Patient 11: *Well I think it would be nice to be asked (about how you are feeling emotionally) and then it's up to you whether you want to... however you want to answer it. It gives you the option.*

Diabetes Patient 14: *I think you want to know the person who's asking you the question. It's usually the practice nurse I see and she is great so I wouldn't mind...(general agreement from focus group on positive benefits of talking with the practice nurse although it was highlighted by patients that this increased the workload of practice nurses).....yes clone her I'd say she always listens and understands.*

Diabetes Patient 7: *I think it's possibly the wording of the question, 'how is your mental health?'..... seems to think you should be locked up somewhere!*

CHD Patient 2: *It is important (they ask about emotional feelings) well you're emotions might add to your illness whatever it is, you know, if your emotions are churning it's not going to help your illness....I think it should be asked in a more generalised way because its probably easier to answer. People don't often respond to direct questions*

Diabetes Patient 8 & 9 & 10: *I think men would naturally find it more difficult than women, that's only a personal view. Yeah, I think it's in a general... Skilful and personable, you know... I think they'll get the answers if they phrase the questions properly.....Like in a conversation, yes..... Probably up here everybody knows each other and probably they feel 'oh I better not tell them what I'm feeling because they'll go on and say it to somebody else!'..... I think generally islanders don't show their emotions the way they should..... Maybe a fear of making a fool of yourself, you know, but I think we are as a people, in this part of the world; we are a bit like that anyway.*

6.8.3 Self Help Exercise Classes and how they benefit social and emotional wellbeing

CHD Patient 14: *I first had surgery in Glasgow where I lived before moving up here... and there was a self-help exercise group. It wasn't just a physical thing, that was the basis of it, but it became a social club and everybody mixed in. It's surprising when you get into that situation and people identify with each other, how much you actually start to open up.... It was an unconscious thing, it just naturally gravitated. You know, things that you normally think you wouldn't share, but you actually start sharing and that I think is helpful.*

Diabetes Patient 13: *I think that will be a great idea to have some sort of informal group thing like this where you can bounce ideas across each other and talk about what you're going through. Because for me, okay I look big and strong but I definitely worry at times, which is a bad thing. Now I've found out I'm diabetic Type 2, when did I progress from Type 1? You know, these sort of questions go through your mind and you can't relate to anybody.*

6.8.4 More Time with Nursing/other Primary Care Staff given Limited Time of GPs

Diabetes Patient 8: *This isn't a criticism of my GP or other GPs who are very good, but I would like more time. I feel as though I've barely sat down then I'm out the door again because they've got a whole waiting room to see.'*

7.0 Summary of Health Professional Comments

Table 3: Summary of what Health Professionals said about challenges of addressing mental health and well-being in people with Diabetes and/or CHD

- Preparatory work around the introduction of QOF and the depression screening questions for diabetes and CHD was inadequate with not enough training around mental health issues in general and specifically in relation to diabetes and/or CHD
- The actual QOF questions and pre-questions are rather basic/crude.
- We use HADS or PHQ-9 but we write down the number but what do we do next?
- Communication with patients around emotional issues of living with diabetes and/or CHD is challenging for health professionals unless they know the patient well.
- A lot of people with diabetes and/or CHD in W. Isles, especially older people are unwilling to speak about their mental health and well-being even with a health professional because of 'stigma' and being on a small Island and would worry 'that everyone will know'
- The stigma of mental ill-health remains a problem, especially in a small island community like Western Isles. Patients still see mental well-being equated with mental illness
- More and varied social support services required to take account of diversity of client's needs and support preferences and time pressures on GPs and Practice Nurses.
- Patients often don't tell health practitioners how they are really feeling when they are asked 'how are you emotionally'
- Need for rapid access to information on community support services for people with diabetes and/or CHD
- Feeling expressed that service locally has made huge strides in physical management of diabetes and/or CHD in last decade but similar progress has not occurred in addressing psychological consequences of these conditions.
- GPs and Nurses feel its fine to talk about holistic assessment but they don't have the time, often even in the annual/6 monthly review
- The waiting list for psychological therapies in primary care is too long

7.1 Summary of Typical Comments from Health Professionals

7.2 Lack of Available Alternatives to People who have Diabetes and/or CHD and are Depressed

Health Professional 3: *I think probably one of our problems here is that the only option they've got is anti-depressants... I know there's one of the HEAT targets that we've got to reduce anti-depressants.*

Health Professional 4: *But the problem is that if you've not got any alternatives in place...I know, and the counselling's popular, but they're so over-booked for places it takes a long time.*

Health Professional 1,3,4: the thing is, given the financial situation of the health board, trying to argue that you need more counsellors or whatever in way of alternative therapies, especially where people maybe don't see the alternative therapies as being.....As being high quality.....You know, tablets... yeah, tablets are tablets, they work!

7.3 QOF is an Advance but has Limitations

Health Professional 7: *There's the guidelines for screening programmes that have included the two mental health questions it's on the system, but it's...? And that's supposed to act as a trigger for onward referral. And any of the screening that's done, you know, formally they're asked, but I don't know how many are asked about their emotional wellbeing day to day, and especially when they turn up with other illnesses. You know, they can turn up with anything and it might be their mental health issues that are really the problem.*

Health Professional 6: *I think the screening questions are seen as a sort of tick box exercise... Yeah. And it's purely... 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'. Like you said, that's not a word that they associate with their illness, and yeah, it's maybe not appropriate the way it's done, because it's done with all your bloods and everything. There's maybe 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!*

Health Professional 9: *And maybe we haven't put enough emphasis on it? Because it's one of these things, isn't it, that in QOF that you've got to ask questions, you've asked questions, that's your money, job done and there isn't really any other way of those people being picked up at the moment. Certainly for CHD now we've got the British Heart Foundation nurses, but they're only seeing a small percentage of people.*

7.4 What to do Next after the Annual or 6 Monthly Review?

Health Professional 8: *I think the annual review probably identifies 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.....so you need to have a variation of ways to address this. A lot of nurses we've trained up on referring patients counselling, you know, they know that counselling can work and can help and can benefit, but it's not open to them. And even although we had nurses doing basic training in CBT, you know, it was only for three days, we don't have anyone who's fully trained and qualified. We used to have, but not anymore, someone who is a therapist in CBT, so it's not like we can refer someone there.*

7.5 Limited Time Availability Necessitates Developing Capacity Out with GP Practice

Health Professional : *The impact of living with diabetes on a person's emotional wellbeing, yes we are aware of the situation and we do want to prioritise it.we're going down the counselling line. Because from our nurses who are hands on with patients, you know, they said 'we just don't have the time', but when they have a patient coming in, you know, they tend to find that they're needing counselling, you know, as well getting their HB1C done, all their clinical stuff, there's particular patients where it maybe just all comes out. And she says, you know, 'if I had someone I could just, say, pass them onto our dedicated diabetes*

counsellor kind of thing, that would be a step in the right direction.. we've began to look at was training up a non-clinical member of staff to do counselling, to work within our diabetes services locally.....We contacted a psychologist down in Stirling, and ran it by her and they were quite... they thought 'this is really quite different and quite innovative' and whatever and didn't see any problem with it being non-clinical, if anything they thought there could be benefit from it being non-clinical because then they know, you know, they're not talking to a nurse, they don't have to worry about their BMs, that's not what we're here for.

7.6 Problems with Group Work in People with Diabetes in Small Island Community

Health Professional 4: *It depends a lot of the type of patient, because we've found that group work doesn't really work here, but that was then, I mean, things... just all group work doesn't work here, I'm a wee bit too quick to say that because everyone knows everyone*

Health Professional 5: *Yes, I knew somebody who was referred to the mental health services here, and he was a youngish person, and they said 'oh you don't get referred to the psychiatrist, we have a group session on Monday night' or whatever it is, and he said 'I'm not going there, I know so and so and so and so'.*

Health Professional 3: *Yes, I knew somebody who was referred to the mental health services here, and he was a youngish person, and they said 'oh you don't get referred to the psychiatrist, we have a group session on Monday night' or whatever it is, and he said 'I'm not going there, I know so and so and so and so'.*

Health Professional 1: *Well, there's probably different reasons... one guy for example I know and his reason is fear of insurance, mortgages, driving licence... I was with him when he was hiring a car and he ticked that he's not diabetic. And I was like... and he says 'ocht, see the hassle, we wouldn't have got the car for hours, they probably wouldn't give it to me, they'd have phoned off...' you know, because there's things that can come against them if they highlight they've got diabetes. So we know patients that don't come to clinic in the hospital, well, you've people that never go anywhere, they just try and manage it themselves until then they're really sick, because they don't want anyone seeing them. Especially coming into the hospital, because into the hospital there's a big sign **Diabetes Centre**... So they come in there and then someone else comes in 'didn't know you were diabetic?' you know, so you get people who just don't want anyone knowing their business, they don't want their employer to know because they just want to be normal, you know, they don't want to be thought about as being different or they don't want to be thought about as being a liability, you know, if they're out in the van or whatever, work van.*

Health Professional 2: *In saying that some people are ok with group support but some would only go for one-to-one so there isn't one size fits all for support.*

7.2 Table 5: Similar Themes and Sub-Themes that emerged from Patient and Professional Focus Groups

Key Themes	Sub-Theme/s
<p>Importance of sensitivity in addressing Mental Health & Wellbeing issues because of Stigma of mental illness especially in small Island community</p>	<p>People with diabetes and/or CHD stated they felt emotional wellbeing was important in managing their long term condition but many felt 'awkward' about talking openly about it because of the stigma of mental illness and living in an island community with a small population.</p> <p>When making contact with the NHS, patients would prefer to discuss emotional issues with a health professional they knew reasonably well. Health professionals tended to agree with this and spoke of the importance of training and skills development in addressing this issue in general but especially with new or relatively unknown patients.</p>
<p>Benefits of Sharing Experiences with Fellow Patients either individually or in Group Setting (but not in group setting for people with diabetes)</p>	<p>For many people with CHD and/or diabetes, shared experience was seen as important and opportunities to discuss with fellow patients, was seen as important in helping to address the stresses of living with the condition. This was mainly the case with CHD patients however, not so in people with diabetes. This was echoed by health professionals.</p> <p>Both patients and professionals stated that most people on the Island would know who had had a heart attack or heart surgery. This would not be the case with diabetes and because of issues such as driving, insurance, employment related matters, people with diabetes would want to keep this to themselves/immediate family.</p>
<p>Benefits of Informal non-medical, non-psychological Support Groups e.g. exercise, cooking classes etc.</p>	<p>Both patients and health professionals underlined the importance of informal non-medical, non-psychological support such as groups linked to addressing exercise, diet and cooking where patients could chat informally, not necessarily about their physical health or mental well-being.</p> <p>CHD patients stated that with the hospital exercise classes this would eventually informal discussion about 'emotional feelings' would evolve and was seen as a positive source of informal psychosocial support.</p>
<p>Users Want an Accessible, Informal and Neutral Venue for Support classes</p>	<p>Importance of accessibility was stressed by people who did not own a car or could not drive. Importance of friendly, open environment; opportunity to discuss non-diabetes/CHD related issues. Having a 'neutral' venue was mentioned by some Islanders in order to protect confidentiality, a point echoed by nurses.</p>

<p>Increasing demands on time for both Nurses & GPs necessitates need for wider support services out with these caregivers.</p>	<p>Because of pressures on time and resources, health professionals spoke of the difficulties of having enough time to 'tease out' the emotional stresses of living with an LTC especially in patients who they had not developed a professional relationship with that allowed for the discussion of personal emotional issues.</p> <p>Nurses pointed out that even in the 6 monthly or annual review time was tight. Many patients identified time constraints during consultations with Nurses and especially GPs.</p>
<p>Importance of People with LTCs and their Carers and Health/Social Care Staff being aware of locally available support services</p>	<p>Unfamiliarity with locally available services that could help and support people living with diabetes and/or CHD. This point was also expressed by health professionals.</p>
<p>Importance and value of rapid access to support and help with decision making</p>	<p>Importance of rapid access to general and specific support and help with decision-making; speedy access to experienced and knowledgeable professionals; access to people with the same condition to share experiences; reassurance of knowing support and information is readily available, whether accessed or not, were all seen as important to people with diabetes and/or CHD and professionals working with them.</p>
<p>Importance of Support being Person-specific</p>	<p>People with diabetes and/or CHD have a variety of support needs; It is important to be aware that each patient situation is unique and therefore so are his/her requirements. Information & support needs are dependent on person's individual circumstances.</p> <p>This finding is in line with of the clearest messages from various national consultations in Scotland and the rest of the UK - patients want the right information delivered at the right time and suited to their personal needs.</p>
<p>Importance of Confidential One-to- One Support</p>	<p>Not all patients were comfortable with the idea of group support and stated they would prefer a more private form of support.</p> <p>There was a strong sense importance of one-to-one confiding one's personal problems with a diabetes/CHD professional, or a Practice Nurse or a person with diabetes and/or CHD or other health/social/voluntary sector related staff.</p>
<p>The Importance of Social Support to both Mental Well-being and Mental Health</p>	<p>Data analysis suggests the impact of illness differs across these two conditions. However, for both conditions, social support was an important buffer to the stresses of living with diabetes and/or CHD. In addition, a lack of or weak social support was identified by patients and professionals as increasing the risk of negatively affecting mental well-being and mental health.</p>

<p>The Benefits of Effective Partnership Working</p>	<p>Effective partnership working improves communication between health, social care and voluntary sector agencies working among people with diabetes and/or CHD in Western Isles. In the opinion of health professionals interviewed in the focus groups, users of services directly benefited from effective partnership working.</p> <p>Patients saw the benefits of using services provided by the local council and voluntary sector in helping them manage their physical and mental wellbeing.</p>
---	--

8.0 Comment and Observation from Initial Analysis of Focus Group Data

As a number of health professionals stated in the focus groups, research has shown that for people generally, especially older people, talking about their mental health (indeed detecting it by using depression/anxiety scales such as HADS and PHQ-9) can be difficult. This was more the case with the diabetes patients than the CHD patients as one would expect as research highlights the experience of such an acute event as a heart attack or major heart related surgery is a particularly acute stressor and these are significantly linked to onset of depression and/or anxiety (especially where social support is weak) [24, 25].

8.1 Social Support and Mental Health and Wellbeing

The concept of social support is very broadly defined one but for the purposes of this preliminary report, the essential component of support focuses on the significance of human relationships and some form of helping element. Pearlin et al (1981) described social support as '*access to and use of individuals, groups or organizations in dealing with life's vicissitudes*' (26). Support can be in the form of meaningful social contacts, available confidant/s, or human companionship (27). As noted earlier, support is important to people affected by chronic illnesses as the stresses of living with them can increase their vulnerability to depression and anxiety (27). When considering the impact of chronic illness, both as an acute and chronic life event, one has to take into account the tensions that people experience as they negotiate specific symptoms, potential and actual changes to valued social roles and positive identities, and disruption to daily lifestyle. General studies show that social support may benefit mental health directly and indirectly, as a mediator, suppressor, and moderator or stress-buffer. For example, perceived emotional support refers to beliefs that one is valued, cared for, and loved, and these beliefs tend to promote mental health (27b). Like other psychosocial resources, social support may also benefit mental health by altering stress appraisals and promoting alternative or healthy coping strategies in the face of stress or burden (27c).

Three or four categories of social support can be distinguished: **emotional support** (warmth and nurturance expressing commitment, reassuring the person that he or she is a valuable individual who is cared for, including approval or appreciation for the patient's situation and behaviour), **appraisal support** (helping a person understand a stressful event better and what resources and coping strategies may be mastered to deal with it) or **informational support** (giving advice and information), **and tangible assistance or practical-instrumental support** (material or other practical help such as services, financial assistance, or goods). This can be in the form of one to one confiding relationships, confiding in group situations, sharing experiences and exchanging information and/or receiving assistance to address a specific stressor (39)

8.1.2. Chronic Illness, Stress, Depression, and Social Support: Why they are Inter-related and Important in the Context of the Living Better Project

Living with a chronic illness and experiencing mental ill-health can be costly to the individual, their family and community and society generally. Chronic illness can have a devastating impact on social, family and occupational functioning. It is commonly associated with disability, pain, mood disturbance and fear of death. Developing a chronic illness may cause a period of adjustment or disruption, promoting feelings of worthlessness or hopelessness that may fuel depressive symptoms (32, 33). Consequently, chronic illness has been considered a chronic stressor that is persistent and associated with negatively impacting on a person's mental health and well-being (34). As a chronic stressor, chronic illness produces limitation in the ability to perform social roles and may interfere with social interaction especially for older individuals whose chronic illness can be more debilitating (34). This can have negative psychological consequences to the individual which may endure over time. At the same time, it may threaten an individual's ability to live alone and decrease a sense of independence or that person's sense of 'feeling in control', which is known to be particularly important for continued psychological well-being (35, 36)

Following the research of Brown and Harrison on depression in different parts of the UK their book '*The Social Origins of Depression*' was published in 1978. This highlighted the importance of social support, to a person's mental health and mental well-being. Research on depression and anxiety over the last 25-30 years has shown a consistent association between acute and chronic life events (e.g., in the context of the Living Better project a heart attack or major heart surgery or a diagnosis of diabetes and/or the accumulated strain of living with the condition over time) and an increased risk of developing depression and/or anxiety (28, 29). The same and similar research has also shown that the presence of social support can not only act as a 'buffer' to stressful life events thus reducing risk of developing depression and/or anxiety conditions, but is also helpful to an individual's general mental well-being and also can be a positive factor in the management of depression and/or anxiety (30, 31). Flowing from the work of Brown and Harris a conceptual outline of the stress process was developed by Pearlin et al in 1981, which contained three central elements: sources, mediators, and outcomes. Pearlin et al (1981) put forward a framework which suggested that stress may impact on an individual either directly as an acute severe life event or as a chronic strain over time. Central to this framework was the buffering/protective role of mediator's notably social support in limiting the negative impact of acute and/or chronic stressors to a person's mental health and mental well-being (26).

Three decades after the publication of '*The Social Origins of Depression*', the World Health Organisation published '*The Commission on the Social Determinants of Health*'. This report emphasised the importance of social support as an important social determinant of health generally and an especially important factor in mental health and wellbeing (56).

8.2 The Importance of Social Support to People with Diabetes and/or CHD and to Health Professionals working with these Patients

As noted above, the concept of social support has a number of forms and can involve the provision of confiding support, emotional comforting or being part of a social group with the opportunity to access confiding support and/or shared understanding all of which can act as a buffer to the stresses of everyday life and/or in the context of Living Better, can 'buffer' the stresses of living with a chronic illness. It can range from one to one confiding support from an individual a person feels comfortable about discussing their innermost thoughts and feelings with, support from a social network of people a person feels they have something in common with, and the exchange of information and advice designed to answer important issues in that person's life. The outcome of such interaction is beneficial to the person seeking that support either emotionally through reducing distress and/or improving a

person's emotional outlook or by providing a buffer to day - to- day pressures which helps them with day-to-day living, or all three (37).

In just recently published research findings involving a study of people with diabetes in the USA, the positive benefits of providing social support in the form of telephone interventions have been highlighted. The research findings highlighted the benefits of conveying empathy for the patients' plight, allowing patients to express difficulties, and providing emotional and informational support while encouraging adaptive behaviour change (53).

It is important to note here that research has shown that whilst shared experience is of importance when confiding one's personal circumstances, a person doesn't necessarily have to confide with someone who is in exactly the same circumstances. The benefits of confiding to a trained professional such as a nurse, or in the recently published research referred to above from the USA a 'paraprofessional' (the UK equivalent of social work or OT assistants) are equally valuable. It is the *process* of confiding in someone who understands, empathises and provides unconditional support that has been shown to be valuable (28, 29, 30). Interestingly,

This support is often needed because of the psychosocial impact of a diagnosis of diabetes and/or CHD. For the purposes of this report, the term psychosocial relates to the psychological and social aspects of peoples' lives. It covers how a person thinks about themselves and their situation, how they feel emotionally and the daily practical aspects of their lives from personal relationships through to day-to-day economic issues such as employment and managing finances and one's social and personal networks. When a person receives a diagnosis of diabetes and/or CHD, all these areas are affected, not just their own but their family's too.

Despite this recognition, psychosocial aspects can often be missed by healthcare specialists, especially at the beginning of a person's treatment. For example, a study by Farrell et al. (2005) identifying the concerns of 33 women undergoing chemotherapy in Northwest England found that experienced nurses could not identify the majority of patients' concerns and were biased towards physical and treatment related issues. The researchers concluded that their study provided clear evidence for the importance of a continued focus on psychosocial aspects of care during the preparation of staff for clinical roles with patients diagnosed with chronic illnesses. They also believed their findings highlighted the need for preparation in listening and responding to non-medical, psychosocial concerns which touch on aspects of care with which health care professionals may feel less familiar and comfortable (38).

In the context of what type of support patients in Western Isles with diabetes and/or CHD said they wanted, this came in a number of different forms. It can be a group form of support such as a diabetes support group, a CHD exercise group where people affected by these conditions share experiences with each other, a more individual one-to-one type of support of sharing or confiding, rapid access to locally available general support services.

These different support forms are usually targeted to one of three points on the illness trajectory: diagnosis/pre-treatment, immediately post-treatment or during extended treatment. Certain types of supportive interventions for people affected by diabetes and/or CHD have been shown to be more effective at one or more of these time periods.

There are numerous studies documenting how social support affects adherence to diabetes self-care activities, such as foot care, exercise, food preparation, taking medications, and glucose monitoring (e.g., 54, 55). When van Dam et al (2005) conducted a systematic review '*Social support in diabetes: a systematic review of controlled intervention studies*' (39), they noted that;

New forms of social support may be discussed and incorporated in the work of diabetes teams, and offered to patients as new. Diabetes care providers in their daily practice should strive for open communication about social support with their patients. Diabetes teams may consider to offer some of the promising new forms of social support that were found: patient group consultations with diabetes care providers, peer social support group sessions or following diabetes possibilities to help them adjust to a life with (type 2) diabetes and make information-based decisions (39).

In their review of psychosocial factors and CHD, Bunker et al (2003) noted strong and consistent evidence across all the reviews that social isolation and lack of quality social support are independent risk factors for CHD onset and prognosis: the risks are increased 2–3-fold and 3–5-fold, respectively. The association exists for both men and women, subjects living in different countries, and various age groups. An association was found in studies that examined some aspect of the size and nature of a person's social network and in studies that examined the type of support received (40). Ikeda et al (2008) noted that studies conducted in Western countries have found a robust association between social support and cardiovascular outcomes (e.g., prognosis after myocardial infarction and functional recovery after stroke) (27).

8.3 Economic Benefits of Social Support to the Wider Healthcare System

When discussing new ways and directions of tackling the growth of chronic illness in modern society, Walker et al (2003) estimated that effective psychosocial support services lower general health service use by between 7% and 17% among people with chronic illness (41).

Other reviews on the benefits of providing psychosocial support also point to cost savings for the wider healthcare system. Carlson & Bultz (2003) reviewed the literature detailing the extent of psychological distress in cancer patients (increasingly being treated today as a long term condition), the staffing needed to treat such levels of distress, and the effectiveness and value of psychosocial treatments for cancer patients were assessed. From their review they concluded that providing psychosocial support for people affected by long term conditions:

shows large savings in medical billing through the treatment of emotional problems, including anxiety and depression, resulting in fewer visits to GPs and specialists alike. Although there is very little research on psychosocial oncology to date, studies seem to support the general findings in other (LTC) groups of fewer visits to primary care physicians after receiving efficacious psychosocial treatment. Clearly, the time has arrived to promote a compassionate model for treating patients' physical and emotional needs as a vital part of our healthcare systems (42).

9.0 Some Preliminary Conclusions based on Focus Group Findings and Literature Review

Recent research in Scotland has shown that people living with chronic illness are at greater risk of developing mental health problems than those without such illnesses; 30% of those with limiting long term conditions scored 4 or more on the General Health Questionnaire (GHQ) rating (indicating potential mental ill health), compared with only 9% of other adults (44).

In the financial year 2007/2008, the number of people in Scotland with diabetes and/or CHD who consulted a GP or nurse at least once in primary care totalled over 1 million (45). It has been predicted that by 2025 the number of people in Scotland who will be diagnosed as having diabetes and CHD will rise to 250,000 and 650,000 respectively (46). Depression and/or anxiety are highly prevalent in these patients (approximately 30%) and having depression and/or anxiety can negatively affect the management and outcomes of diabetes and/or CHD (47, 48). Despite this association being known for some time, organisations like Long Term Conditions Alliance Scotland (LTCAS), as recently as 2007, pointed out that the mental health needs of people with chronic illnesses such as diabetes and/or CHD are still not being adequately addressed (49).

Recognition of psychological distress is an important function of General Practice, yet approximately 50% of patients experiencing mental health problems remain undiagnosed and un-treated (50, 51, 52). Social support comes in various forms including individual one to one confiding with a health professional or an individual or individuals who may have the same chronic illness and provide shared understanding. It can also take the form of group classes such as exercise classes or general groups not related to health per se. Compared to other treatments and interventions, providing social support is a non-complex, low cost intervention. Research has consistently shown it has the potential to bring significant benefit to patients with chronic illnesses such as diabetes and/or CHD. It is therefore vital that greater consideration of this important aspect of mental health and well-being, during screening, assessment and treatment must be increasingly considered in patients with diabetes and/or CHD.

Following the focus group findings and literature review contained in this report, the next steps for the Living Better reference group in Western Isles will be to discuss what to do with this data in terms of linking it to re-assessing services for people with diabetes and/or CHD locally. One clear finding to emerge from both the patient and health professional focus groups was a feeling that existing primary care services were under-prepared to address mental health and mental well-being issues in people with diabetes and/or CHD.

Statistics from ISD NHS Scotland show that in the financial year 2007/2008 most diabetes and/or CHD consultations' in primary care were with nurses (see Appendix 1 & 2). Nursing staff we spoke with in Western Isles (and elsewhere in Scotland) were aware of their client's mood being low or lower and thus they became conscious of their mental health needs, but usually only if they knew them quite well. A telling comment from staff in the Western Isles working with people who have diabetes and/or CHD (and elsewhere in Scotland) regarding the QOF questions (*During the last month, have you often been bothered by feeling down, depressed or hopeless? During the last month, have you often been bothered by having little interest or pleasure in doing things?*) was that whilst they asked patients these questions, and if necessary followed this up by using PHQ 9 or HADS, they were often unsure what happened to the patient afterwards. For some, the process felt like a purely operational exercise which they believed was not sufficient in '*getting to grips*' with addressing the emotional and social complexities that people with diabetes and/or CHD can experience.

Addressing depression and anxiety is a complex process, especially, as highlighted earlier in a small Island community. Teasing out emotional distress is a skilful process and whilst the QOF questions represent progress in addressing the issue of mental health and wellbeing in people with long term conditions, they are only one aspect of the equation. As highlighted earlier, as much as 50% of people with depression/anxiety in primary care can be undiagnosed, even after completion of HADS/PHQ9 scores.

If future systems of care are to be effectively equipped and operational in addressing the mental health needs and mental well-being of people with diabetes and/or CHD - greater consideration on how to improve the mental health awareness, knowledge, and skills of primary care nurses and primary care staff in general working with this client group is vital. Equally important is the need to make primary staff and their partners in social services aware of locally available support services that could provide valuable social support to people living with diabetes and/or CHD.

Dr Eddie Donaghy

Research Fellow, Living Better Project, on behalf of Living Better Executive Project Team.
For enquiries regarding the Living Better research, please email:
edward.donaghy@stir.ac.uk

10.0 Bibliography

1. Davies SJC, et al (2004). Treatment of anxiety and depressive disorders in patients with cardiovascular disease *BMJ* 2004;328:939-943.
2. Barth J et al (2004) . Depression as a Risk Factor for Mortality in Patients With Coronary Heart Disease: A Meta-analysis. *Psychosomatic Medicine*, 2004;**66**:802-813.
3. Whooley M (2006) Depression and cardiovascular disease: healing the broken-hearted. *JAMA* 2006; 295(24): 2874-81
4. Lin EHB, Katon W, Rutter C et al (2006) Effects of enhanced depression treatment on diabetes self-care. *Ann Fam Med* 2006;**4**:46-53.
5. Fryers T et al (2005) . The distribution of the common mental disorders: social inequalities in Europe. *Clinical Practice and Epidemiology in Mental Health* 2005, 1 (14) 1-14
6. Watt GCM (2002) . The inverse care law today. *Lancet* 2002;360:252-4
7. Boardman AP (1987). The general health questionnaire and the detection of emotional disorder by GPs: a replicated study. *Br J Psychiatry* 1987; 151: 373-387.
8. <http://www.pcpoh.bham.ac.uk/primarycare/QOF/PDF/Depression.pdf>
9. Howe A (1996). Detecting psychological distress: can general practitioners improve their own performance? *Br J Gen Pract* 1996; 46: 407-410.
10. Wittchen HU (2002). Generalized anxiety and depression in primary care: prevalence, recognition and management. *J Clin Psychiatry* 2002; 63 (Suppl 8): 24-34.
11. Stirling M, Wilson P, McConnachie A (2001). Consultation length, deprivation and identification of psychological distress in general practice. *Br J Gen Pract* 2001; 51: 456-460.
- 11b Cameron S, Lawton, K, Reid, C (2009) Appropriateness of antidepressant prescribing: An observational study in a Scottish primary-care setting *British Journal of General Practice*. September, 2009.
- 12a. Scottish Diabetes Survey 2008. Scottish Diabetes Survey Monitoring Group.
- 12b Diabetes Action Plan Scottish Executive 2006
- 13a. Better Coronary Heart Disease and Stroke Care: A Consultation Document (2008). www.scotland.gov.uk/Publications/2008/07/30105717
- 13b Scotland Coronary Heart Disease Statistics Fact sheet 2008/2009. British Heart Foundation Scotland.
- 14 Vieweg et al (2006). The treatment of depression in patients with coronary heart disease. *Am J Med* 2006;119: 567-573.

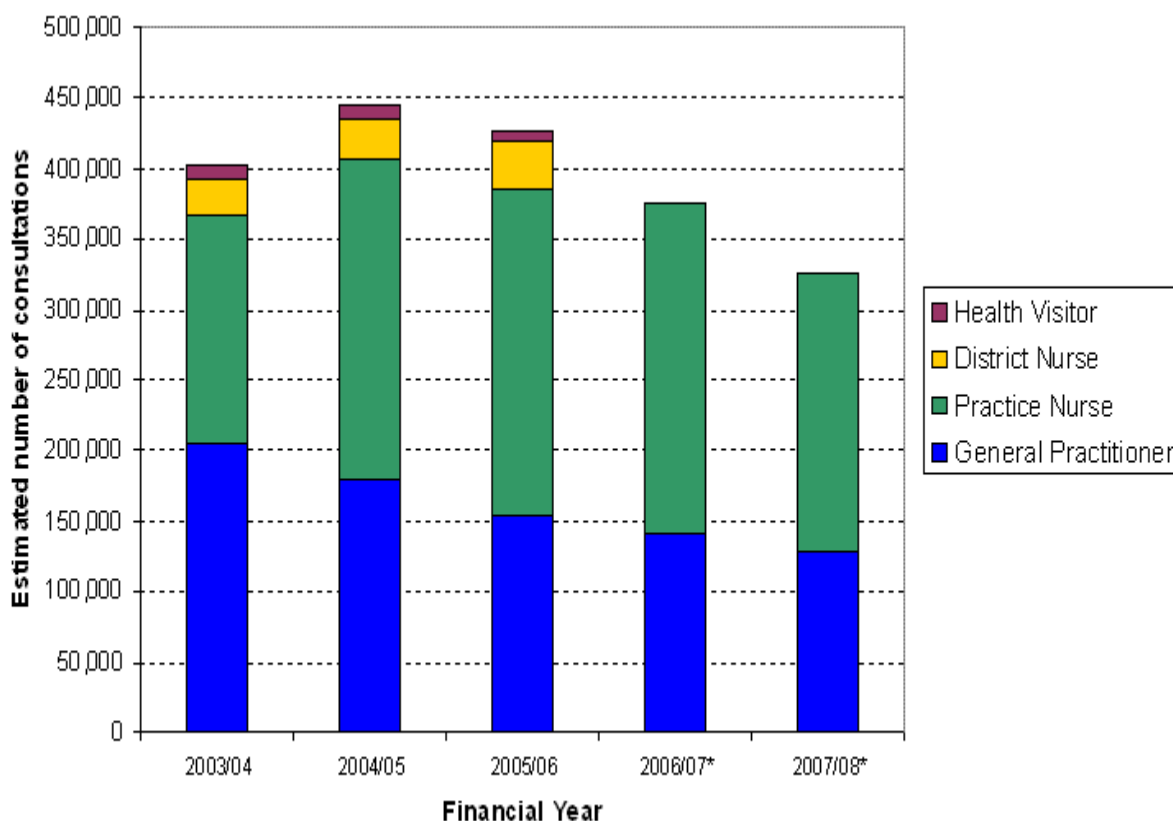
- 14a ISD (2008) Coronary Heart Disease in Scotland. <http://www.isdscotland.org>.
- 15 Zellweger et al (2003). Coronary artery disease and depression. *European Heart Journal* 2003; 25 (1): 309
- 16 Anderson et al (2001). The prevalence of co-morbid depression in adults with diabetes. *Diabetes Care* 2001; 24(6): 1069-1078
- 17 Katon, W et al. (2004) The pathways study: A randomized trial of collaborative care in patients with diabetes and depression. *Archives of General Psychiatry* 61, 10
- 18 Katon, W, et al (2006) Cost-effectiveness and net benefit of enhanced treatment of depression for older adults with diabetes and depression. *Diabetes Care* 29, 2, 265 – 270.
19. Scottish Executive 2005a, Building a health service fit for the future. A national framework for service change in the NHS Scotland. SE, Edinburgh.
20. Strauss, A. and Corbin, J (1998) Basics of qualitative research (2nd ed).Sage.
21. Scottish Executive 2005b, Delivering for health, SE, Edinburgh.
22. Scottish Executive 2004, NHS Reform Act Scotland, SE, Edinburgh.
24. Champion, L. (1995) "A developmental perspective on social support networks," in Social support and psychiatric disorder, T. S. Brugha, ed.
25. Davison, K. P et al (2000), "Who talks? The social psychology of illness support groups", *American Psychologist*, vol. 55, pp. 205-217.
26. Pearlin, L. et al (1981) "The stress process", *Journal of Health and Social Behavior*, vol. 22, no. 4, pp. 337-356.
27. Ikeda A, et al. (2008) Social support and stroke and coronary heart disease: The JPHC study cohorts II. *Stroke* 39:768–775.
- 27b Cohen, S et al (2000). Social relationships and health. In S. Cohen, L. Underwood, & B.H. Gottlieb (Eds.), *Measuring and intervening in social support: A guide for health and social scientists* (pp. 3–25). New York: Oxford University Press.
- 27c Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior*, Spec. No.: 53–79. Review.
28. Brown, G and Harris, T (1978) *The Social Origins of Depression*. London. Tavistock.
29. Brown, G and Harris, T (1989) '*Life Events and Psychiatric Illness*' in *Life Events and Illness*. (eds) Brown, G & Harris, T. London, Unwin Hyman.
30. Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310–357.
31. Krause, N. (1986). Social support, stress, and well-being among older adults. *Journal of Gerontology*, 41, 512–519.

32. Boerner, K. (2004). Adaptation to disability among middle-aged and older adults: The role of assimilative and accommodative coping. *Journal of Gerontology: Social Sciences*, 59B, S35–S42.
33. Bruce, M. L. (2001). Depression and disability in late life: Directions for future research. *American Journal of Geriatric Psychiatry*, 9, 102–112.
34. Friedman et al, (2005) Depressed Mood and Social Support as Predictors of Quality of Life in Women Receiving Home Health Care. *Quality of Life Research*, 14: 1925-1929.
35. Taylor, M. G., & Lynch, S. M. (2004). Trajectories of impairment, social support, and depressive symptoms in later life. *Journal of Gerontology: Social Sciences*, 59B, 238–246.
36. Gignac, M. A. M., Cott, C., & Badley, E. M. (2000). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journal of Gerontology: Psychological Sciences*, 55B, P362–P372.
37. Jang, Y., Haley, W. E., Small, B. J., & Mortimer, J. A. (2002). The role of mastery and social resources in the associations between disability and depression in later life. *The Gerontologist*, 42, 807–813.
38. Farrell et al (2005) Identifying the concerns of women undergoing chemotherapy. *Patient Education and Counselling*, Volume 56; 1 Pages 72-77
39. van Dam et al (2005) Social support in diabetes: a systematic review of controlled intervention studies. *Patient Education and Counselling* 59; 1–12.
40. Bunker et al (2003) Bunker SJ, et al. Stress and coronary heart disease: psychosocial risk factors. *Med J Aust*;178 :272–6
41. Walker, C., Peterson, C. L., Millen, N., & Martin, C. 2003, *Chronic illness. New perspectives and new directions* Tertiary Press, Croydon.
42. Carlson, L. E. & Bultz, B. D. 2003, "Benefits of psychosocial oncology care: improved quality of life and medical cost offset", *Health and Quality of Life Outcomes*, vol. 1, no. 8.
43. Hipsley- Cox, J et al (1998) Depression as a risk Factor for Ischemic Heart Disease in Men *BMJ* 316:1714-1719.
44. Scottish Executive Social Research Unit (2007) *Characteristics of Adults in Scotland with Long-Term Health Conditions: An Analysis of Scottish Household and Scottish Health Surveys*. Edinburgh.
45. Coronary heart disease and diabetes in Scotland - estimated number of patients in Scotland consulting a GP or practice nurse at least once in the financial year 2007/08 per 1,000 patients registered by gender and age Group. Source: Practice Team Information (PTI), ISD Scotland, March 2009.

46. NERA (2005) The Future Burden of CHD and Diabetes in Scotland - The Value of Health Care Innovation. Final Report for ABPI Scotland.
47. Barth J, et al, (2004) Depression as a Risk Factor for Mortality in Patients with Coronary Heart Disease: A Meta-analysis. *Psychosomatic Medicine*;66:802-813;
48. Lin EHB, (2006) Effects of enhanced depression treatment on diabetes self-care. *Ann Fam Med* 2006;4:46-53.
49. <http://www.ltcas.org.uk/>
50. Howe A. Detecting psychological distress: can general practitioners improve their own performance? *Br J Gen Pract* 1996; 46: 407-410.
51. <http://www.pcpoh.bham.ac.uk/primarycare/QOF/PDF/Depression.pdf>
52. Wittchen HU et al (2002) Generalized anxiety and depression in primary care: prevalence, recognition and management. *J Clin Psychiatry* 2002; 63 (Suppl 8): 24-34.
53. Sacco, WP et al (2009) Effect of a brief, regular telephone intervention by paraprofessionals for type 2 diabetes. *Journal of Behavioral Medicine*. 32:349-359.
54. Gallant, M. P. (2003). The influence of social support on chronic illness self-management: A review and directions for research. *Health Education & Behaviour* 30, 170-195.
55. Gonder-Frederick, L. A., Cox, D. J., & Ritterband, L. M. (2002). Diabetes and behavioral medicine: The second decade. *Journal of Consulting and Clinical Psychology*, 70, 611-625.
56. WHO (2005) The Social Determinants of Health: The Solid Facts. WHO
57. NHS Quality Improvement Scotland (2008) *Working to standard: Final project report. Pilot for the regulation of healthcare support*. NHS Quality Improvement Scotland: Edinburgh.
58. Sortus, T et al (2005) Patients' views on chronic illness and its care in general. *Australian family physician* vol. 34, n^o5, pp. 397-399

Appendix 1

Coronary Heart Disease¹ - estimated number of consultations in Scotland in the financial years 2003/04 to 2007/08^{2,3} by staff discipline

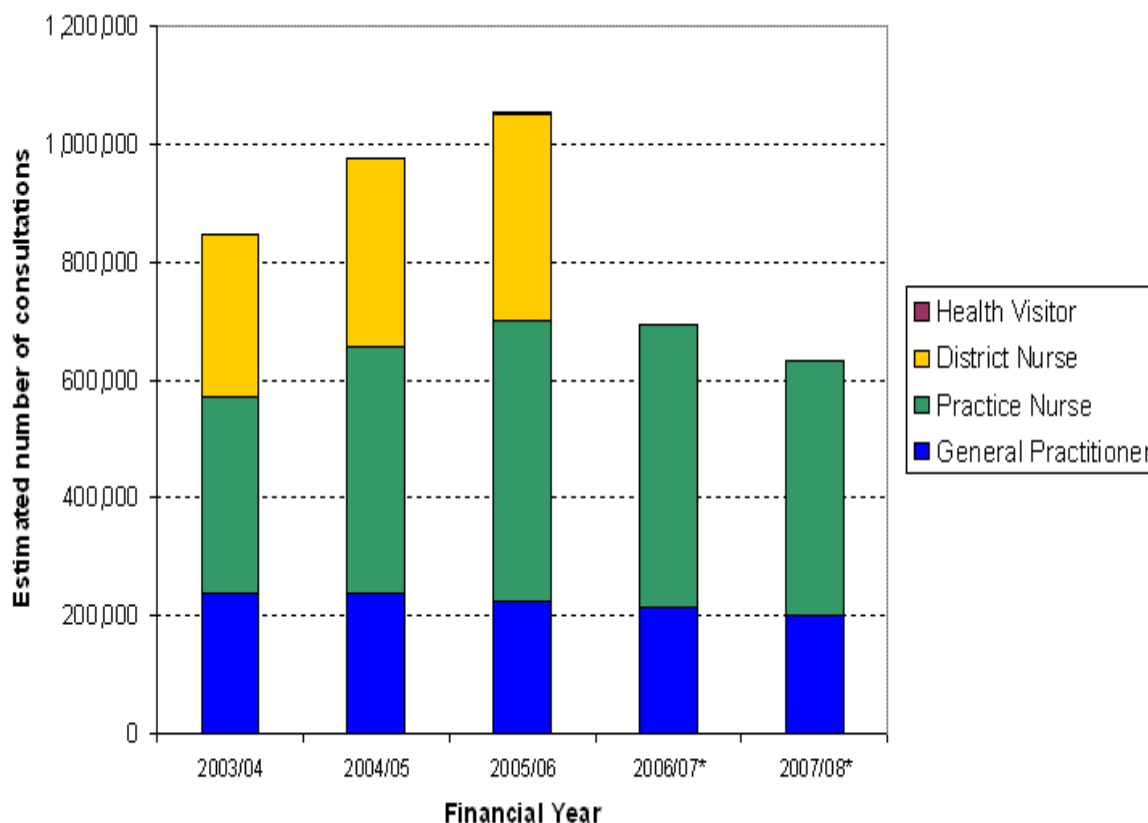


* Health visitor and district nurse data are not available from the financial year 2006/07 onwards. ¹ Based on ISD's Read Code Grouping (RCG) 'Angina', 'Acute myocardial infarction', 'Ischaemic heart diseases excluding angina & acute myocardial infarction' and 'CHD monitoring'. ² Based on 59, 53, 51, 49 and 47 PTI practices that submitted complete data for the years ending 31 March 2004, 2005, 2006, 2007 and 2008, respectively. Figures are standardised by age, gender and deprivation. ³ Population source: Community Health Index (CHI) record, as at 30 September 2003, 2004, 2005, 2006 and 2007.

Source: Practice Team Information (PTI), ISD Scotland (last updated 31 March 2009).

Appendix 2

Diabetes¹ - estimated number of consultations in Scotland in the financial years 2003/04 to 2007/08^{2,3} by staff discipline.



* Health visitor and district nurse data are not available from the financial year 2006/07 onwards. ¹ Based on ISD's Read Code Grouping (RCG) 'Diabetes'. ² Based on 59, 53, 51, 49 and 47 PTI practices that submitted complete data for the years ending 31 March 2004, 2005, 2006, 2007 and 2008, respectively. Figures are standardised by age, gender and deprivation. ³ Population source: Community Health Index (CHI) record, as at 30 September 2003, 2004, 2005, 2006 and 2007.

Source: Practice Team Information (PTI), ISD Scotland (last updated 31 March 2009).