



The Living Better Project

Addressing Mental Health and Mental Well-being in People Living with Chronic Obstructive Pulmonary Disease (COPD)

East Dunbartonshire CHP Focus Group Findings (Draft)

November 2009

1.0 General Background

A long term condition (LTC) is a condition that requires long-term medical care, limits what one can do, and is likely to last longer than one year (1). Examples include epilepsy, diabetes and chronic obstructive pulmonary disease (COPD). In their 2007 report '*Managing Long Term Conditions*', Audit Scotland reported that people with a long term condition account for 80% of all GP consultations, are twice as likely to be admitted to hospital as those without one; account for over 60% of hospital bed days and stay in hospital disproportionately longer. In 2005 the CASS City of London Business School estimated that managing chronic disease and the loss in earnings that resulted from people living with them totalled £12 billion a year. With the percentage of the UK wide population of those over 50 set to increase by 30% by 2025, they estimated this bill will increase to a minimum of £15.6 billion over the next two decades.

The real cost of long term conditions however are the physical and emotional impact they have on people.

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 limiting effect they can have on 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. The Audit Scotland report that around one million people have a long term condition and nearly a third of households contain at least one person with a long term condition.

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 COPD in particular.

2.0 The Living Better Project

The Living Better project is a three year, Scottish Government funded 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 mental health care for people with Coronary Heart Disease (CHD) and/or diabetes and Chronic Obstructive Pulmonary Disease (COPD) who, because of the acute and chronic strains of living with these conditions, are at significant risk of developing depression and/or anxiety disorders which can often go undiagnosed and untreated. The project 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 the project is focusing on diabetes and/or CHD and in 1 CHP site Chronic Obstructive Pulmonary Disease (COPD).

3.0 Chronic Obstructive Pulmonary Disease (COPD)

COPD is an important cause of morbidity and mortality in Scotland and worldwide. It is ranked by the WHO as the fifth leading cause of death globally with more than three million estimated deaths from COPD in 2005. This burden is predicted to increase further in line with the world's ageing population and with ongoing exposure to COPD risk factors (2).

The World Health Organization (WHO) defines chronic obstructive pulmonary disease (COPD) as: '*a lung disease characterised by chronic obstruction of lung airflow that interferes with normal breathing and is not fully reversible*' (2). (This is in contrast to the variable airways obstruction seen in asthma which can be reversed by drug treatment.) The airflow obstruction in COPD is due to damage to the lung structure and destruction of lung tissue. This is mainly related to smoking (more than 80% of COPD cases being smoking related), but recurrent infection also contributes to the process. Other causes of COPD are occupational, environmental and genetic. Gender may be an important factor with the condition as women develop COPD at lower smoking rates than men. Whilst increasingly treatable, the airflow obstruction seen in COPD is usually progressive. Recently the broader effects of more severe COPD have been identified and these include weight loss, nutritional troubles, abnormal skeletal muscle function, depression, and chronic infections. COPD is also frequently associated with, and may contribute towards, numerous co-existing diseases such as heart disease, osteoporosis and diabetes, which influence morbidity and mortality.

This co-morbidity is important, as it adversely affects the course and outcome of both disorders. Mortality is elevated for a number of medical conditions when associated with depressed mood, and the course of depression is worsened when there is accompanying physical illness (3). The combination of depression and medical illness is associated with increased disability, and the extent of lost productivity, health care use and associated costs is markedly increased when these conditions co-exist (3).

Again, the real cost is to people living with COPD. There is increasing recognition that patients are more likely to die from these co-morbidities than from the COPD alone (4, 5).

Common symptoms of COPD include chronic cough, sputum production and shortness of breath which can at times be very acute. People with COPD are at increased risk of chest infections, some of which will be severe enough to require hospitalisation. Measurement of lung function using spirometry confirms the diagnosis and helps to classify the severity of the disease. Spirometry is also useful to monitor the progress of the disease and the response to treatment. (1, 3, 5).

It is widely accepted that estimates of COPD prevalence underestimate the true burden of the disease. A cross-sectional study in Northern Sweden by Lindenberg et al (2006) found that only 20–30% of a random population sample fulfilling the criteria for COPD had been correctly diagnosed, with under-diagnosis being more likely in patients with mild disease than in those with severe disease (5% diagnosed versus 50% diagnosed respectively). These findings are consistent with other studies in the literature which highlight the extent of COPD under-diagnosis.

In the UK COPD is major cause of morbidity and mortality. There are approximately 30,000 COPD related deaths each year in the UK and over 1.4 million GP consultations. COPD patients occupy approximately one million hospital bed days and costs the NHS over £800 million each year (6). The socio-economic impact is considerable with both patients and their carers having to take time off work. This impacts economically on them through loss of earnings and society generally with COPD estimated to cost the UK economy nearly £3 billion a year (7, 8). Given these facts, COPD is seen as a major priority for health care services throughout the UK

Following the last review of the Quality Outcomes Framework (QOF), the Commission for Healthcare Audit and Inspection conducted an Improvement Review

of COPD (9). Their 2006 report of the review identified significant cases of unmet need and wide variations in care, with many patients not having access to the services identified in national COPD guidelines as important. The review highlighted poor awareness of COPD at primary care level and considerable under-diagnosis of the condition. The report recommended the need for personalised, structured and integrated care for people with COPD if the disease burden is to be more appropriately and better managed (9).

Every winter, hospitals across Scotland and the rest of the UK experience a surge in demand for emergency admissions, especially from older patients with acute respiratory infections or chronic obstructive pulmonary disease (COPD). This incurs huge costs (over £100 million annually in the UK), but could potentially be avoided for some patients. In addition, for older people, there is an increased risk of contracting hospital-acquired infections while in hospital, and of reduced functioning and weakened social networks after a hospital stay.

4.0 COPD in Scotland

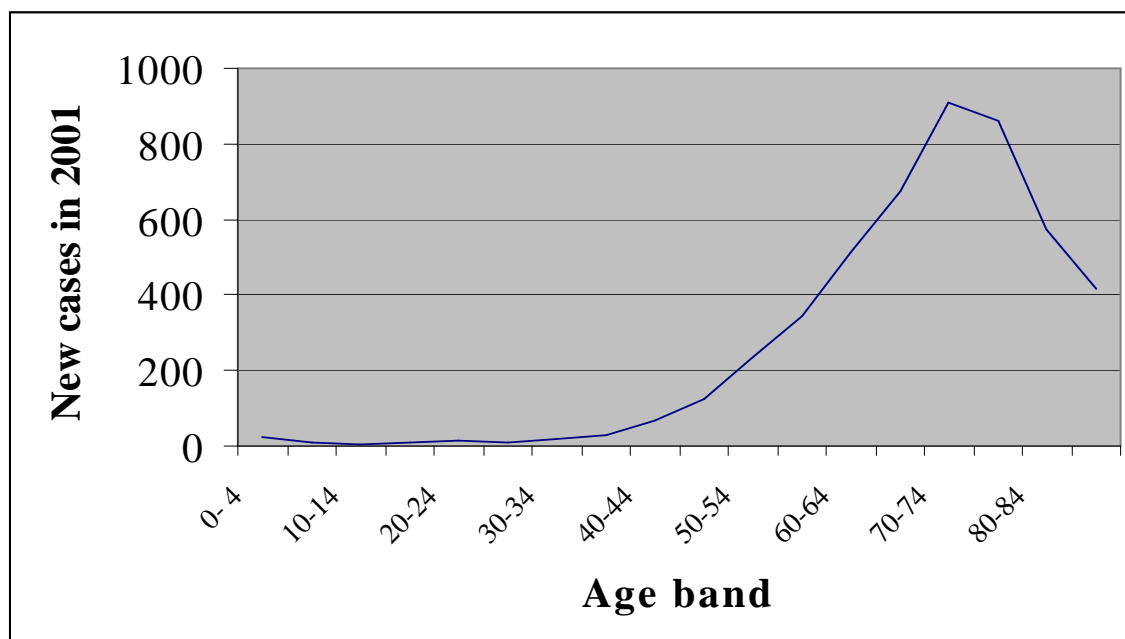
COPD is a major health issue in Scotland. Our country has many of the localities with the highest COPD admission rates in the UK. COPD accounts for over 122,000 bed days and 4,500 deaths every year and Audit Scotland has estimated the direct cost of COPD to NHS Scotland to be around £100 million per annum (2).

The real cost of the condition however is to those patients living with the condition. British Lung Foundation Scotland have highlighted that COPD is a significant problem for many people in Scotland and is a condition which limits a patient's lifestyle, opportunities and potential. They report that there are approximately 100,000 people living with COPD in Scotland with the number expected to rise by 33% over the next 20 years. The burden of COPD is widely recognised to be underestimated with as many as two thirds of cases undiagnosed. People in deprived areas are nearly four times as likely to be admitted to hospital for COPD as from more affluent areas. COPD is the third most common reason for an acute hospital admission in Scotland. Despite a considerable decline in smoking rates over the past 25 years morbidity and mortality from COPD in Scotland remain high (9). The Information and Statistics Division (ISD) of NHS Scotland estimate that in 2007/08 there were over 200,000 COPD patient consultations with doctors and practice nurses in primary care.

Whilst the burden of COPD has historically been greater in males, over the past 25 years females in Scotland have had a greater increase in the rate of COPD admissions compared with the increase seen in men; dramatic increases in the rate of deaths attributed to COPD (compared with a decrease in males); and a slower rate of decline in smoking rates compared with men (2). The ageing of Scotland's population does not fully account for these trends, which may be explained by the fact that COPD rates fall many years after declines in smoking rates. Thus the current burden of COPD in Scotland may, in part, be due to the high smoking rates seen 30–40 years ago. Increased awareness of COPD and its inclusion in the primary care quality and outcomes framework (QOF) may also have contributed to increased diagnoses (1,2, 3, 4).

5.0 Epidemiology of COPD

Although COPD can exist in all age groups, as the graph below demonstrates it is most common in older people aged 65 years and over.



Source: British Lung Foundation Scotland (2008).

6.0 COPD: The Impact of Illness to the Individual and their Families

Research studies have highlighted that providing effective management of COPD can be difficult with care providers sometimes experiencing a sense of nihilism from COPD sufferers (11, 12). It is believed this is related to perceptions in many patients that COPD is self-inflicted through smoking (despite the fact that when they took up smoking they were unaware of the consequences and that it was frequently advertised as stylish), that people with COPD can be comparatively resistant to treatment and that the COPD is progressive and incurable (11, 12). To add to this, patients often do not receive a formal diagnosis until they have moderate or severe COPD (11, 12). Research has also found that the burden of living with COPD can have a very negative impact on quality of life, with COPD patients experiencing high levels of anxiety/depression; poor quality of life including pain; information needs not being met; poor social support, specialist palliative care lacking; and intermittent support from respiratory nurses (11, 12).

Given the impact of illness, spouses and wider family members of COPD patients are also affected by the condition. In two studies, the spouses of COPD patients reported levels of loneliness and depressive mood comparable to the levels reported by the COPD patients themselves (13, 14).

Compared with non-depressed COPD patients, COPD patients with elevated depression scores show lower health-related quality of life (15, 16), a lower level of functioning (Kim et al 2000), longer and more frequent hospital stays (16), and increased mortality, as shown in prospective studies (17). Similarly, increased levels of anxiety lead to impairment of quality of life (18, 19) and more frequent hospital admissions in COPD patients (20).

7.0 The Psychological Impact of Living with COPD

As well as being physically debilitating, COPD presents a significant challenge to the psychological well-being of individuals and their families it is recognised to have an impact on health-care services, resources and time. Individuals with respiratory illnesses like COPD have a complex psychological profile and about a 50% chance of experiencing panic and/or clinical levels of anxiety (16)

Patients with COPD appear to have a significantly higher risk of becoming clinically depressed than healthy individuals and patients with another common chronic condition such as diabetes. Depression affects approximately 40% of patients with COPD, however research by Kunik et al (2005) found that only 31% of COPD patients with depression or anxiety are being treated (22, 23, 23b).

Health-care providers in the UK recognize the importance of the early detection and management of chronic degenerative respiratory diseases due to their high mortality and morbidity rates (one in four deaths in the UK National Institute for Health and Clinical Excellence (20) (NICE, 2004). However, there is less awareness of the need to manage the extensive psychological needs of respiratory patients living with a chronic condition like COPD. In 2004 NICE guidance on the management of COPD (NICE, 2004) highlighted the need to manage the psychological well-being of people living with chronic respiratory conditions and to assess and treat mood disorders in particular, rather than simply focusing on medical care and treating the lung pathology. Research suggests that symptoms such as dyspnoea, persistent cough, sputum production, fatigue and progressive disability lead to considerable difficulties with psychological adjustment and quality of life (21- 23b).

8.0 Recent National Institute for Clinical Excellence (NICE) Guidelines on Depression & Chronic Illness

Last month, the National Institute for Clinical Excellence (NICE) published their new guidelines for depression with a chronic physical health problem. Of particular concern to the Guideline Development Group was the high incidence of depression in patients with COPD (which is also known to be associated with a high incidence of anxiety disorders). The Guideline Development Group considered it important to measure the effectiveness of antidepressant medication in the treatment of COPD. The answer to this question has important practical implications for service delivery, particularly for a patient group with mental health needs that are traditionally under-treated within the NHS.

Despite these factors, evidence has been forthcoming that quality of life in COPD patients can be improved and morbidity and mortality levels reduced (McKenzie et al. 2006) with a shift from reliance solely on pharmacological management to a range of interventions including patient education, pulmonary rehabilitation, self management of exacerbations (McKenzie et al. 2006) and a more holistic patient-centered approach when providing care (Barnett 2004, Casas et al. 2006). These more proactive, integrated chronic disease management approaches are very much in tune with Scottish health care policy, i.e., focusing on self management of long term conditions and a more holistic approach to patient care.

9.0 The Living Better Project's Research Questions in East Dunbartonshire

- (i) How does Living with COPD affect People's Mental Health and Wellbeing
- (ii) What Type of Support do these people Want and Need to Address their mental health and wellbeing needs.

- (iii) Do Health Professionals Working with these Patients feel Suitably confident/trained to Address Mental Health and Wellbeing Issues in these Patients
- (iv) What has to be done at CHP and GP Practice Level to Develop Appropriate Support/s to Address These Patient's Mental health & Wellbeing.

10.0 The Research Process in East Dunbartonshire

To discuss how living with these long term conditions affects peoples' mental health and wellbeing patients with COPD were selected from 2 GP practice registers and invited to attend four focus groups in their respective areas. Two focus groups involving health, social care and voluntary sector staff working with these patients were also organised.

11.0 Methods

1. Working with East Dunbartonshire Living Better reference groups consisting of appropriate health and social care staff working in COPD and COPD related care.
2. Patients with COPD selected from COPD registers.
3. Four patient focus groups (involving over 35 people) were organised
4. One health professional and one Living Better Reference Group focus groups (involving over 12 professionals)
5. The research findings are reported back to the CHP Living Better reference group to help them develop appropriate plans to address the mental health and wellbeing needs of COPD patients.

12.0 The Research in East Dunbartonshire

The focus groups discussed;

- (i) what it was like to live with COPD;
- (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;
- (iv) 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;
- (v) whether health, social care and voluntary sector professionals believed services at CHP level were equipped to address these issues and
- (vi) in the opinion of both patients and professionals, what changes should occur locally to address mental health and wellbeing of people with these conditions. The same questions and methods were used across all 5 participating CHP sites.

7.0 Summary of Research Findings in East Dunbartonshire

7.1 Summary of Findings from Patient Focus Groups

Living with COPD is both an Acute & Chronic Stress and Impacts on Patients in the Following Ways

- Shock of being diagnosed with COPD and/or acute event around COPD
- Feeling that family and friends do not understand the strains of living with COPD
- Frustration over lifestyle changes
- Loss of confidence
- Strains on family and wider personal relationships during acute phase of COPD
- Frustration
- Anger over lifestyle disruption
- Worry about contracting a chest infection
- Fear – especially with acute bout of coughing and lack of breath
- Financial difficulties can lead to social isolation as can't afford tax
- Social isolation due to having to stay in the house
- Loss of purpose in life
- Restrictions to lifestyle and employment opportunities
- Embarrassment
- Guilt
- Accessibility/Transport problems

7.1.2 Some Typical Focus Group Comments from People Living with COPD.

The Impact of Living with COPD

Patient 1

Well I've got COPD, had it for three years. Now I'm not under any stress and I'm not breathless, it's only when I get breathless. And when I get breathless I'm not interested in anybody else except me. Once I come out it I'm fine, I forget about it and I carry on, but just when it's happening. And I know when it's happening because I get a pain right through my back and round my shoulder blades, and I know it's coming and it's quite bad, you know. I've got three puffers I've got to use. At this time I've not got it, I feel fine, it doesn't bother me so I can cope with that, it's just when I've got it I've no time for anybody, I'm not interested in anybody or what anybody's got to say. It's just me, I'm only in my own wee world.

Patient 2

Well I contracted the condition about a year and a half ago. I'd been off smoking for 16½ years, so I felt cheated that I contacted that condition! what I got was it was like a rising in the chest, I couldn't understand. It was rather like a bottle filling up, you know, you felt this rising in the chest.

Patient 3

I find I get quite stressed, not frustrated but stressed. When I go into a mixed company where there are people smoking, that's very difficult to deal with. And also if women wear heavy perfume that really, really catches me, and also exhaust fumes are very bad for me personally. And I find myself getting quite uptight when I'm in that sort of situation which I can't do anything about.

Living with COPD can be Frightening

Patient 4

'I would say (the feeling) is fright. When you really can't get your breath in the middle of the night and you wonder... your heart's racing... and you wonder if it's the last breath you'll ever take'.

Patient 5

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

Patient 6

You think you're going to die. See when I took pneumonia, you feel you're going to die because the oxygen's not coming to your brain, you begin to hallucinate. And I remember saying to myself at the time 'don't let me go without saying goodbye' because I thought that was it. But lucky enough I got a breath and I went to the hospital and that's when they found out... Now, when I get this attack, it minds me of pneumonia, I feel as if I'm going to die.

Living with COPD is Frustrating

Patient 7

Frustration I think is the word. I've had it for 16 years, I've lived with it 16 years and I find the same, frustration. People don't understand the condition, they say 'oh you look great', you walk ten yards and you're like that... and you're saying 'aye, I feel great'. It grows on you gradually. When I first got it I was terrible, I really was, and then the frustration was waking up through the night with an attack, that's the worst thing, through the night.

Financial/Transport Problems can cause Social Isolation

Patient 8

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

Living with COPD can be Embarrassing

Patient 9

I found it embarrassing. When you're coughing and spluttering and you're not able to draw a breath and you don't know where to go to get rid of whatever it is that's bothering you, and you're very much aware that everybody round about is looking at you. People rush to give you a drink of water and you're really not needing a drink of water, but you just want to get rid of it and I find that really embarrassing.

Patient 10

And, you know, it was pretty embarrassing and unpleasant, because like that lady said, I was in London with my husband before Christmas and every night after dinner, I had about half an hour as you had, just coughing up this stuff; and it was just revolting' .

Patient 11

These secretions, and it was embarrassing, because I had a cough like ... d'you know what I mean.... Coughing all night long and I felt my neighbours would be taking out an anti-social behaviour order, it was just so awful'.

Worry about Catching a Chest Infection

Patient 12

Could I say that I worry sometimes when I'm surrounded by people who've got the cold, because I know I don't take the cold, I take a chest infection, and before I know it I'm on nebulisors and drips and all that. And I dread being near people with the cold. And you can't always withdraw from that situation really, and you can't always cover your nose and people don't always cover their nose, and I know that I worry, I get myself quite uptight about that.

People don't understand what its like living with COPD

Patient 13

They don't, ah but see if you tell them you've got COPD or you've got emphysema, they don't know what that means. But if you tell them you've got lung disease then they go 'oooh!'

Patient 14

I mean, people don't think there's anything wrong with me, do you? I mean, I look fit and I look fine, and I'd be walking along the road or be cutting the grass, somebody passing and they're talking to you, but as soon as I hit that wall, it's like a marathon runner, soon as I hit that wall, that's it. I could be bending down cutting the grass and it just gets me and that's it, I'm finished, stop, I can't go anymore. I'm not interested in anybody else, somebody could pass and say hello, I'm not interested

Living with COPD is both an Acute & Chronic Strain

Patient 15 - Chronic strain

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

Patient 16 – Acute strain

I timed it one night, I coughed for an hour and a half non-stop in my bed. Non-stop, and you just couldn't take a breath in; and again, they were starting again, and I got up in the morning and coughed my guts out and the inhalers weren't doing any use'.

Living with COPD can strain Relationships

Patient 17

It annoys them (family). My husband would say 'you're coughing again, you wanting attention', and I'm saying 'no, I'm not, I can't help it' this is it. And I've told them to go on the internet and read all about it, but I don't think they did.

7.2 Types of Support Patients Wanted/Needed to Help Ease the Stresses of Living with COPD

Living Better asked people what type of support/s they would like to help cope with the emotional demands of living with COPD. This is a summary of what people wanted.

- **Broad social support services – Levels 1 & 2, e.g., support classes (exercise, breathing, general talking) to share experiences exchange information and improve self care to ease the burden of living with COPD.**
- **Easier and more rapid access to health worker or fellow patient/s to confide in on a one to one or group basis.**
- **General talking support, either face to face or on the telephone.**
- **Access to COPD only exercise classes to help manage their physical condition so as not to feel awkward/embarrassed in the event of getting into physical difficulties e.g., coughing bout.**
- **Financial/benefits advice to address financial consequences of living with COPD**
- **Greater support with and access to public transport.**
- **More information about locally appropriate support services provided by health, social care and voluntary sector services.**
- **More' talking time' with nursing or other health/social care staff.**
- **Counselling**
- **Greater advice & information about drugs they have to take for their condition.**
- **For people living alone the chance to speak with someone late at night/early hours of the morning**

8.0 Key Findings from Health Professional and Reference Group Focus Groups

In both focus groups there was a belief that advances had been made in addressing mental health and well being issues in people with chronic illness in East Dunbartonshire. Attention was drawn to the preparations and planning of training for Practice nurses in East Dunbartonshire to address mental health issues in people with chronic illnesses like COPD. The event had to be postponed but the feeling was expressed that the time invested in this event indicated that addressing mental health in people with COPD was 'on the radar' in the CHP. The view was expressed that progress had been made with partnership working between health and social care in the CHP area. The following is a summary of key issues raised in both focus groups.

- **The Quality Outcomes Framework (QOF) mental health questions can feel like 'going through the motions'. A feeling of '*what happens next*'? after QOF questions or using HADS/PHQ9**
- **Missed opportunity to improve mental health awareness skills when the planned training for practice nurses on addressing mental health issues in people with chronic illness had to be postponed. Nurses expressed a desire for the mental health and mental well-being awareness training that was postponed to go ahead next year.**
- **Adequately addressing mental health issues in patients with COPD is influenced by time and the experience of practice nurses.**
- **Lack of time to draw out emotional issues in COPD patients can cause 'hesitancy' in addressing these issues and concern over opening 'Pandora's Box'. Nurses would like more time with patients to tease out mental health issues**
- **Need to improve on how we signpost existing services that could help address mental health and wellbeing of COPD patients**
- **The stigma of mental illness remains a problem in addressing mental health and wellbeing in people with COPD.**
- **As a service Practice nurses should draw on patient knowledge of other health and social care workers who can sometimes have more time to spend with their COPD patients (e.g., local authority support workers and District nurses). They can use this knowledge to get information of their emotional state of mind and whether a house visit or quick phone call is required.**
- **Need for greater knowledge of how to access, and signpost, existing COPD support services. More information about COPD relevant NHS and non-NHS services at CHP level.**
- **Greater integration of appropriate community health, voluntary and social care services, especially between CHPs, GP practices and social services.**
- **Whilst progress has been made in taking a more holistic approach to managing COPD patients – the predominance of the medical model and cultural outlook of patients – can make taking a holistic approach difficult**
- **Build on progress made in partnership working with local authorities to utilise and also develop social support services for patients with COPD.**

8.1 Some Typical Comments from Health Professional and Reference Group Focus Groups.

Need to be more Subtle about asking COPD Patients about their mental health and well being

Health Professional 1

I used to be a practice nurse myself and looking at the (QOF) questions.....before you actually speak to the patient, you should be aware of what kind of questions you're going to ask them regarding their mental health and sort of incorporate that in the conversation and just draw out how they're feeling over the course of the conversation, rather than just asking them blunt questions. And that's probably down to experience of the individual professional but you can train people around that.

Hesitancy about asking people about their mental health if don't know patient well

Health Professional 2

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

Given the time Nurses can address mental health and wellbeing in patients with COPD in a more thorough way but time isn't always available

Health Professional 3

I would say certainly as regards experienced practice nurses... many of the practice nurses have been working with the mental health template now since 2003/2004 and I would say for those practice nurses they would probably argue with you that, certainly if they're given 30 minutes, that they would be able to engage with the patient on mental health issues.

Health Professional 4

But I mean, nine times out of ten, practice nurses only have a limited period of time to deal with things like properly addressing mental health or even giving advice on what would help and the only other thing they would do is invite them back. The time's a big constraint when you've got people sitting outside. The time constraints are as bad as the GPs.

Communicating with COPD patients is important for the mental wellbeing

Health Professional 5

From the feedback the research findings from the patient focus groups have said is that people are keen on low grade activities, peer support, socialisation, I think even somebody phoning up and saying 'how are you?' on a regular basis... and then reporting it back to someone at a higher level that can make decisions. So you're not really looking for this person to analyse how these people are feeling, they're actually just task orientated.

Address time constraints and strengthen knowledge of COPD patients' emotional wellbeing by inking up with other health & social care workers working with these patients

Health Professional 6

I think the other on tap resource is to look at homecare workers, because they're often in people's houses. And I know even from a personal point of view, my father listens to homecare workers more than he listens to me because they've established that relationship. I think we put a lot of pressure and emphasis on homecare workers to signpost people to a lot of things, but it's still maybe worth an opportunity.

Need to give nurses the confidence to address mental health issues

Health Professional 8

I think we also need to train the staff because we're talking about a plethora of long term conditions and anxiety and depression may underpin a lot of those. We need to be competent whoever asks those QOF questions, that they can deal with whatever comes up, or to signpost to a mental health specialist if required, but at least at the minimum level to be confident to deal with it at the time.

Progress has been made in taking a more holistic approach to managing patients living with COPD

Health Professional 7

There's the local enhanced service which certainly looks at lifestyle management and takes into more a sort of holistic social component of living with COPD and that was due to be rolled out in May of this year, and unfortunately that didn't take place. There was a lot of preparation and, you would say, hype around it as well too, and the practice nurses were very, very much ready to engage with that, and it really was a big disappointment for them when it didn't happen. And we actually received the backlash of it at primary care.

Partnership working between health and social services helps address mental health and wellbeing of COPD patients

Health Professional 9

In this area, the relationship between home carers and is really, really good, so they work quite closely with the district nurse, so they're familiar with each other so they can come back and have the conversation face to face, or they phone, do it in a phone call. it has been in the past that maybe the home carer has come back and said 'oh Mr so and so is not eating, he hasn't eaten for over two days or whatever', she feeds that back to the district nurse. The district nurse will go in and speak to him about it, if there is a problem she could then feed that back to the GP who then takes it on and has a discussion with the district nurse how they're going to take that forward.

Need to strengthen partnership working with voluntary sector

Health Professional 10

I think where we're not good at partnership either health or social work with the voluntary organisations. That is a massive gap and is inconsistent and sporadic, and that's a phenomenally on tap resource that we don't use.

Need to improve on how we signpost existing services that could help address mental health and wellbeing of COPD patients

Health Professional 11

We have to be more cohesive in what we are providing, because as you said, the services are out there, but they're not linked together; if we could provide a resource pack or information or something that you can give to patients that they can refer back to, because their needs will change at different stages of the disease process.

9.0 Conclusions from Focus Group Findings and Recommendations

- **Nurses, AHP and health support workers, in collaboration with social and voluntary sector colleagues, have a vital role to play in addressing the mental health and wellbeing needs of patients living with COPD.**
- **Greater mental health and mental well-being awareness training should be provided to nurses, AHP and health support staff working with COPD patients.**
- **Improved signposting of existing health, social care and voluntary sector services is needed to address mental health and wellbeing issues in people with COPD**
- **Build on existing Partnership working with local council and voluntary sector services to address access/transport issues, provide easily accessible financial/benefits advice, and accessible and affordable exercise/leisure facilities and other social support needs of people living with COPD**
- **Social support services are non-complex and low cost interventions that have the potential to bring significant benefits to these patients.**
- **Greater recognition of the benefits of developing appropriate social support services as highlighted in the report should be discussed and planned by East Dunbartonshire Living Better reference group.**

10.0 Some Comments and Observation from Initial Analysis of Focus Group Data: Locating the Data in the Literature

10.1 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)

10.1.2. 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 CHD and COPD and 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).

Approximately three decades after the publication of '*The Social Origins of Depression*', the World Health Organisation published '*Social Determinants of*

Health: The Solid Facts. This report emphasised the importance of social support as an important social determinant of health generally and an especially important factor in positive mental health and wellbeing (56). The report noted that:

Social support and good social relations make an important contribution to health. Social support helps give people the emotional and practical resources they need. Belonging to a social network of communication and mutual obligation makes people feel cared for, loved, esteemed and valued. This has a powerful protective effect on health. Supportive relationships may also encourage healthier behaviour patterns.

People who get less social and emotional support from others are more likely to experience less well-being, more depression, and higher levels of disability from chronic diseases (56: p.22).

10.2 The Importance of Social Support to People with Chronic Illness

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).

This support is often needed because of the psychosocial impact of a diagnosis of COPD. 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 COPD, 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 Scotland with COPD said they wanted, this came in a number of different forms. It can be a group form of support

such as a COPD support group, a COPD exercise or Breath Easy group where people affected by the condition share experiences with each other, a more individual one-to-one type of support of sharing or confiding, rapid access to locally available general informational/educational 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 COPD have been shown to be more effective at one or more of these time periods.

10.3 The Importance of Psychosocial & Social Support to Patients with COPD

The British Lung Foundation Scotland has noted that in people with mild to moderate COPD, psychosocial and social support are effective in helping COPD patients live with their condition (2). COPD patients with breathlessness can often avoid exercise and become unfit and de-motivated. They can become anxious, depressed and socially isolated. Pulmonary rehabilitation addresses all these issues (Diagnosis and management of chronic obstructive pulmonary disease in primary care: A guide for those working in primary care (2007). Gore (2000) noted that social support was often lacking for COPD patients in community but that where social support was provided it made a positive difference to COPD patients' psychological well-being.

A key feature when considering the psychological impact of COPD is that there is no cure and therefore interventions are designed to minimize the worsening of the disease process, assist the patient to regain the best quality of life attainable and to prevent the secondary effects of chronic disease such as depression and social isolation. Scott (2004) noted that people with COPD have to cope with highly changeable and distressing symptoms and that they manage their condition much more effectively when they feel that there is someone whom they can contact for healthcare advice and support.

When Young et al (1999) conducted a project to determine whether persons who declined participation in, or failed to complete, a COPD rehabilitation programme they aimed to find out whether there were significant differences in terms of socio-demographics, physiological parameters or psychological factors, from those who completed the rehabilitation programme. They found that a substantial proportion of eligible subjects who did not participate in a COPD rehabilitation programme were not more physiologically impaired, but were more likely to be: socially isolated, lack chronic obstructive pulmonary disease-related social support, still be smoking and be less compliant with other healthcare activities. The researchers concluded that identification of one or more of these factors reliably allows prediction for non-adherence to a rehabilitation programme.

After reviewing the treatment options for addressing depression in people living with COPD, Alexopoulos et al (2008) suggest that pharmacotherapy, psychotherapy, and interventions aimed to increase treatment adherence can be helpful in depressed COPD patients. However, administered alone, each approach offers limited long-term benefits in reducing depression and disability. Many COPD patients will be offered anti-depressants as a result of the impact of the illness to their emotional state of mind. This offer is often refused and patient reluctance to receive antidepressants further reduces their impact. One study showed that 72% of depressed elderly COPD patients refused antidepressants, and only 50% of those agreeing to treatment completed a trial of fluoxetine (Yohannes et al., 2001). Alexopoulos et al (2008) argue that limited efficacy and poor acceptance of anti-

depressants in patients with COPD suggests that psychosocial interventions may play an important role in the treatment of these patients.

10.3.1 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).

11.0 Some Observations and 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 Scotland for the financial year 2007/2008, the number of consultations with a GP or nurse at least once in primary care for a patient with COPD totalled over 200,000(45). 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 COPD 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 can 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 COPD. 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 COPD.

Following the focus group findings and literature review contained in this report, the next steps for the Living Better reference group in East Dunbartonshire will be to discuss what to do with this data in terms of linking it to re-assessing services for people with COPD locally.

12.0 Quality Outcomes Framework (QOF) Questions are a Step Forward – But More Needs Done to Sensitively Address Mental Health issues in People with Chronic Illness

Statistics from ISD NHS Scotland show that in the financial year 2007/2008 most COPD consultations' in primary care were with nurses (see Appendix 1). Nursing staff we spoke with 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 East Dunbartonshire working with people who have COPD (and elsewhere in Scotland from health professionals working in diabetes and/or CHD care) 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 COPD often experience.

Addressing depression and anxiety is a complex process. 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 many as 50% of people with depression/anxiety in primary care can be undiagnosed, even after completion of HADS/PHQ9 scores.

12.1 Nurses, AHP Staff, Health care Support Workers and Social Care Staff have a Key Role in Addressing Mental Health & Wellbeing in COPD Patients

With at least 80% of patients with depression being treated entirely in primary care practice and specialist nurses are already seeing these patients for a variety of other reasons (59, 60). As noted earlier however undiagnosed depression remains a problem in primary care with approximately 50% undetected (stigma remains a problem) [11b, 60]. A key finding of Living Better focus groups is that for practice and specialist nurses to feel confident and competent in taking a more active role in detecting and treating depression, vital they have access to evidence-based training, mentoring and supervision. It has been found that, with effective training, Practice & Specialist Nurses can achieve excellent patient outcomes working with GPs in assessing and managing depression (60, 61, 62).

In the February 2009 special edition on depression the British Journal of General Practice editorial '*Managing Depression in Primary Care*', noted

"Evidence suggests collaborative models of care may be most effective here using a multi-professional approach to patient care involving a GP and a case manager (a professional or paraprofessional providing regular contacts with the patient about medication or psychosocial support)...Balint's idea of 'Dr is the drug' needs to be enhanced and broadened to include the whole health care team....and non statutory services".

A 2007 issue of Practice Nurse (63) carried an article on training practice nurses in mental health & wellbeing which concluded;

“Greater Integration will enable nurses to offer improved, fully holistic, individualized care to their patients by working with them to achieve improved wellbeing..... nurses can also encourage patients to engage with community activities that can impact positively on their mental health....

Practice Nurses can, with training, take on an enhanced mental health role (it has been) illustrated that the wellbeing agenda, which is currently so high in our government’s health priorities, can be embraced by practice nurses who will find that, with targeted training, they can better support patients to achieve a sense of increased purpose, meaning and fulfilment in their lives” (16: p. 227).

12.2 New Nice Guidelines Underline Key Role of Nurses in Addressing Mental Health & Wellbeing in People with Chronic Illness

Last month the *International Journal of Nursing Studies* contained an editorial on the new NICE guidelines on managing depression in people with chronic conditions published on 31st October. The editorial was aimed specifically at nurses and midwives. In the section ‘Implications for Nurses’ the editorial notes

Nurses play a key role in the detection and the management of depression. Practice and district nurses, and nurses working in general hospital and intermediate care settings are particularly likely to be caring for people who are experiencing chronic physical health problems..... these individuals have increased vulnerability to depression, and the combination of mental and physical problems has clear and marked effects on quality of life, functional disability, and disease course. Nurses – who play a central role in all aspects of the care of these patients – there is a crucial opportunity to identify and assist in the management of depression.

This work requires knowledge of the presentation and evidence-based management of depression, and skills in assessment and interventions that will promote appropriate adaptive responses and concordance with treatment plans. Working with people with chronic physical illness, and their families and carers necessitates a central focus on patient and carer education and the promotion of self-management approaches; and where depression is a part of the clinical picture this guiding principal of care remains of key importance and will require additional knowledge and skill on the part of health professionals.

Practice innovations in a number of countries have highlighted the role of nurses in primary care within a collaborative system of care, and this new NICE guidance gives added impetus and direction to these developments based on rigorous evidence review. (page 1414).

12.2 The Benefits of Pulmonary Rehabilitation Exercise to Physical and Emotional Health of COPD Patients

In the four patient focus groups, COPD patients spoke of the positive benefits both physically and socially in attending the exercise classes for people with breathing difficulties and respiratory illnesses. They spoke of how these classes were;

'good because they get you out the house', 'because they are attended by people with the same or similar condition as you, you don't feel embarrassed if you get a coughing fit', 'you can talk with people who are have the same problems as you and that's good because they understand'

In 2007, in co-operation with the British Lung Foundation, the General Practice Airways Group published '*Diagnosis and management of chronic obstructive pulmonary disease in primary care: A guide for those working in primary care*'. The report highlighted the benefits to COPD patients of pulmonary rehabilitation in the form of mild exercise. Pulmonary rehabilitation (PR) is a multidisciplinary programme of care for patients with chronic respiratory impairment such as COPD that is individually tailored and designed to optimise each patient's physical and social performance and autonomy. Rehabilitation is a key aspect of COPD management. Whilst the report notes that PR is not suitable for patients unable to exercise, COPD patients who lack motivation do need encouragement. COPD patients with breathlessness often avoid exercise and become unfit and de-motivated. They become anxious, depressed and socially isolated. Pulmonary rehabilitation (PR) addresses all these issues.

The General Practice Airways Group report pointed out that there is strong evidence that PR exercise is cost-effective. However, despite its proven benefits, they estimated that it is only available to 2% of suitable patients.

The Components of PR Exercise Involves:

- Individually tailored and increased during the programme
- Involves supervised exercises preferably twice weekly, although once weekly can be effective
- Upper- and lower-limb exercises
- Usually in a group with an exercise regime to be followed at home

There is also an educational and informational element to the PR programme with the main topics being:

- Relaxation
- Breathing control
- Pathophysiology
- Drug treatment
- Self-management
- Benefits, social services

Setting of PR Exercise

In the past PR was mainly hospital based, but increasingly it is performed in the community. The report highlights the advantages for COPD patients in terms of access, but notes it is important that location and the programme are risk-assessed and accessible via public transport.

Follow-up

The 2007 GPs report concludes on the importance of offering a means of continuing the exercise programme. Some have regular follow-up sessions, some refer to exercise on prescription schemes, and some to the local patient support group, e.g. *Breathe Easy*.

13.0 The Importance of Partnership Working in Addressing Mental Health and Wellbeing in People with COPD

In addition to training nursing, AHP and health support staff in primary care to address mental health and wellbeing in people with COPD, equally important is the need to develop effective partnerships with local authority staff and services. Areas such as transport, financial and benefits advice, and exercise facilities are all under the auspices of local authorities. Given the importance of these issues to people with LTCs, effective working to address mental health and wellbeing in these patients will therefore be partly dependent on good partnership working between CHPs, the voluntary sector and local authorities.

Long Term Conditions Alliance Scotland and the Scottish Government have highlighted the importance of partnership working to address mental health and wellbeing in people with long term conditions with the launch of the Self Management Fund. This was a key recommendation of 'Gaun Yersel' - The Self Management Strategy for Scotland' published in 2008.

The Self Management Strategy is informed by the lived experiences of people with long term conditions very much like those who participated in the Living Better focus groups held throughout Scotland. The Strategy calls for:

- People to have more access to high quality information about their condition and its impact on their life.
- People to have more access to support including peer support.
- Increased provision of emotional and mental health support for people with long term physical conditions.
- A change in culture so that people - those receiving and those delivering services - have the confidence and capacity to work together as partners.
- Better partnerships working by NHS, voluntary sector and local authorities.

14.0 An Example of Partnership Working to Address the Financial Concerns in People Living with a Long Term Condition

A practical example of the importance and benefit of effective partnership working was seen in August this year with the '*Extension of the Macmillan Tayside Welfare Benefits Project*', initially a project aimed at providing benefits advice to people affected by cancer (increasingly being treated as a long term condition). Following discussion between Macmillan Cancer Support; Dundee City Council, Angus Council; and Perth and Kinross Council a joint working arrangement has been proposed to augment the Tayside Welfare Benefits Project into long term conditions. In parallel to the development of cancer specific services this will be designed and delivered through a partnership between the relevant clinical teams and the advice professionals with the Macmillan Tayside Benefits Project. In turn it will pilot the value and impact of integrated benefits and financial advice for people and their families who are dealing with the social/economic impact of living with a long term condition.

Home visiting and direct advice in clinical settings will be used to deliver an effective service to both cancer and long term conditions patients and their families. The project will also provide a 'gateway' into established specialist welfare benefits advice, money advice and information services provided by Angus Council, Dundee City Council and Perth and Kinross Council. Initiatives such as this represent the way forward in developing collaborative, 'joined up', holistic support systems for people with long term conditions.

15.0 Living Better and Learning from other Scottish Wide Initiatives

It is important to note that given existent time pressures on GP and nursing staff, 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). This is especially relevant given the recently published *'Nurses' Employment and Morale Scotland 2009 Survey'* which was released in October and showed that over half of nurses (52%) said they were too busy to provide the standard of care they would like and 51% saying that there are not sufficient staff to meet patient needs.

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 long term conditions' care may falter unless this is addressed (58). Nevertheless, developments across Scotland, England, Australia and the USA point to a growing recognition that traditional health/social care service provision is not addressing mental health issues in people with long term conditions in the required manner.

16.0 Partnership Working is Essential: The Need for Joint Action Planning and Collaborative Working

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 COPD - greater consideration on how to improve the mental health awareness, knowledge, and skills of specialist & primary care nurses, AHP staff and wider primary care staff in general working with this client group is vital.

Equally important is the need for primary care staff and their partners in social services and the voluntary sector to sit down together and draw up joint action plans for addressing the mental health and wellbeing of people with long term conditions. The importance of this was highlighted by patients in our focus groups when they spoke powerfully about how difficulties in accessing transport, information on benefits advice, and access to leisure services made living with their long term condition more stressful.

Changes around developing a more psychosocial, holistic, collaborative form of care will be required to address the projected growth in long term conditions in East Dunbartonshire in general and the mental health and wellbeing of people with COPD

in East Dunbartonshire in particular. Practice and specialist nurses, Allied Health Professionals and associated primary care staff have the potential to play an increasingly pivotal role in this area of health care – but crucially, this must be developed in partnership with relevant local authority and voluntary care staff and associated services.

The Living Better project will produce its final report, conclusions and recommendations to the Scottish Government, pulling together the data from all 5 CHP sites, in an all Scottish context, in March 2011.

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

References

1. Audit Scotland (2007) Managing Long Term Conditions.
2. NHS Quality Improvement Scotland 2009, Chronic Obstructive Pulmonary Disease (COPD) Services: Draft Clinical Standards.
3. Global burden of COPD: risk factors, prevalence, and future trends. *Lancet* 2007;**370**:765–73.
4. McLean et al, 2009 *The Cochrane Library* 2009, Issue 4. Telehealthcare for chronic obstructive pulmonary disease
5. Alexopoulou, S et al (2008) Developing an intervention for depressed, chronically medically ill elders: a model from COPD. *Int J Geriatr Psychiatry* 2008; 23: 447–453.
6. Chief Medical Officer. *It takes your breath away. The impact of chronic obstructive pulmonary disease.* Annual report 2004
7. The Respiratory Alliance. *Bridging the Gap* 2003
<http://www.gpiag.org/news/bridging.php>
8. Gore JM et al. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000; 55: 1000-6
9. Commission for Healthcare Audit and Inspection. *Clearing the air. A national study of chronic obstructive pulmonary disease* Commission for Healthcare Audit and Inspection. 2006
10. The British Lung Foundation Scotland (2008). COPD Policy Briefing.
11. Mannino DM, Buist AS (2007). Global burden of COPD: risk factors, prevalence, and future trends. *Lancet* 2007;**370**:765–73.
12. Gore JM et al. 2000) How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000; 55: 1000-6
13. Keele-Card G, Foxall MJ, Barron CR. 1993. Loneliness, depression, and social support of patients with COPD and their spouses. *Public Health Nurs*, 10:245–51.
14. Kara M, Mirici A. 2004. Loneliness, depression, and social support of Turkish patients with chronic obstructive pulmonary disease and their spouses. *J Nurs Scholarsh*, 36:331–6.
15. Mikkelsen LR, Middelboe T, Pisinger C, et al. 2004. Anxiety and depression in patients with chronic obstructive pulmonary disease (COPD). A review. *Nord J Psychiatry*, 58:65–70.
16. Ng T-P, Niti M, Tan W-C, et al. 2007. Depressive symptoms and chronic obstructive pulmonary disease. *Arch Intern Med*, 167:60–7.

17. Crockett AJ, Cranston JM, Moss JR, et al. 2002. The impact of anxiety, depression and living alone in chronic obstructive pulmonary disease. *Qual Life Res*, 11:309–16.
18. Kim FHS, Kunik ME, Molinari V, et al. 2000. Functional impairment in COPD patients. The impact of anxiety and depression. *Psychosomatics*, 41:465–71.
19. Di Marco F, Verga M, Reggente M, et al. 2006. Anxiety and depression in COPD patients: The roles of gender and disease severity. *Respir Med*, 100:1767–74.
20. Gudmundsson G, Janson C, Lindberg E, et al. 2005. Risk factors for rehospitalisation in COPD: role of health status, anxiety and depression. *Eur Respir J*, 26:414–9.
21. McSweeney AJ, Grant I, Heaton RK, et al. (1982) Life quality of patients with chronic obstructive pulmonary disease. *Arch Intern Med* 1982;142:473–8.
22. Mengistu, A (2005) *British Journal of Community Nursing*, Vol. 10, 1, 42 – 46
23. van Dam et al (2005) *Patient Education and Counselling* 59; 1–12.
- 23b Kunik, M et al (2005) *CHEST*; 127:1205–1211

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.

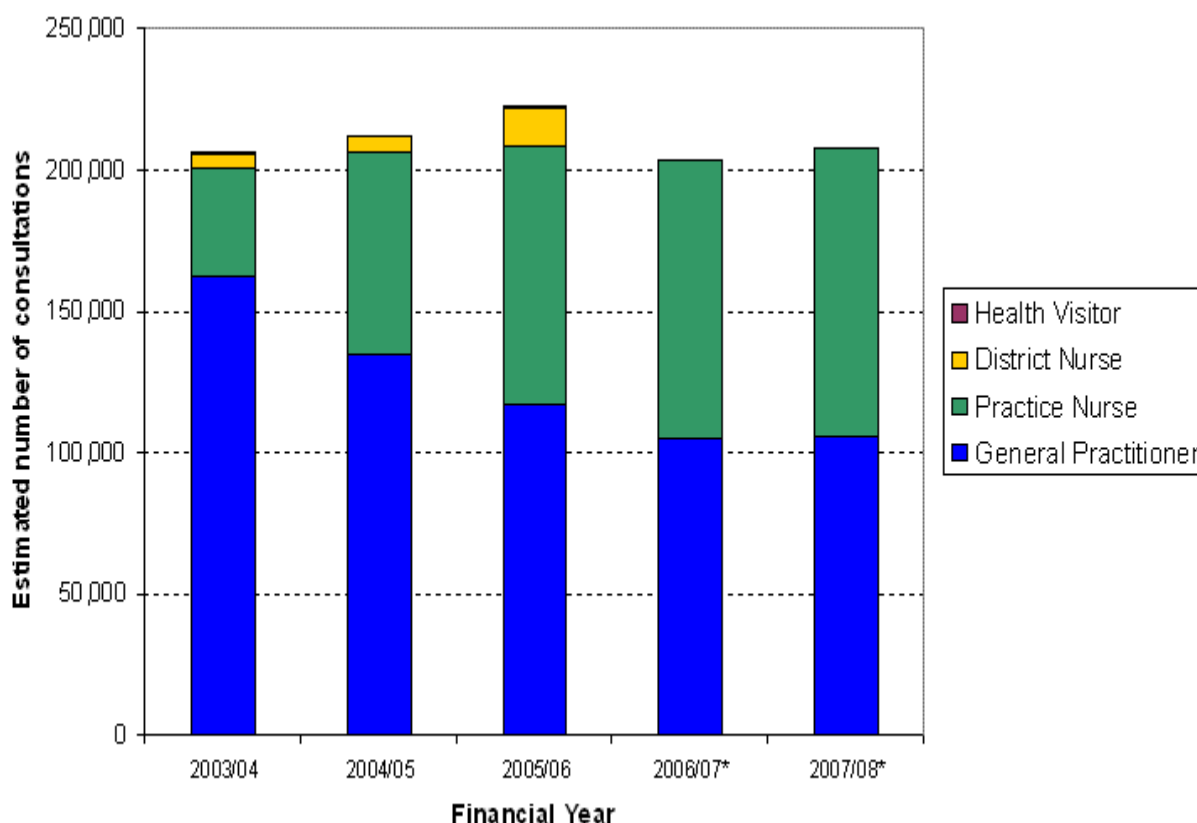
30. Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310–357.
31. Krause, N. (1986). Social support, stress, and well-being among older adults. *Journal of Gerontology*, 41, 512–519.
32. Boerner, K. (2004). Adaptation to disability 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 independence. *Journal of Gerontology: Psychological Sciences*, 55B, P362-72
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
59. Fairhead, C (2002) Depression Training Void (Editorial) *Practice Nursing* 2002, Vol 13, No 12
60. Boardman, J, Walters, P (2009) Managing Depression in Primary Care. *BJGP* February 2009, p.76-78.

61. Morgan et al (2009) The True Blue study: Is practice nurse-led collaborative care effective in the management of depression for patients with heart disease or diabetes? *BMC Family Practice* 2009, 10:46 <http://www.biomedcentral.com/1471-2296/10/46>
62. Plummer SE (2000) Detection of psychological distress by practice nurses in General practice. *Psychol. Med* 30: 1233–37
63. Scanlan, M et al (2007). Evaluation of the effect of practice nurses on the management of depression. *Primary care mental health*, 4(2), 107-13.

Appendix 1

COPD¹ - 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 \(RCG\)](#) 'COPD'.

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.

Note: Due to improvements made to the statistical model used to calculate PTI estimates for all years and the larger number of practices now included in the PTI sample for the years 2003/04 to 2005/06, figures shown here are not strictly comparable to these provided prior to 31 March 2009. See the [Note of Revisions](#) for further information.

