



LTCAS

LONG-TERM CONDITIONS
ALLIANCE SCOTLAND
people not patients

**Better
Together**

Scotland's Patient Experience Programme



Self Management Fund –Special Report

Valuing People's Experiences

December 2010

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Overview and Background

The Self Management Fund has been available to voluntary organisations and community groups throughout Scotland since March 2009. The Self Management Fund has been set-up and administered by Long Term Conditions Alliance Scotland (LTCAS).

The Self Management Fund has been made possible through funding from the Scottish Government. £4 million was available over two financial years - £2 million across 2009/10 and £2 million across 2010/2011.

The aim has been to improve work to expand the capacity of people living with long term conditions to learn more about the management of their conditions and to become active partners in their own care.

The Value of Experience

The Self Management Fund supports projects and organisations which maximise the experience of people living with long term conditions, and their unpaid carers, to work in partnership with health and social care professionals.

This Special Report looks at how the Self Management Fund has encouraged the experiences of people living with long term conditions, and their unpaid carers, to be maximised.

'Gaun Yersel' the Self Management Strategy for Scotland¹ recognises that people living with long term conditions, and their unpaid carers, should be involved in the design, development, implementation and evaluation of the services that are intended to support them.

This became a key criteria of the Self Management Fund, and the 81 successful projects all have the lived experience of people living with long term conditions, and their unpaid carers, at their heart.

This report is the first of a series of Special Reports which highlight some of the key themes of the Interim Evaluation Report launched in October 2010². A full evaluation report will be produced at the end of the current funding period, June 2011.

¹ http://www.ltcas.org.uk/self_man_gaun.html

² http://www.ltcas.org.uk/self_basics.html

Experience in context

Principles of Self Management

The Principles of Self Management (see appendix 1) were developed by LTCAS to encapsulate the core messages of the Self Management Strategy. The Principles provide a useful tool for underpinning any work being done to support self management. The Principles reflect the approach people need from services and practitioners to enable them to take on the responsibility of self management.

The first Principle is;

'Be accountable to me and value my experience'

The Principles also form the basic criteria of the Self Management Fund for Scotland.

Self Management Fund

The inclusion of people's experience in the design, development, implementation and evaluation of the 81 Self Management Fund projects has been a key to their success. Working in a person-centred way to promote self management, all the projects have used the experiences of people to inspire and encourage others to become involved.

People's experience have been incorporated into projects in a variety of ways;

- by involving peers in delivery and support
- by encouraging people to share their stories
- by asking people what is important to them, from their experience, and building services from that starting point
- by measuring the experiences of people using current services, and making improvements based on this

The 81 funded projects, and other examples of self management support across partnerships within the voluntary, health and social care sectors, have illustrated the value of maximising experience when designing and delivering services.

Better Together

Better Together – Scotland’s Patient Experience Programme aims to improve the care experience of people using NHS services. The commitment to improve the care experience has recently been reinforced through the publication of the Healthcare Quality Strategy for NHS Scotland³.

The Programme to date has focussed on improving experience along two specific service lines –namely adult hospital inpatient and GP services. A third work stream now seeks to improve the care experience of people living with long term conditions and is being taken forward in partnership with the Long Term Conditions Collaborative and the Long Term Conditions Alliance Scotland.

While the programme is focusing on the aspects of experience that the NHS can influence and is accountable for, it is recognised that the experience of living with a long term condition is of course much broader than this.

In contrast to the other two work streams, where a programme of national surveys has been established, informed by initiatives conducted within the UK and internationally, long term conditions is an area where little ‘patient experience’ work has been conducted to date. The work stream has the potential to provide insights into how to approach experience measurement and improvement more generically – for instance by looking at the care experience of people with conditions that cut across organisational boundaries, together with complex care and multiple service use. It also recognises however that most people with a long term condition are leading full and active lives, with only occasional contact with health and social care services, and provide much of the care themselves. As self management will become increasingly important as people live longer, many with more than one condition, understanding and improving the experience of support for self management is crucial, demanding a holistic approach, closely coupled with the delivery of improved outcomes.

The partnership with LTCAS is therefore important, enabling Better Together to link with and share the learning to emerge from the interim evaluation of the Self Management fund.

³ <http://www.scotland.gov.uk/Publications/2010/05/10102307/0>

Learning from the Self Management Fund

Peer Support

'Rather than "chew the fat" over the past and go over and over old problems, we spoke about our experiences in a positive way and I found that I could laugh about half of it already' – Pink Ladies course participant

The value of peer led support, education and awareness raising can be seen directly and indirectly in many projects. Although 14% of current projects are involved in formal direct peer support to encourage self management through sharing experiences, many others are reporting on the benefits of peer support informally in their programmes – see **Lothian Centre for Inclusive Living** case study.

Some further examples of are;

- **COMAS** are running a 'serenity café' for those living with an addiction in addition to mental health conditions, offering formalised peer support, information and advice on self management
- **Parents of Autistic Spectrum Disorder Adults (PASDA)** are developing workshops focusing on management of stress and anxiety for those living with Autism and their families or carers
- **Clydeside Action on Asbestos** are developing support groups in Aberdeen and Ayrshire, working with people living with asbestos related conditions to create and run self management peer support programmes

Personal Stories

'Being one of the hub editors has been such a great experience for me. Its given me hope and built my confidence in my own ability, I am learning new skills and hope to use my new experiences to help me return to work'. – Rebecca Young, Action for M.E. project participant

The value of sharing personal stories to encourage others to become involved in self management, to raise awareness of conditions and approaches and to increase understanding of the

impact of self management can be seen in a number of the projects – see **Moray Carers** case study.

Some further examples are;

- **Strathclyde Lupus Group** are creating a series of Lupus awareness workshops aimed at student doctors led by people living with the condition themselves. The workshops will raise awareness of the condition and give people living with Lupus the opportunity to inform doctors about how they self manage
- **Genetic Alliance UK** are working with those living with rare genetic conditions to produce a series of personal story podcasts which will provide information on the management of rare conditions
- **Deafblind Scotland** are running a drama self management programme for those who are deafblind to explore the issues for self management and to inspire and encourage others living with the condition to take control

Using Personal Experience to Improve Services

'I feel strongly that we should look at issues from a personal experience viewpoint – I really want to lead an organisation that can truly support people at the end of the day' – Shona Sinclair, SKS Scotland

The value of capitalising on the personal, lived experience of people living with long term conditions, and their unpaid carers, as the starting point for a project, idea or service can be seen in the majority of the 81 projects. These experiences continue to be integral to the development of the projects – see **Parkinson's UK**, **Moray Carers**, and **Lothian Centre for Inclusive Living** case studies.

Some further examples are;

- **Aberdeenshire Signposting Project** are providing a virtual self management support service for women living with post natal depression in a geographically isolated area
- **Stammering Association Scotland** are working with people living with a stammer to support them to devise their own strategies for managing it - offering a monthly self management group by telephone, video conferencing or

Skype for those who are unable to attend a self management group

- **RNIB** are supporting young blind and partially sighted people to educate their sighted peers about sight loss and to distribute a toolkit to youth work organisations

Measuring Experience

'I thoroughly enjoyed the course - it was the best thing that has happened to me. It was great and enlightening and I learnt more in 6 weeks than 40 years of having psoriasis' – PSALV course participant

The projects are working to develop and adapt improvement tools to measure and evaluate their work, and demonstrate the value of maximising lived experience in the design, development, implementation and evaluation of services – see **Parkinson's UK**, **Moray Carers**, and **Lothian Centre for Inclusive Living** case studies.

Some further examples are;

- **Carr-Gomm** use a whiteboard in their sessions to keep a weekly visual record of what people cook and what impact it has had on their week, in terms of confidence and self worth. The whiteboard information is then captured, collated and compared throughout the course to give a representation of the journey each participant has had, and to show the links between cooking, healthy eating and feelings of wellbeing
- **Action for Sick Children** are working to capture the experience of young people who are self managing themselves, and are using a Big Brother style video booth to record the experiences of the course participants in a 'safe' and fun way
- **Psoriasis Scotland and Arthritis Link Volunteers (PSALV)** have encouraged participants on their self management courses to measure their development over the length of the course on a 'confidence ladder' to give a visual representation of their progress

More details of all the improvement tools used by the funded projects, and the results they produce, will be available in the Final Evaluation Report for this allocation of the Self Management Fund after June 2011.

Conclusions

The Self Management Fund for Scotland has enabled projects to incorporate the experience of people living with long term conditions, and those that care for them, throughout all aspects of their projects. The Fund is capturing the learning from these experiences, and has so far shown the value of;

- involving peers in delivery and support
- encouraging people to share their stories
- asking people what is important to them, from their experience, and building services from that starting point
- measuring the experiences of people using current services, and making improvements based on this

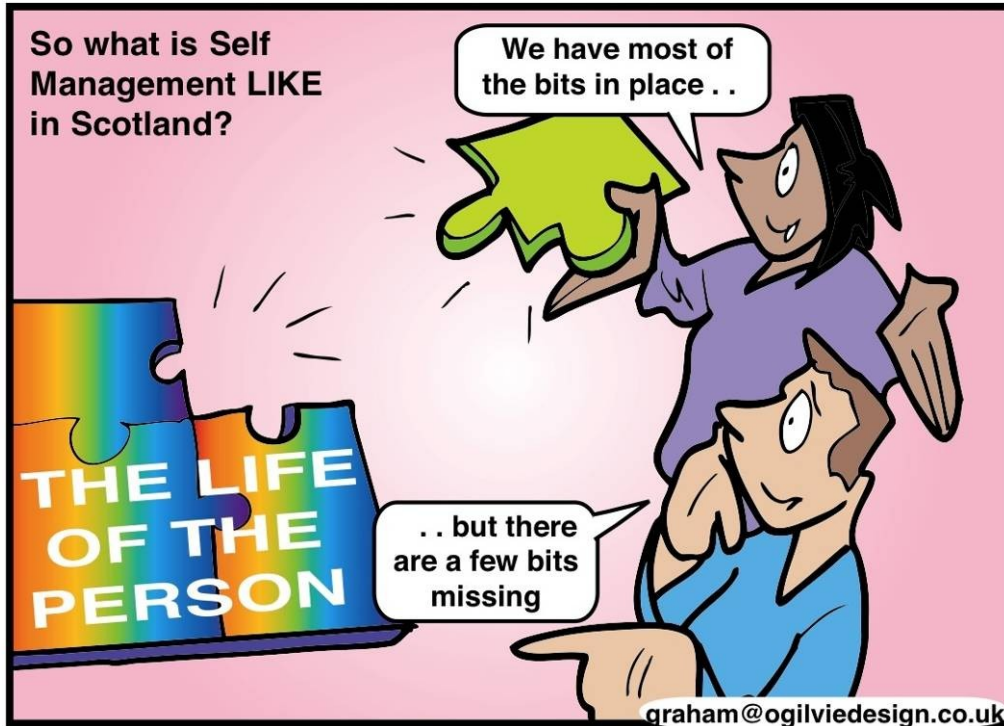
The Better Together Programme has been working to measure and understand people's experience of using health services in Scotland to make improvements. The partnership with LTCAS will enable Better Together to link with and share the learning to emerge from the interim evaluation of the Self Management fund and to inform future work in improving the experience of people living with long term conditions through the implementation of the Healthcare Quality Strategy for Scotland.

Working in partnership, and valuing the experience of people living with long term conditions is central to both the Self Management Projects and the Better Together programme.

For further information about LTCAS - our work and our membership – the Self Management Projects and the continued development of the Self Management Fund for Scotland, please see our website www.ltcas.org.uk

Further information about Better Together can be found in Appendix 2

Case Studies



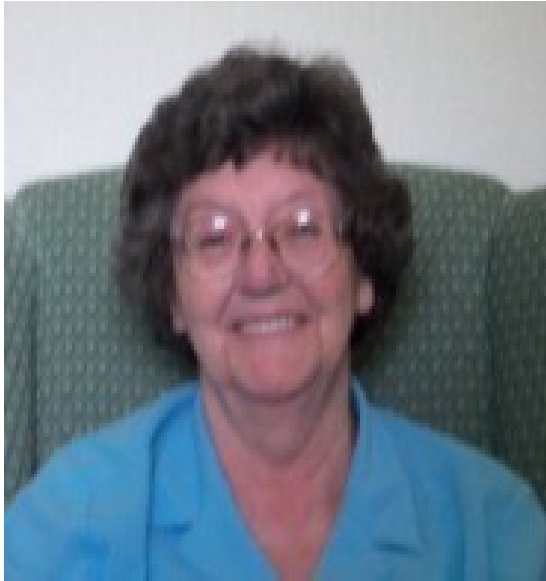
The following Case Studies illustrate the impact, emerging themes and learning points that the Self Management Fund in relation to valuing experience.

- Parkinson's UK
- Moray Carers
- Lothian Centre for Inclusive Living

The Case Studies also demonstrate the impact that LTCAS has had on shaping, expanding and sustaining these themes.

Parkinson's UK

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



Parkinson's UK are the leading support and research charity for Parkinson's. For more than 40 years they have been working to find a cure and to improve life for everyone living with, or caring for someone with, Parkinson's. The Scotland team provide a range of support and information services as well as campaigning to raise the profile of Parkinson's.

Jean Ballantyne, Carer and Steering Group Member

Parkinson's UK knew that sleep had an impact on people's lives and that some specialist nurses felt confident to give support in sleep management – although this support often came in the form of a written information sheet. Jean Ballantyne, who cares for her husband Mel who lives with Parkinson's, suggested to Parkinson's UK that they apply for funding for a sleep project because of the hundreds of people they knew who are affected by little sleep.

Parkinson's UK were successful in their bid to the Self Management Fund to focus on this important area for 40% of people living with Parkinson's in Scotland and their families.

'In the 25 years since Mel was diagnosed, I could count on one hand the nights I'd had a 'good' nights sleep' – Jean Ballantyne

Gathering together a broad partnership of Nurse Specialists, Consultants, Sleep Counsellors, Psychologists, staff from Parkinson's UK and people with direct experience of Parkinson's, they set to work to find out more about the issue, and investigating the options for developing some standards for self management support in this area.

The different perspectives enriched the experience of the group. Jean was able to bring her practical experience, and that of many

other people who faced the daily battle that little or no sleep can bring, to highlight the emotional and psychological side of lack of good sleep and its impact on life with a long term condition.

'I have learnt so much about the effects of lack of good sleep for people living with Parkinson's and their families – it was invaluable to be there from the start' – Consultant

The programme that the group developed was based on generic materials from the Sleep Research Centre at Loughborough University, adapting them to reflect some of the specific issues of living with Parkinson's. The structured, step-by-step approach allows people flexibility to develop new techniques to manage their sleep better. The '10 Rules of Sleep Hygiene' included in the programme support a change of attitude towards sleep, shifting to a focus on a better quality of sleep rather than the number of hours. This shift in behaviours has been found to also improve self esteem and decrease feelings of depression, allowing people to interact more with their families.

Specialist Nurses and other professionals working to support people living with Parkinson's have also reported that they feel more competent in their skills and ability to offer an additional service to the families they are working with. People living with Parkinson's, and their families, have been encouraged to share their experiences to support the knowledge and qualifications that the professionals have.

'We can all relate to the issues lack of sleep can bring, with or without a long term condition' – Anna Lynall, Parkinson's UK

Parkinson's UK feel that this project is only just the start of work in this area. They hope to make the programme available to other professionals and people across the UK as well as other organisations supporting people living with different long term conditions.

'It seemed natural to me to suggest to the Scotland team that an application for funding looking at the impact of sleep could improve the quality of life for people living with Parkinson's' – Jean Ballantyne

For more information please visit www.parkinsons.org.uk

Moray Carers



Moray Carers Project works with Carers of all ages throughout Moray to ensure they are recognised, valued and supported to manage the impact of caring on their lives.

Liz Thomson, Will Burgess, Chryssy Gibbs - Moray Carers

Moray Carers Project realised that many services available to carers focused on the needs of the person they cared for. They often failed to recognise the importance of responding to the individual needs of the carer in relation to health and well-being. This represented a significant gap in local service provision, and support for self management.

'Carers are key partners in self management. Effective self management means recognising the needs of the carer and the cared for. The wellbeing of both parties must be considered' - Chryssy Gibbs

Local carers began expressing a desire to be heard and to have an opportunity to share their stories. With funding from LTCAS, Moray Carers began working with carers to create a library of digital stories. These short films aim to give carers the opportunity to share their experiences and raise awareness of issues that matter to them, by portraying both the challenging and positive aspects of caring.

Moray Carers Project knew that in order to achieve these aims they had to develop a person centred method of production. The team recognised that the carer was the expert therefore each film became a consultative process, shaped around the carer's situation.

'Our role was to listen and respond to the needs of the carer. We learned from them and helped them communicate the experiences they wanted to share' - Will Burgess, Digital Stories Project Co-ordinator

Many carers have found the filmmaking process therapeutic. Voicing their experiences has become an important emotional outlet for

feelings of isolation and stress. So much so that many carers can make stories for themselves and their families rather than for distribution. Those who have been comfortable sharing their stories understand that they are a remote peer support tool, not only giving the carers the opportunity to speak out for themselves but also for other carers in similar situations.

These honest and personal insights have become an affirmation of the carer's value. Many people who have watched the films, as well as those who participated in making them, have reported an increase in self confidence.

'As carers become more confident they become more effective in their ability to support the cared-for in their self management journey'

The stories are also used as a tool to communicate with family and friends, who often don't fully realise the complexities of caring. After watching a film, one family member commented:

'I was hugely moved by your film. It gave a deeply moving insight into what full time care involves and how your needs are just as important as the needs of the person you care for'

This work has enabled Moray Carers to effectively demonstrate the importance of supporting the carer and the how their wellbeing impacts on the person they care for.

'You are allowing us a voice and that gives us a sense of worth. It makes us stronger and more effective in our caring roles' - Val Ireland, Carer

The stories are currently being promoted widely, with great feedback. Moray Carers Project want to continue to develop this resource by widening dissemination to include websites, community screenings and even festivals. The team aim to collaborate with other organisations that support those living with long term conditions to promote digital stories as an effective medium for raising awareness and sharing experiences to support self management.

For more information please visit <http://www.moraycarers.co.uk/>

Lothian Centre for Inclusive Living



Lothian Centre for Inclusive Living is a user-controlled organisation which supports disabled people to live independently. 'Your Call' is a free telephone counselling service led by disabled people themselves who work as volunteers, and are trained to a professional standard in counselling.

Pauline and Katrina, Your Call Counsellors

'Your Call' was developed in response to feedback from LCiL service users who felt that telephone counselling would increase the accessibility of counselling provision for disabled people and those living with long term conditions.

Difficulties encountered by disabled people who were looking for counselling included accessibility, expense, transport and a lack of understanding among non-disabled counsellors of the issues and challenges which disabled people meet on a day-to-day basis.

LCiL felt that a telephone counselling service would have many advantages in terms of accessibility. It would also allow the counsellors to work in a flexible way which would also support their own self management.

'A telephone service means that you can access counselling even if you aren't well enough to get out. You don't have to exacerbate your symptoms unnecessarily' - LCiL Counsellor

LCiL also identified a lack of joined up working around counselling for disabled people. Statutory services tended to medicalise a person's physical condition, but provide no support for associated

psychological and emotional issues. Your Call's aim was to link these for disabled people across the whole of Scotland.

The success of the Your Call pilot demonstrated the importance of peer counselling and the value of emotional and mental support for people with long term conditions. The Self Management Fund presented an opportunity to expand the service.

The experience of already professionally trained LCiL counsellors was integral to the design of the new national service. They have become project consultants advising on every aspect of the service from the technology used to the need for flexible working practices.

'Your Call used the experience of those living with long term physical disabilities to combine peer support with emotional support in a package that was accessible and appropriate' - Ian Fuller, Counselling Coordinator

LCiL believes that the success of the service is based upon the mutual understanding between counsellor and client of what it means to live as a person with long term conditions. The counsellors personal experience is strengthened by the counsellors holding professional qualifications.

'A disabled counsellor is better able to understand your situation and what it is to be disabled and physically unwell. The support from the You Call counsellors has helped me to make positive changes in my life' - Service user

The benefits that have arisen from the service are specific to each individual. However, initial evaluation found that 95% those who have engaged with Your Call have reported an increase in their sense of wellbeing.

'Your Call has made me stronger. It has helped me deal with emotional issues and overcome my fears. It has boosted to my confidence' – Service user

Looking to the future, the Your Call team are keen to work towards the provision of diploma level counselling training for disabled people and to investigating new approaches to service delivery using technology for those people who have difficulty in using the telephone.

For more information please visit <http://www.lothiancil.org.uk/>

Principles of Self Management

July 2008

Principles: Self Management Health, Social and Voluntary Sectors

"Be accountable to me and value my experience"

Evaluation systems should be ongoing and shaped by my experience. They should be non judgemental and focus on more than medical or financial outcomes.



"I am the leading partner in management of my health"

I am involved in my own care. I, those who care for me and organisations that represent me, shape new approaches to my care.

"I am a whole person and this is for my whole life"

My needs are met along my life journey with support aimed at improving my physical, emotional, social and spiritual wellbeing.

"Self management is not a replacement for services. Gaun yersel doesn't mean going it alone"

Self management does not mean managing my long term condition alone. It's about self determination in partnership with supporters.

"Clear information helps me make decisions that are right for me"

Professionals communicate with me effectively. They help ensure I have high quality, accessible information. They also support my right to make decisions.

Better Together Programme

Overview

Better Together (Scotland's Patient Experience Programme) is gathering and using people's experiences of healthcare services to make local and national improvements. The Programme comprises three work streams:-

1. Better Together Patient Experience Inpatient Survey (reporting September 2010)
2. Better Together Patient Experience GP Survey (reported July 2010)
3. Better Together Long Term Conditions Work Stream (reporting March 2011)

Long Term Conditions

The Better Together long term conditions work stream aims to improve the experience of care and support for people living with long term conditions. It is being taken forward in partnership with the Long Term Conditions Alliance Scotland (LTCAS) and the Long Term Conditions Collaborative (LTCC). A Steering Group has been established with representatives from Better Together, LTCAS, LTCC and other key stakeholders. In addition, a Virtual Reference Group of a wider group of stakeholders will provide advice, critical friend challenge and expertise to the work stream which will conclude in March 2011.

The work stream philosophy was largely informed by the "*It's All About Me*" event, hosted by Better Together and the Scottish Health Council in April of this year. This event was organised in collaboration with LTCAS and its member organisations, LTCC and the Mental Health Collaborative and was attended by people living with long term conditions, their representatives, clinicians and service managers.

Person-centred Care

Encouragingly, services are increasingly being developed in a person centred way, involving the voluntary sector and wider community, and are looking at long term conditions more holistically. The *It's All About Me* event provided further evidence that many organisations are already carrying out a range of activities to use people's experience of long term conditions to inform improvements. The partnership approach with LTCC and

LTCAS presents a unique opportunity to build on and begin to embed this current activity.

For instance, LTCAS led work resulting in the publication of *Living Well with Long Term Conditions* (2007) and *Gaun Yersel, The Self Management Strategy for Long Term Conditions in Scotland* (2008), and currently administers the Self Management Fund on behalf of Scottish Government, supporting a wide range of self management projects. The partnership approach will therefore enable Better Together to link with and share the learning to emerge from the interim evaluation of the Self Management fund. LTCAS has also undertaken to work with member organisations to identify and share approaches to gathering and using the experience of people with multiple conditions and those of children and young people, and to share good practice of NHS working in partnership with the voluntary sector, through the showcasing of case studies.

Similarly, LTCC is actively supporting care teams across NHS Scotland to use tools and techniques to deliver more person centred services and to improve the way care is provided with and for people with long term conditions. Lean in the Community, Telehealthcare and Anticipatory Care Planning work have been identified as a key focus for capturing and sharing existing good practice in using experience data for improvement, identifying opportunities to test and spread different experience approaches, and building the capability and capacity of care staff. There is also an opportunity to build on and share good practice being undertaken by Managed Clinical Networks in gathering and using people's experience to inform and make improvements.

Further Information

Regular updates on the Better Together LTC work stream will be shared through the LTCAS network and through the LTCC Community of Practice⁴.

For further information please contact:

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⁴ <http://www.knowledge.scot.nhs.uk/ltc/discussions/better-together--long-term-conditions-collaborative-workstream/bt--ltcc-workstream.aspx>

Appendix 3

Useful Links

Long Term Conditions Alliance Scotland

www.ltcas.org.uk

Gaun Yersel – the Self Management Strategy for Long Term Conditions in Scotland

www.ltcas.org.uk/self_man_gaun.html

Better Together

www.bettertogetherscotland.com

Long Term Conditions Action Plan

http://www.sehd.scot.nhs.uk/mels/CEL2009_23.pdf

Long Term Conditions Community

www.knowledge.scot.nhs.uk/ltc.aspx