Royal College of General Practitioners Scotland

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scottishdevelopmentcentre for mental health

University of Stirling

The Living Better Project

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

Feedback from North Lanarkshire Focus Groups (1)

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Summary
Scotland has high and growing rates of diabetes and Coronary Heart Disease (CHD). Depression and/or anxiety are increasingly common in these patients and can negatively affect the outcomes of diabetes and/or CHD. Given current methods, is primary care effectively equipped to screen, diagnose and treat depression and/or anxiety in these patients? Recent research involving diabetes and CHD patients and health professionals working with them suggests not, but the solutions are not necessarily complex or expensive.

The Living Better project is working with 5 Community Health Partnerships and 10 GP practices across Scotland. North Lanarkshire CHP is one of our project participants 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 North Lanarkshire. Focus groups involving these patients and primary care staff working with them were conducted to discuss; (i) what it is like to live with a chronic illness; (ii) the emotional strains and mental health issues that arise; and (iii) how these factors could be most effectively addressed by primary care health services.

Data analysis from focus groups with people with diabetes and/or CHD and health professionals working with them in North Lanarkshire CHP 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 psychological distress, and negatively affecting mental health and well-being in general in patients with diabetes and/or CHD.

Recognition of psychological distress is an important function of General Practice, yet approximately 50% of patients experiencing mental health problems 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 patients with diabetes and/or CHD.

If future systems of 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, 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.

As the Conclusion section notes, more and more consultations in primary care involving people with CHD and/or diabetes are with practice 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 these patients.

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), 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 also have mental health needs which research has found 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 in massively under-diagnosed (hence the rationale for the QOF points), and this is likely to be exacerbated by deprivation.

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]. 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].

Coronary Heart Disease (CHD), also known as Ischemic Heart Disease, is one of 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 ischaemic attack visit their GP each year. The prevalence of all conditions increases markedly with age. [13a, 13b]. 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 [14]. 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].

Overall the evidence demonstrates the significant morbidity associated with having depression and CHD and/or diabetes and the increased likelihood of depression occurring within these populations. The evidence indicates there can be significant benefits obtained by improving best practice in relation to these patient groups and stepped/collaborative approaches offers the most promising mechanism for quality improvement for these patients. In this proposed project we aim to draw on best practice in depression management as outlined in recent NICE guideline, and on evidence-based guidelines currently being developed by the Scottish Executive Health Department as part of the national Mental Health Delivery Plan (2006).

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.

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 North Lanarkshire 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 50 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 North Lanarkshire CHP. Health, social care and voluntary sector professionals were identified through discussions with North Lanarkshire 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 summaries 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

- **Chronic and acute strain of living with one or more LTCs**
- **Shock of experiencing cardiac event and/or having to undergo surgery**
- **Shock of being diagnosed with diabetes and/or CHD**
- **Loss of confidence**
- **Strain on family and wider personal relationships**
- **Frustration**
- **Stress in lead up to and (if not good news) after the annual or 6 monthly review**
- **Fear**
- **Feeling isolated**
- **A feeling that some family and friends do not understand the strain of living with a diabetes and/or CHD on a daily, weekly, monthly, yearly basis.**
- **Frustration over lifestyle changes**
- **Financial concerns**
- **Lack of someone to talk to about 'real feelings' on a one to one basis**
- **Strains of lifestyle re-adjustments**
- **Lack of support, especially in CHD patients after discharge from hospital and ending of exercise classes**

Table 2: Summary of what Patients said about the type of support they would found/ would find find helpful to address the emotional consequences of living with Diabetes and/or CHD (see section 6.0 for patient quotations)

- **More time with health professionals particularly nurses given time constraints on GPs**
- **Longer term access to exercise classes for CHD patients**
- **Opportunity to confide emotional feelings on a one to one basis**
- **Support groups as they are beneficial emotionally as well as physically**
- **More information regarding locally appropriate support services**
- **Support to address financial concerns**
- **For people feeling 'very down' or 'feeling depressed' more rapid access to local services**
- **Easily accessible information regarding concerns over condition/s**
- **Longer lasting follow up support services**
- **Having opportunity to talk with a person with the same condition to share experiences with**

6.0 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: *Friday night- 'right, I'm going out', woke up on the Saturday morning and thought it was a bad hangover, dehydration. But this dull pain right in the centre of my chest that kept pinning me to the bed…my brother's an army paramedic checked me… phoned the ambulance straight away. They came in, put the wee machine on and says 'aye, your heart rate's abnormal' (next day in the hospital) they came and says 'no, you've had a heart attack'. I says 'no', my brain wasn't taking it in. I says 'not me, how have I had a heart attack?' I says 'I'm only 35, how can this be…?' He says 'Believe me wee man, you've had a heart attack.' ………….. And it's as if somebody's just pressed a big pause button on your life…… Pause and that's you, you're stuck there for that bit of time.'*

CHD Patient 2*: I felt pains in my chest all day. I never said nothing… as brave as I am, and I was in the Monklands at 12 o'clock at night. So I asked what the……………. they said the only thing they could do would be a by-pass, which obviously didn't go down too well' and the anaesthetist said to me 'you don't have a choice.'…… Another thing he said 'you're looking as if you're really uptight', I said 'by the way, you better believe it!' So it was a case of I had to get it done.*

6.2 Diabetes Patients: Shock of being diagnosed as having diabetes

Diabetes Patient 3: *And when you went, they just made you feel as if you had something terrible, it was just…'this is what you've got', 'this is how you deal with it', 'get on with it', 'you'll never touch sugar again, you'll never do this, you'll never do that', 'that's how you're going to live', 'contact your insurance company, you can't*

drive.' 'Can't do this, can't do that'. I'm adopted…. So I knew nothing of my history, and that just terrifies me. I know nothing, I don't know what's coming…… Horrendous. I remember the day I came home from the hospital and I thought 'right, what are we having for our dinner?'. And you took something out the freezer and everything has got sugar in it.

Diabetes Patient 4: *I thought 'diabetes, dear God, there's a course of antibiotics and that's it gone sort of thing', really. He* (the doctor) *went 'oh no, you can have toes and things start dropping off, you can have heart attacks' and I was like 'what?' It stung me, and every article… it's featured a lot in the newspapers, television, a lot of articles in different… like if you're sitting in the dentist or the doctor's surgery, there's always magazines. Everything that comes out, I'll read about it. I bought myself diet books etc. It's frightening the things that you hear, and it's worrying.*

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

CHD Patient 1*: To live with it…I've never really thought about it. At first after getting out of hospital and then going to the rehab centres at Monklands, you were kind of scared, you got twinges here and there and you think 'oh, this is going to happen again.' It's just a matter of confidence and that's what the big thing is, getting your confidence back……….. It's amazing, I didn't realise how much strength I would've lost through this as well.*

CHD Patient 2: *I don't go out as much anymore. I lost a lot of confidence in going out, I'd rather stay in a wee bit more. Just in case… like, wee pains here and there walking about. What if collapse here? What if I go down? What if I don't feel well? What am I going to do? Who's going to be round about me so I can tell them? So I tend to stay in the house a lot more.*

CHD Patient 3*: Initially when I come out, I remember sitting in the house… my niece and wife come in for me and … and when I got back to the house and my brother-in-law was waiting…….I was crying a bit, this is where I felt the confidence thing because I suddenly realised there isn't a nurse or a doctor there.*

6.4 Diabetes Patients: Disruption to lifestyle

Diabetes Patient 1: *I just conk out. And that cracks me up; I don't have the energy. I walked up here, like, at snails pace, right, 20 minutes; I normally walk from the one end of Bellshill to the other in five/ten minutes. I just find myself shattered all the time, that's the drawback for me. I just can't do the things I used to*

Diabetes Patient 5 : *I mean, it's taken me a year to do a job in this house and I'm not finished, it's a job that normally I'd have it done in a month. I just pick up the tools some days and I go 'to hell with it!'…… I put them back down and I don't know why I'm doing that. I normally attack a job and get on with it, same with everything else in life, but that just doesn't happen anymore.*

6.5 Strain on Personal Relationships

CHD Patient 2: *My wife had a hard time. I didn't know what was happening so my wife suffered greatly with that……And if anything she came out the worse of it. And that kind of annoyed me.*

CHD Patient 3: *You know people are trying to help but you end up snapping at them…….'I can do it myself'.*

6.6 Fear

CHD Patient 4: *And this is the thing you know. I'd a vision of I'm going to be housebound here and that was the thing that really….at that particular point, although I was frightened, I wasn't content to remain the way I was. So I said I'm going to have to go with this (surgery). But I always had the fear, I always had the thought in my head 'do I really need this'.*

6.7 Financial Concerns

Diabetes Patient 5: *I'm on disability - have been for a while, I'm getting re-assed in a few months and if its anything like the last time….it was touch and go for a while…regarding my benefits. I cannae work not because of my diabetes but because of my arthritis but I've been a grafter all my life*

6.8 Benefits to Mental Health and Mental Well-being of Getting out and Going to A CHD Support Group

CHD Patient 4: *'We were all in the same boat really…so we all just talked 'what medication are you on?....'oh I'm on this'…'oh what are you getting that for'.'Once I got to know a few of them we would all ask each other 'what happened to you', what procedure did you get', 'well that happened to me away back then' and it was a good laugh at times'……..The problem is afterwards.. it stops and there's nothing really there…well there is the local gym but I'm not physically ready for that'*

CHD Patient 2: *I've got a lot more confidence back. I can walk about now, that's down to the class that's given me my confidence back as well. You wouldn't know where to look if they didn't send you to these classes you've not got anywhere to go apart from the GP…because I wouldn't know where to look"*

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

- **A lot of people with diabetes and/or CHD in N. Lanarkshire, especially older people are unwilling to speak about their mental health and well-being even with a health professional**
- **The stigma of mental ill-health remains a problem. Patients still see mental well-being equated with mental illness**
- **Patients often don't tell health practitioners how they are really feeling when they are asked 'how are you emotionally'**
- **Preparatory work around the introduction of QOF and the depression screening questions was poor with no adequate training**
- **We need to rapid access to information on community support services for people with diabetes and/r CHD**
- **We've 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.**
- **Communication with diabetic and/or CHD patients remains challenging for health professionals unless they know the patient well.**
- **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?**
- **Its fine to talk about holistic assessment but we don't have the time, even in the annual review**
- **Part of the problem is that the community mental health teams are essentially dealing with moderate to severe mental illness and are not tuned in to ch*ronic* illnesses like diabetes and/or CHD in the way Living Better is trying to address**
- **There is a long waiting list for Psychological therapies in primary care**

Health Professional 1: *As a manager for district nurses, if they felt the patient had a problem with depression they'd take it to the GP'.*

Health Professional 2: *As a physiotherapist we would re-refer people we think might be depressed back to their GP or hopefully be able to direct them to other services.*

Health Professional 3: (replying to above statement) *Yeah but how often does that actually happen…you write back to the person who referred them to you….I've never seen that.*

Health Professional 4: *Its ok saying practice that day than if it had been a quiet day...holistic care….I think it depends on how much time you have with the patient but if you've got 20 patients in a morning people might find there'd be less holistic care…we're all in the same boat if you are constrained by time we're less likely to pick up something in the first place.*

Health Professional 5: *It depends if you know the patient, yes you'll pick up their depression, if someone comes in the door as a new referral it depends where they are on the depression scale.*

Health Professional 6: *A lot of us don't like using the (depression) scale…… we're supposed to use it for every patient we think is depressed whereas before (the introduction of QOF) we would just ask the relevant questions and base the*

diagnosis on the severity of the answers the patient gave you. Now we print the scale off of and hand it over rather than talk to them so it does take away quite a bit I think but we have to do it.

Health Professional 7: *The depression screening came in without the training. We've been floundering for a couple of years…..the (QOF) depression questions came in, handed down on high…we've kind of evolved a system how to approach it, ask them, there's been no training in anything.*

Health Professional 8: *I think in terms of training, with practice nurses, it would be training in detection rather than assessing severity, that would be us as GPs*

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

Key Themes	Sub-Theme/s
Importance of People with LTCs/their Carers and Health/Social Care Staff being aware of locally available support services	Some people with diabetes and/or CHD were aware of locally available support services to help people with diabetes and/or CHD whilst others were not. This was also the case with some health professionals working with people with diabetes and/or CHD.
Importance and value of rapid access to support and help with decision making	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.
Importance of Support being Person-specific	People with diabetes and/or CHD have a variety of support needs; It is important to be aware that each individual's situation is unique and therefore so are their requirements. Information & support needs are dependent on person's individual circumstances.
Benefits of Sharing Experiences with Fellow Patients	For many people with diabetes and/or CHD, shared experience is important in living with diabetes and/or CHD and opportunities to discuss with fellow patients is important
Benefits of Informal non-medical, non-psychological support e.g. exercise, cooking classes etc.	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.
Importance of Confidential One-to- One Support	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

The Importance of Social Support to both Mental Well-being and Mental Health	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.
Users Want an Accessible, Informal and Neutral Venue	Importance of accessibility; Importance of friendly, open environment; opportunity to discuss non-diabetes/CHD related issues, having a 'neutral' venue.
The Benefits of Effective Partnership Working	Effective partnership working improves communication between health, social care and voluntary sector agencies working among people with diabetes and/or CHD in North Lanarkshire; In the opinion of health professionals interviewed in the focus groups, users of services directly benefited from effective partnership working

8.0 Comment and Observation from Initial Analysis of Focus Group Data

In contrast to some participants in focus groups in other research sites, a majority of people with diabetes and/or CHD who spoke about the emotional strains of living with their condition/s did so quite expressively. The older people in attendance were slightly less expressive however. 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. Patients in the focus groups, even though they did not talk about mental health (and some even refused to use the word stress) did explain and discuss that living with diabetes and/or CHD was demanding and posed significant problems that often had a negative impact on them emotionally.

As highlighted in section 2, research in the wider population has shown for some time that living with a long term condition such as diabetes or CHD can increase the risk of these patients developing depression/anxiety disorders. This is not surprising as a diagnosis of diabetes or the onset of CHD is a major life event and research has shown consistently (and not just in the case of long term conditions) that life events both acute and chronic increase the risk of onset of depression and/or anxiety, especially where social support is weak (24, 25).

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).

8.1 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 can result in a considerable loss of human potential and resources.

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 and increasingly recognised as an important social determinant of health and an important factor in tackling health inequalities (56). 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 live 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).

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).

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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 North Lanarkshire 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 North Lanarkshire 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 North Lanarkshire (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 North Lanarkshire 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.

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.

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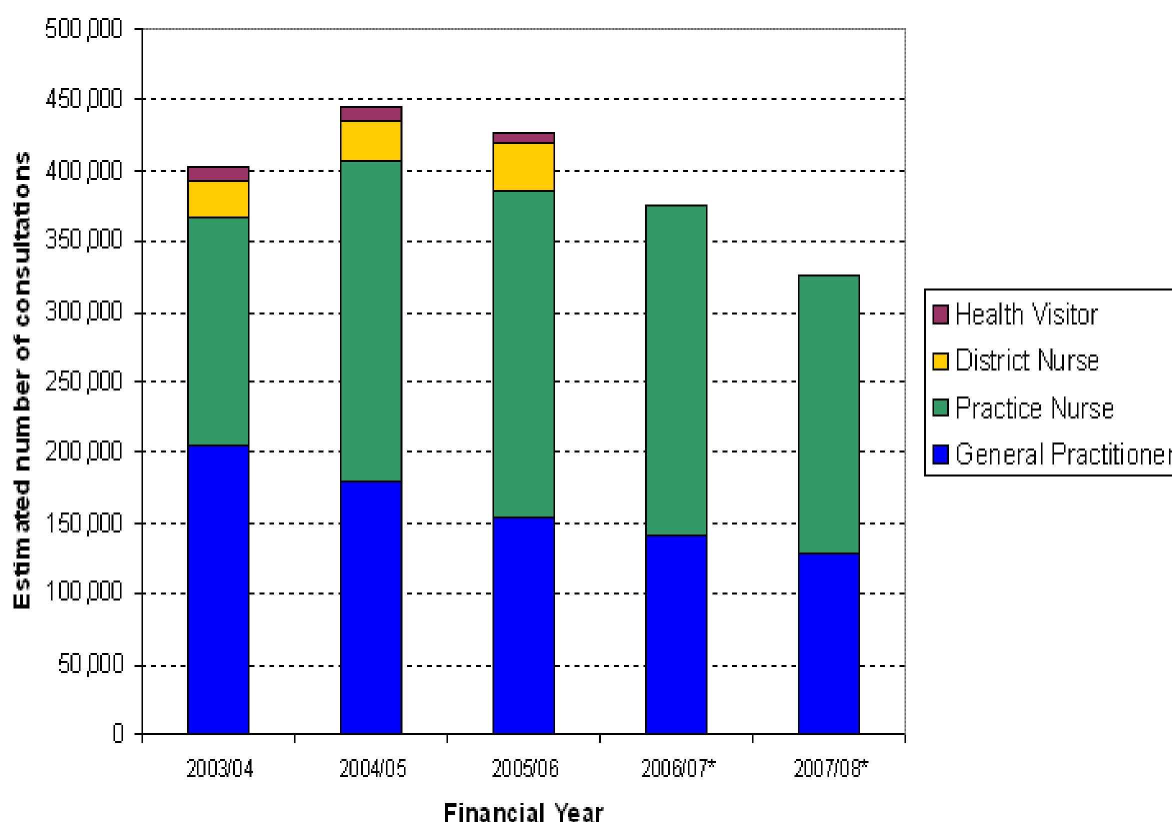
Appendix 1

Coronary Heart Disease[1] - estimated number of consultations in Scotland in the financial years 2003/04 to 2007/08 [2, 3] by staff discipline

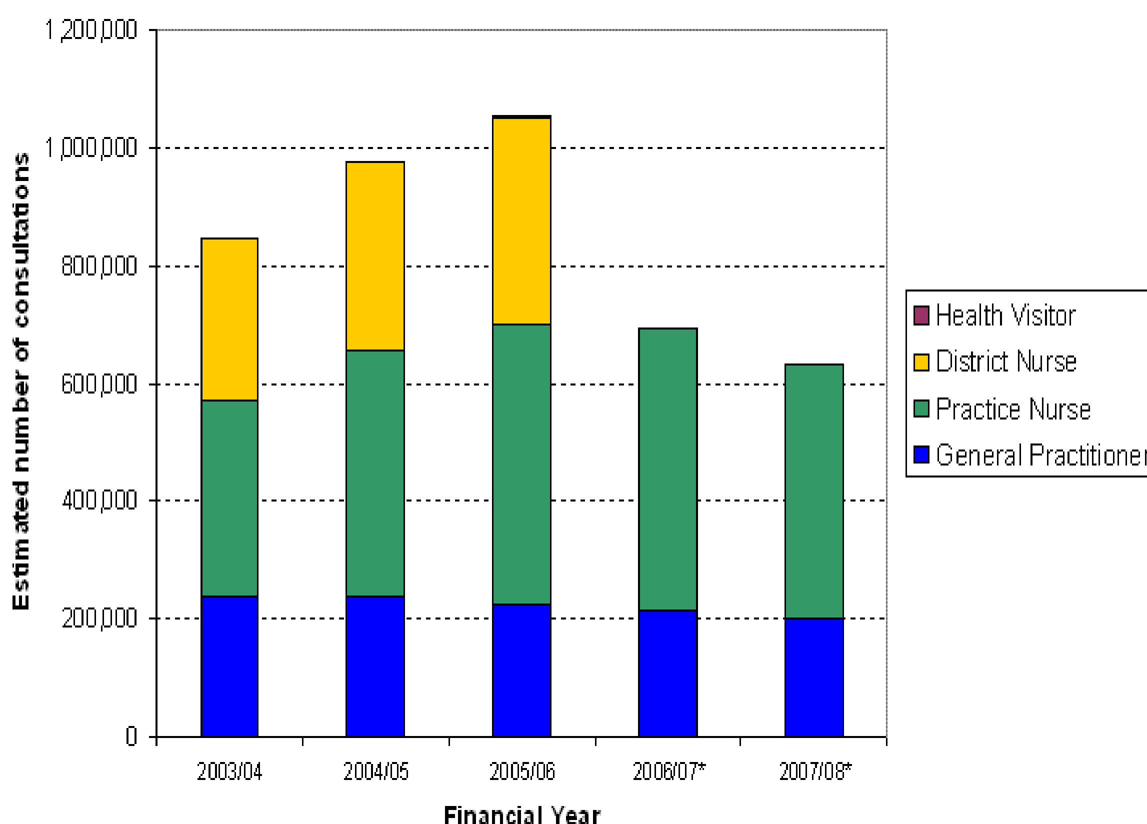


* Health visitor and district nurse data are not available from the financial year 2006/07 onwards. [1] Based on ISD's Read Code Grouping (RCG) 'Angina', 'Acute myocardial infarction', 'Ischaemic heart diseases excluding angina & acute myocardial infarction' and 'CHD monitoring'. [2] Based on 59, 53, 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

Diabetes[1] - 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).