**We are fast approaching the end of Year 2 ....and it’s great to see so much happenning around the country !**

I’m sure our Spread Roadshow helped you increase the pace and reach of your improvements. That’s why it’s so important to continue to share lessons learned by buddying across boards. I would urge you to use the excellent Community of Practice site for discussion forums, exchange of ideas and to help you share resources.

Earlier this year we added a new resource to our publications: FAQ on Anticipatory Care Planning – developed jointly with colleagues from Living and Dying Well. Hear more about this and about telehealthcare at our learning session on April 1st.

Through our condition pathways work we have strong links with QIS and with MCNs. We are pleased to be working with QIS on their implementation and improvement support programme for chronic neurological services and on their emerging work on COPD. We welcome Jennifer Burn who has been appointed to QIS to support practice development in self management.

The self management grant administered by LTCAS has now funded a second round of projects. We look forward to working with our voluntary sector partners as these local initiatives move forward. Congratulations to LTCAS for their successful first conference held in Perth on Feb 23rd.

The last three months have seen the launch of a LTC delivery network of executive sponsors, clinical leads, programme managers and our partners from special health boards. This network will meet quarterly to support reporting to the LTC Programme Board, review our performance against the T6 target and inform development of future LTC targets or quality indicators.

We are now in the first phase of implementing the Quality Strategy. It’s heartening to see the focus on safe, effective and person centred care with and for people with long term conditions. And recognition that often it’s the little things that make a difference to the experience of care resonates so well with our approach. We are delighted to join with the Scottish Health Council and the Better Together Programme in hosting ‘It’s All About Me’ on April 29th.

Indeed it’s a very busy calendar and with LTC network sessions in April and June, we have decided to defer our main national event until after summer. In doing so I trust you will participate fully in your Board’s engagement work for the Quality Strategy - and that you’ll take the opportunity to make your mark on the NHSScotland event in June. The call for abstracts has just gone out – let’s see the EICC lit up by posters from every local LTC team to showcase quality in action across all six dimensions. I’m immensely proud of our Team LTC and I know that we all share the ambition to be world leading. As a network of LTC quality champions I know we can make quality count !

For further information please contact Fraser McJannett, Programme Officer: fraser.mcjannett@scotland.gsi.gov.uk
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The Long Term Conditions Community of Practice (LTC CoP) will support the work of the Long Term Conditions Collaborative (LTCC).

The LTC CoP is a communication network to encourage multi-disciplinary and cross-organisational sharing of information, knowledge and experience relevant to long term conditions.

The main aims of the LTC CoP are:

- To support the work of the LTC Collaborative
- Encourage peer support and shared learning between members
- Provide access to information resources and materials that focus on Long term Conditions
- Develop a website to support the community

The LTC CoP website provides access to published information available through the NHS Education for Scotland e-Library and in addition, members can share and store resources in an online community resource library. The LTC CoP website also provides the technology for collaborative project work using wikis, blogs and discussions.  

www.knowledge.scot.nhs.uk/ltc

Key features of the Long Term Conditions Community of Practice website are:

- Find published resources that other members have found useful
- Share experiences and examples from practice
- Collaborate with colleagues
- Support for evidence based practice (e.g. policy and guidelines).
- Access educational and learning resources

Who can become a member of the community and LTC CoP website?

- Anyone interested in Long Term Conditions
- Anyone interested in collaborative methodologies and technologies
- Practitioners, policy makers, researchers, service users, voluntary organisations

Specific communities and special interest groups requiring online technology to boost communication, networking and knowledge sharing.

In order to log-in and join the community, you will require an NHS Scotland Athens username and password. If you do not have a username and password, please register by visiting this address www.knowledge.scot.nhs.uk/ltc/login where you will find information and guidance on registration. If you have any questions on the Long Term Conditions Community of Practice, please contact Kathleen McGuire, Kathleen.McGuire@aapct.scot.nhs.uk.
NHS Highland Staff Receive Awards

Two staff in Argyll & Bute CHP in NHS Highland received national awards recently in recognition of the work they have been undertaking to support the Long Term Conditions agenda.

Maggie Clark, LTC Manager for Argyll & Bute CHP was awarded a Partnership in Practice (PiP) award by The Queen’s Nursing Institute Scotland (QNIS) at their annual awards ceremony on 5th November 2009.

The award was in recognition of the work that Maggie has undertaken in Partnership with the University of Highlands and Islands (UHI), Skills for Health and NHS Highland to develop an education package for health and social care staff to undertake 2 modules consisting of enabling self management and supporting change in practice.

Maggie was awarded a £2,000 grant to help fund a study tour to Australia to explore the Flinders model of self management and their approach to implementing self management and chronic disease management into practice. Whilst she is out in Australia, Maggie also hopes to explore Telehealth and its uses in rural Australia.

Also recognised for their contribution for developing innovative ways for allowing people with Long Term Conditions to live independently and in their own homes for as long as possible was Lynn Garrett, TeleHealth Project Manager in A&B CHP.

Lynn received an award for Improvement and Innovation at the Scottish Health Awards, sponsored by the Daily Record, at an awards ceremony at the Corn Exchange in Edinburgh on 11th November 2009.

Lynn accepted the prize on behalf of the A&B TeleHealth Project Team for their work in developing and using TeleHealth technology in Argyll & Bute to monitor and care for patients within their own home using remote monitoring. The TeleHealth project includes remote monitoring of COPD patients and Heart Failure patients as well as the installation of ‘multi user kiosks’ in various community locations across Argyll & Bute. The project is currently under evaluation and further information about the success of the project will be available next year.

For further information please contact Alexa Pilch, NHS Highland, Long Term Condition Programme Manager, alexa.pilch@nhs.net.
East Ayrshire Medicines Management Training for Home Care Staff

As part of the Shifting the Balance of Care agenda there is an increasing focus on the provision of higher levels of personal care for people with more intensive care needs supported in their own homes. The number of people receiving more intensive support of more than 10 hours of home care each week doubled between 1998 and 2007. Clearly, this change has implications not just for social care services, but for the support that people living at home need to sustain them, including changes in medical and nursing support and access to pharmacy services.

Delivering this type of support within community settings requires effective co-ordination between all different services involved and an innovative approach to ensuring the delivery of efficient services which have a lasting positive impact on patients and service users.

The East Ayrshire CHP Pharmacy Advisor has been working closely with Community Care Services of East Ayrshire Council in developing an improved East Ayrshire Medicine Policy which reflects the requirement to provide more intensive care for a greater number of service users at home.

An Innovative Approach — Community Pharmacies in East Ayrshire were experiencing a capacity problem in terms of responding to increased requirements for assessing and dispensing patient’s medication into Monitored Dosage Systems (MDS).

In partnership with the local authority and community pharmacists the Community Pharmacy Advisor obtained approval from the CHP to set up a new and innovative Medication Management Training Service for East Ayrshire home care staff facilitated by local Community Pharmacists. The idea addressed the capacity issue and enhanced partnership working whilst providing a sustainable and value for money approach that most importantly has improved the quality of care and support for patients and service users.

Commencing in September 2008 four local community pharmacists have been trained as Medication Management Trainers and they in turn have delivered training to over 600 community care staff!

The key topics covered are as follows: ordering, collection, storage and types of medicine. Information on administration, recording and disposal of medicine and commonly occurring side effects.

Following the training, Carers are assessed on their knowledge of the Medication Policy and their competence to administer medication. Feedback from participants has been extremely positive and the approach has reduced the capacity issues in local pharmacies. This in turn increases the support and improves the care experience for patients living at home.

This initiative is an excellent example of working in partnership to provide innovative, creative and cost effective solutions to enhance patient care in the community and ultimately deliver better outcomes for vulnerable people living in East Ayrshire.

For further information please contact Kathleen McGuire, LTC Programme Manager, NHS Ayrshire & Arran. Kathleen.McGuire@aapct.scot.nhs.uk.
NHS Western Isles AHP LTC Learning Together Event

NHS Western Isles Allied Health Professional (AHP) Practice Based Education Facilitator, Rhoda Mackay, had organised an AHP Learning Together Event. The event was for AHPs, Comhairle nan Eilean Siar Social Care staff, the voluntary sector and members of the public involved with people with long term conditions. The aim of the event was to explore services that are in place and to improve and develop those services for people with long term conditions.

The event was chaired by the NHSWI Board Chair, John Angus Mackay, who is enthusiastic about the local collaborative programme and realises the value that the programme can bring to improve care for people with LTCs. Dr Anne Hendry from the National Programme Team was asked to be one of the keynote speakers and gave a well received overview of the National Collaborative Programme.

In the morning session there were presentations from the voluntary sector and a carer, who gave an informative talk on the stresses involved in being a carer. All the local AHP disciplines gave a presentation, each highlighting the good practice that is happening throughout the Western Isles. The LTCC Programme Manager gave a presentation on the local aspects of the collaborative, and how it was important that service improvement is collaborated. After the presentations, there was time for the attendees to write on post-its areas they would like to see improved.

In the afternoon there was an open space session, which Mandy Andrew, Regional Manager (North) and Audrey Taylor from NES helped facilitate. At this session the attendees proposed themes that could be looked at in more detail. Then they were asked to divide into groups based on the theme that they would like to work on. Working in small groups they then identified and discussed areas that they would like to see improved.

After the event, Rhoda Mackay then used the post-its and the A1 sheets to draw together the themes of the conference to be presented to the AHP Forum. The themes included, Self management, Rehabilitation, Discharge Planning, Referrals, Opportunities for role development and communication. This links in with, and will help inform the work that the Programme Manager is doing. A follow on session about what has been achieved since the workshops from the Learning Together Event will take place later this month. In January Susie Forbes, National Improvement team SIM will facilitate a service improvement event around discharges and communication.

For further information please contact Pat Welsh, Long Term Condition Programme Manager, NHS Western Isles, patwelsh@nhs.net
**NHS Grampian Update**

**Self Management**—The Met Office Health Programme has developed an alert service, Healthy Outlook® that anticipates weather conditions which are likely to increase the risk of COPD symptoms worsening. Patients will receive automated telephone calls to inform them of pending forecast risks, as well as an information pack supporting the self management of their condition.

This winter access to the service will be opened up to all COPD sufferers in Moray thanks to an idea by Lorna Bernard, the Telehealthcare Project Manager for the Moray CHSCP. This means that any person in Moray with COPD can self refer into and receive the service if they feel it would be beneficial for them.

Evaluation of the service UK-wide has shown a reduction in COPD related hospital admissions of 20%. Local evaluation will take place in relation to this project. For further information please contact lorna.bernard@moray.gov.uk

Our work with the voluntary sector and public groups continues with an aim of developing generic self management groups. The A3 plan is developing well with the involvement of these stakeholders. Breatheasy are in discussion with Moray CHSCP with the aim of supporting a support group being established. For further information contact Linda Duthie, Self Management Strategy Manager, Linda.duthie@nhs.net

**Complex Care and Condition Management**—Work continues for move forward in the introduction of ACP across Grampian. We are using the Highland model alongside the local Aberdeen-shire model to support our aims with this work.

Respiratory Care is also progressing alongside the introduction of ACP processes and our lead clinicians within the MCN are taking this forward.

An A3 project plan is underway in the management of inpatient care for Diabetes in Dr Grays Hospital in Moray. The focus on the project is on training and developing staff in the assessment and management of diabetic care in generic settings, with a particular emphasis on self management aspects of care. Understanding of the data in particular length of stay and whether there is an opportunity to reduce this is part of the project.

Falls and Osteoporosis is being looked at across Grampian, the implementation of the Grampian Strategy for Falls sits alongside this work. Some early improvement work in a Primary and community care setting in Dufftown is being taken forward with home care staff implementing the use of a falls risk identification tool. An A3 project plan is in place with measures for improvement being developed further and plans for improving data management in place.

For further information please contact Pam Gowans, Long Term Conditions Programme Manager, NHS Grampian, pamelagowans@nhs.net
In October 2008, The Scottish Government produced the document, ‘Living and Dying Well: a national action plan for palliative and end of life care in Scotland’. Responsibility for producing an Action Plan to deliver the report’s recommendations was given to Fife Palliative Care Group and a Short Life Working Group was set up to produce a generic palliative care clinical pathway. The pathway has been completed (enclosed) and is now in the process of being disseminated widely to all those responsible for providing general palliative care for patients with long term or life threatening conditions. The aim is for this pathway to be assimilated within existing care pathways.

For further information on this please contact Ingrid Hale, Programme Manager, Long Term Conditions, NHS Fife, Ingrid.hale@nhs.net.

### Overview of Fife Palliative Care Integrated Pathway

#### Primary Care
- Diagnosis of life threatening condition
- Clear referral to secondary care for diagnostics/specialist opinion
- Recognition of the requirement for palliative care
- Recognition of the requirement for end of life care
- Timely access to equipment
- Referral to and discharge from specialist palliative care
- Frequent appropriate visits during acute episode
- Self management plan available as appropriate
- Support and re-assessment for manual handling as required
- Access to information and advice on finances, legal rights and benefits
- Support from Carers Centre for both carers and patients
- Voluntary sector support mechanisms, eg. Mab Centre
- Access to patient information directory
- Early access to care education
- Care of the patient in the home
- Access to service information directory
- Available when required on financial issues, legal issues, benefits

#### Secondary Care
- Diagnosis of life threatening condition
- Investigations for staging
- Written information about disease process or condition and prognosis
- Recognition of the need for palliative care
- Recognition of the need for end of life care
- Timely, clear referral to primary care for ongoing care and support
- Admission for medication review/acute medical treatment
- Relevant and appropriate ongoing treatment as required
- Referral to and discharge from specialist services
- Referral to other Consultants as appropriate
- Referral to and discharge from specialist palliative care
- Shared care between consultants and primary care
- Access to 24 hour nursing
- Clear referral pathway to other services as available (e.g. Palliative care, home care assessment, Financial, Voluntary Sector, Dietitian, Community Services etc.)
- Spiritual care
- Counseling available at any time throughout the pathway
- Support for patients and carers, including information on finances, benefits, legal rights and manual handling
- Access to service information directory
- Written information on what to expect when approaching end of life (e.g. legal issues, what to do after death, funeral arrangements etc)
- Verification of Death if patient dies in this environment

#### Tertiary Care
- Diagnosis of life threatening condition
- Surgical procedures and treatment not performed in Fife (Thoracic surgery, radiotherapy and some chemotherapy)
- Referral to specialist services including palliative care
- Referral to clinical psychology

#### Interface (To Tertiary)
- Appropriate referral pathway
- SAS backup as required
- IT compatibility

#### Interface (To Primary & Secondary Care)
- Clear referral pathway
- Rapid access to support and advice between Primary and Secondary care

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### Underpinning Structure

- Patient safety
- Preferred place of care
- Patient/Care experience
- Scottish Ambulance Service Guidelines
- Self management plans
- Single Shared Assessment (SSA)
- Workforce planning

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**COMMUNITY SERVICES**

- Regular assessment and review of patient's palliative care and end of life needs
- Access to appropriate, regularly reviewed home care
- Timely access to equipment
- Out of hours care from all health and social care professionals
- Support and re-assessment for manual handling as required
- Supportive care by Macmillan nurses
- Counselling available at all stages of process
- Referral to clinical psychology
- Social work involvement as required
- Spiritual care
- Support from Carers centre for both carers and patients
- Voluntary sector support mechanisms, eg. Mab Centre
- Access to patient information directory
- Palliative care education
- Advice and information available when required on financial issues, legal issues, benefits
Developing and Piloting a new Anticipatory Care Plan (ACP) in Forth Valley

Following feedback from GP’s on how the current ACP’s in use could be improved, a meeting to discuss the development of a new single ACP and plans for pilot was held on 21st October 2009. The outcome of this meeting attended by Dr Stuart Cumming, GP and Clinical Lead for Stirling CHP, Dr Neil Houston, GP and Clinical Lead for Palliative Care, Sandra Campbell, Nurse Consultant Cancer Team and David Arundel, LTCC Programme Manager was to finalise amendments to the ACP and agree to pilot in six practices covering the three CHP areas of Falkirk, Stirling and Clackmannan. Invitations were sent out along with a participation pack that included the draft ACP, guidance notes and a questionnaire. As a result six practices are now participating in the pilot and each has agreed to use the new ACP for 6 patients (two care home, two palliative care and two long term conditions patients). A questionnaire is included to get feedback from each of the six participating practices and if this is positive the new documentation will replace the three separate ACPs currently in use. A single page ‘Transfer of Care’ document is also being piloted initially for palliative care patients being discharged from hospital. Both the new ACP and transfer of care documents use the SBAR assessment criteria and conform to guidance received from the National ACP planning sub group of Assessment Tools and Advance Care Planning (SLWG3).

For further information on the latest developments of ACPs in Forth valley, please contact David Arundel, Long Term Conditions Programme Manager, NHS Forth Valley, David.arundel@nhs.net.
Age Matters Event—Perth & Kinross CHP

To celebrate National Older Peoples Day in October 2009, multi-agency planning group utilised the National VOICE (Visioning Outcomes in Community Engagement) tool to plan the event, which was aimed at the over 50s.

The event promoted healthy, active ageing through the signposting of available services and enabling them to take part in a range of physical, mental activities and promoting positive messages about getting older. There were 43 stalls including health, benefits advice, P&K Leisure, P&K Council Carers, Fire, Police, the Voluntary Sector and support groups.

Health promotion, wellbeing and self management workshops and demonstrations were held throughout the day. These included exercise; quality of life, feel good activities; home safety checks and demonstrations; Telecare Demonstrator Unit; community learning and presentations from Care and Repair and the Princes Royal Trust for carers.

The event was widely publicised through local press and radio; poster displays across Perth and Kinross; awareness raising with older people groups; home care and the mobile library service for the housebound. A free transport service was available across Perth & Kinross.

Over 220 older people attended the event. 87 completed the event evaluation with 97.5% rating the stalls as very good/good and 94.6% rating the workshops as very good/good. Stallholders reported the event as extremely worthwhile and an excellent opportunity for networking and learning about locally available services.

Long Term Conditions Collaborative (LTCC) representatives and P&K CHP LTC Manager promoted the aims of the LTCC workstreams and in particular Self-Management Programmes. Visitors to the stand were invited to complete a questionnaire designed to gain an understanding of the publics’ perception of a long term condition; and whether self-management would be high on their agenda. 21 Questionnaires were returned.

Questionnaire feedback highlighted that patients and carers feel long term conditions involve prolonged failing health, is something you just get used to and commented on the frustration of not being able to do what they used to.

In response to the types of services and support required to help build confidence in managing their condition, high on respondents agenda was the requirement for clear, understandable information of their condition and what to expect as it progresses, this was along with the need for rehabilitation, self-management groups for patients and support carers. Eighteen respondents also commented that they had attended Groups or Programmes to learn about self managing or other aspects of Long Term Condition care and felt that this was very important to them.

Contacts:
Carolyn Wilson                     Joan McGinnis
Falls Service Manager, Perth & Kinross CHP               LTCC Information Manager, NHS Tayside
01738 473146 - carolynwilson@nhs.net     01382 740265 - joan.mcginnis@nhs.net
Sharing and Learning Network

Margaret-Anne Dale, RES Manager at South West Glasgow CHCP, had received a number of requests from partnership areas to share the learning from the “Working in Partnership” Demonstrator Project at SW CHCP with ISD Scotland and the research with Talking Points following presentations at a range of national events with the LTC Collaborative and NHS Scotland. To facilitate the sharing and learning, the partnership areas were invited to the event held at SW CHCP on 24 June 2009. The meeting was attended by representatives from Greater Glasgow and Clyde, Lothian, Lanarkshire, Ayrshire and Arran and Tayside.

Following this successful meeting the group agreed to meet on a quarterly basis. A further two meetings have now taken place. Items for detailed discussion have included, SPARRA, Talking Points, Single Shared Assessment, Evaluation of Outcomes approaches and Training and Development requirements across partnership organisations.

The next meetings will take place on 7 May, 17 September, 10 December and 11 March. If you wish to attend these meetings please contact Jillian Blair, jillian.blair@ggc.scot.nhs.uk or phone 0141-201-4820. The theme of the next meeting will be based around the Rehabilitation and Enablement Framework.

To aid further communication within the group and a wider audience a “discussion forum” has been created on the Long Term Conditions Community Website. http://www.knowledge.scot.nhs.uk/ltc Please go to this website and register as a member to gain access to all the previous documentation and outputs from earlier Sharing and Learning Network events.

If you have any further questions about the network please contact Margaret-Anne Dale, Margaret.Anne.Dale@glasgow.gsx.gov.uk or Nigel Pacitti, nigel.pacitti@scotland.gsi.gov.uk.
Living Well with Chronic Pain – All about Time, Empathy, Enablement and Expertise?

To echo a phrase, there’s never been a better time to work on chronic pain in Scotland. Chronic pain is associated with fascinating pain magnifying mechanisms involving the spinal cord and brain - the “pain neuromatrix”. Knowledge of such mechanisms helps us to understand why pain persists when tissue or nerve pathology has resolved or cannot be found. Studies are showing trophic brain changes and reduced life expectancy.

People with chronic pain are often faced with very difficult psychological and social problems that stem not just from pain but also limited understanding and fear of their pain. Condition recognition in education and service planning is required. Imagine being a person with severe pain during a healthcare appointment being told there is nothing further that can be done and perhaps even worse that there is no explanation for your symptoms. For many people with chronic pain, encounters with doctors and other health professionals can be pivotal moments in their lives. With the right advice and, if necessary, treatment, people with chronic pain can live well and work.

The rewarding experience of helping people with chronic pain helps to explain why expert pain professionals working in pain clinics are so passionate about spreading support and services for such people. Chronic pain is recognised as a condition in the Long Term Conditions Action Plan which requires Health Boards to establish Regional Managed Clinical Networks to implement the aims of the NHS QIS GRIPS Report from 2009. Links with other key health improvement programmes such as the Rehabilitation Framework, Long Term Conditions Collaborative (LTCC), 18Weeks Referral to Treatment(18 WRTT) and Shifting the Balance of Care are being fostered locally and nationally. Recent 18WRTT meetings in Glasgow and Clyde and Forth Valley were devoted to chronic pain. Fife Health Board has confirmed £400000 investment in chronic pain as a result of its’ Shifting the Balance of Care programme.

Interesting conversations are emerging amongst those involved with the Quality Strategy and Long Term Conditions Action Plan delivery about empathy and evidence. This work has an immediate and sustained measurable impact on patient enablement. Giving these factors priority in strategic healthcare planning for chronic pain makes sense for patients but can also make work more rewarding for staff.

The vision of the Scottish Government Chronic Pain Steering Group is to ensure individuals with chronic pain are given the help and support they need as soon as possible to ensure they are given the best possible chance to live healthy, productive lives. A strategic plan is in development with service, education, audit and research components as well as work on pathways aligned with the Kaiser Permanente structure, involving the third sector. We want to promote not only the establishment of Regional MCNs for chronic pain but also to share ideas through local and national engagement with key improvement vehicles. Consequently local teams and other interested parties are encouraged to work on chronic pain and share ideas and examples of good practice.

If you would like to get in touch please e-mail me on petemackenzie@scotland.gsi.gov.uk
New Care Champion Appointed for Older People

A new specialist Rehabilitation Consultant has been appointed to act as a Scotland-wide champion to help people with long term conditions.

Edith Macintosh, a highly-experienced occupational therapist, will spend the next two years working with care homes and day care services to help drive up standards of care and support. In particular the appointment, which has been funded by the Scottish Government, is expected to play a major role in helping to improve the lives of people with dementia.

Mrs Macintosh was chosen for the role after an extensive 26-year career as an occupational therapist in both NHS and Local Authority sectors as well as her work within Allied Health Professionals and as chair of the Scottish OT Managers Forum. She said: “The main purpose of this post is to promote and increase access to rehabilitation and enablement to ensure older people in care homes and day services realise their full potential and enjoy a fulfilling life. In simple terms, this could be something as basic as people being encouraged to exercise more or people having a wider access to a bigger range of activities within the care services or in the community around them”.

“It is so important we support and empower those involved in providing care for people in care homes and day services to promote and facilitate rehabilitation and meaningful activity. One size does not fit all and personalisation of care is critical in adding life to years.”

The creation of the rehabilitation consultant post follows the success of the appointment of a Nurse Consultant in 2006 (now held by Susan Polding-Clyde) – the first position to be established to provide care homes with specialist advice and support to improve levels of care. There has since been an appointment of Gillian Stevenson as Nurse Consultant for Infection Control, who is tasked with influencing improvements to the quality of care to minimise risk of infection.

The appointment follows the publication of the Scottish Government’s Delivery Framework for Adult Rehabilitation in Scotland Document in 2007, which examined the evidence for coordinated and focused approaches to rehabilitation gaps.

The post will provide visible leadership and direction to service providers, commissioners and policy makers within adult care as well as providing links with many key agencies within and beyond the care sector. The post is pivotal to the implementation of the National Framework for Adult Rehabilitation in terms of care homes and day services.

Marcia Ramsay, Director of Adult Services for the Care Commission, warmly welcomed Mrs Macintosh’s appointment. She said: "We are delighted the Scottish Government has shown its foresight in recognising the value of the Rehabilitation Consultant role. We hope this appointment will be a force for positive change by providing much-needed support and leadership for those working in this challenging sector. "An important part of the Rehabilitation Consultant’s role will be to work with a range of stakeholders to improve communication and sharing of best practice among care workers thus reaffirming the very real rewards of a career in care. For more information on this new post please call 0131 561 2244 or send an e-mail to info@holyroodpr.co.uk."
It seems obvious that working well as a team can make a big difference to health or social care services. But building and maintaining a good team culture isn’t easy. It takes time and skill. Where do you find resources that can help you? How can you tackle problems that your group may be facing?

Effective Teams is a new website developed by NHS Education for Scotland which is building a collection of news and links to resources that can help you to work and learn well together. The site already has pointers to exercises and guidance, particularly those in the Toolkits already developed for NHS Scotland. But this is just a start. You’ll know what works and what doesn’t, which tips and tricks can make the difference.

The site provides an opportunity for users to suggest new resources for the collection, share stories and connect with each other. This is a toolkit with a difference - it’s your chance to build a collection of resources that can help us all to build great teams.

For more information visit the site [www.effectiveteams.scot.nhs.uk](http://www.effectiveteams.scot.nhs.uk) or contact andy-hyde@blueyonder.co.uk
In recent years, government policy has meant there have been more opportunities for service users to give their views and to contribute to the development of services.

Patients and their carers can be involved in policy and planning at all levels, however despite the opportunities, there has been very little support available to those who wish to get involved. The project aims to provide this support for people representing issues which are important to them and their carers.

The project has four main aims;
• To develop a network of patient/carer representatives who will receive regular newsletters containing project updates, details of opportunities to get involved & information about training events.
• Provide people affected with specific conditions, and their carers, with the skills and confidence to work with the NHS to improve local services.
• Empower patients and carers by giving them access to information, training and support
• To encourage partnership working between the NHS bodies & the patient/carer network

Those living with Chest, Heart or Stroke illnesses or those caring for someone who has are welcome to participate in the project as are those who aren’t currently involved but who would like to make their voice heard. Finally, professionals and organisations who want to hear the patient/carer voice are all eligible to participate in Voices Scotland.

The objectives of the interactive & informal one day session are to enable participants to understand the structure of the National Health Service (NHS) in Scotland, to know what is happening at a local level with user involvement and have contact details of the relevant local health professionals. Participants will also learn how to access national and local resources in order to obtain credibility and influence change within the NHS, to discover ways of making their views heard and how to effectively communicate with health professionals and how to share ideas & experiences in a relaxed environment, with people in the same position. Participants will also be encouraged to consider becoming a patient/carer representative. Patient or carer representatives are people who are engaged routinely in active partnerships with health professionals in the planning, monitoring and development of health services.

Patient or carer representatives can sit on committees that consider planning & service redesign and those that review research proposals. They can also respond to questionnaires, focus groups & interviews, attend public meetings/consultations & workshops, sit on patient user representative groups and attend professional committees, steering groups, working groups and advisory groups. To find out more please send an e-mail to nicola.cotter@chss.org.uk or call her on 0131 225 6963
80% of GP consultations relate to long term conditions and, due to the ageing population, this incidence is expected to double over the next 20 years. So what is important to people when visiting their GP? Well.....Better Together are finding out.

Better Together is an improvement programme which has been established to gather feedback from patients and staff in order to improve NHS services in Scotland. In November 2009, Better Together launched its survey to ask people about their experience of their own GP practice, including how easy they find it to make an appointment and their experience of consultations.

In November and December 2009, 500,000 people (who have been randomly selected from each GP practice in Scotland) will receive this questionnaire. Practices will find out their results in summer 2010 and will be supported to identify areas for improvement which their patients have told them are important to them.

The results of this work will also help inform further work on long-term conditions, which Better Together will take forward in 2010 in partnership with other agencies. Look out for further information in future editions of the Better Together newsletter.

If you are interested to hear more about patient experience or if you or anyone you know would like to share their story of healthcare, why not visit our website, www.bettertogethetescotland.com. This facility allows people to see examples of good practice as case studies, with the facility to view, and upload, patient and staff stories. If the website doesn’t answer any questions that you might have, please contact Carol Sinclair, Programme Manager, Better Together, carol.sinclair@scotland.gsi.gov.uk.
The Princess Royal Trust for Carers Update

Carers of those with long-term conditions often feel isolated and alone. They are more likely to suffer from depression and stress, which in turn can lead to carers themselves falling ill – a situation no-one wants to happen. That’s where we at The Princess Royal Trust for Carers come in! Our unique network of Carers’ Centres situated all over Scotland promotes the needs of carers and provides them with support. Workers can talk to carers about what they need and what they are entitled to receive – a carer’s assessment for example – or how to go about claiming carer’s allowance.

The centres are also a place for carers to meet others in the same situation, share information and make new friends.

The Princess Royal Trust for Carers also campaigns nationally for greater understanding of the importance of carers. In Scotland alone, unpaid carers and young carers are estimated to save the Scottish Government £7.68 billion a year. And yet carers often give up jobs and pension rights and struggle financially because of this and the economic impact of looking after someone who might need frequent hospital appointments and all-year heating in the house, adaptations to the home for a wheelchair and more.

Our interactive websites – www.carers.org and www.youngcarers.net – allow carers and young carers (the children who may be helping a parent or sibling with a long-term condition) to make their views known and chat online to others. The young carers’ website also has help on hand through its online youth support workers who can advise children and young people directly.

In addition, The Princess Royal Trust for Carers has a grants and funding programme which provides financial help to eligible carers to support self-identified management of their caring role. For more information on the work of The Princess Royal Trust for Carers, please contact Emma Baird, press and PR manager, on 0141 285 7938 or email e Baird@carers.org or visit our websites.

The Princess Royal Trust for Carers is also promoting partnership work between the local Carers’ Centre’s, health and social care professionals to identify carers early on in their caring role. The aim is to make sure that all carers who come into contact with health are identified, directed to appropriate services and advice and made aware of their rights. Spon- sored by the Moffat Charitable Trust, the Moffat Programme is working with four NHS areas in Scotland and is all about preventing crisis for carers. The programme looks at who the carer is, whether they know where they can go for help, whether they’re aware of the local carer’s centre and the benefits and training available to them.

It also means that the person being cared for will benefit from having a carer who is more able to cope with them at home; hospital discharges will be safer and less likely to result in short-term readmissions to hospital; and carers will have better access to carers’ assessments. The findings from the Moffat Programme are being independently evaluated by Glasgow Caledonian University. The programme will end early next year. To find the location and phone number of your local Carers’ Centre, please visit our website: www.carers.org or call our Glasgow office on 0141 221 5066. For more information on the Moffat Programme, see the website: www.carers.org/professionals
Tayside Institute for Health Studies (University of Abertay, Dundee) has been supporting the educational provision for long term conditions in our BSc (Hons) Nursing Programmes since 2006. Developed for undergraduate students and allied health care practitioners the Managing Long Term Conditions module explores the needs of individuals living with a long term condition.

The module explores evidenced based evaluation of theoretical concepts in long term condition management, including models of care, self management, communication and collaboration and working with families and carers. Assessment skills, medication review, and the role of the health care practitioner in proactive long term conditions management, audit and evaluation are also critical elements of the module.

This Honours level module can either be accessed as a stand alone module or as part of the BSc (Hons) Nursing and BSc (Hons) Nursing (Community Health) year 4 pathway offered by the university.

For more information please contact Dawn Coleman, module tutor email d.coleman@abertay.ac.uk Telephone 01382 308387

Scottish Health Information Service

The Information Services Division (ISD) aims to provide a world class intelligence service and one of the latest developments to modernise the delivery of information is the Scottish Health Information Service (SHIS).

SHIS enables authorised NHS staff to carry out analyses of nationally held datasets using Business Objects software. Access to data within SHIS can only be granted by the local Caldecott Guardian. Initially, only data relating to an employee’s own Health Board will be available, however a benchmarking facility is currently being planned which will enable comparative analysis.

The first four datasets to be made available through SHIS are collectively known as ‘ACaDMe’. ACaDMe contains information from January 1981 to present day on hospital episodes for Acute specialties (SMR01), Cancer registrations (SMR06), General Registers Office (GRO) death records and hospital episode information for mental health specialties (SMR04) for NHSScotland. Health Board access to ACaDMe has recently been piloted with the information teams in NHS Ayrshire and Arran and NHS Lothian. This will be rolled out across other Health Board areas during 2009/2010. ACaDMe will also be used by ISD staff for routine analysis and reporting, and it is intended that the 75+ emergency admissions report will be produced using ACaDMe. If you would like to find out more about SHIS or discuss access for your Health Board area, please contact Doug Kidd, SHIS Project Manager at d.kidd@nhs.net
Meeting the needs of families living with complex needs as a consequence of genetic change.

The Single Gene Complex Needs service has two distinct but related elements

The development of a strategic approach to delivering services to adults living with single gene complex needs in Scotland. Identifying need; improving service delivery; and working in collaboration to optimise patient outcomes.

To provide direct support to families living with a single gene condition that results in complex physical, cognitive and/or psychiatric change. Building the capacity of patients/families and other health and social care providers.

The Scotland wide team (6 members, 1 national lead, 4 clinical nurse specialists and 1 national administrator) are co-located in each of the 4 clinical genetic centres Edinburgh, Glasgow, Aberdeen and Dundee. The SGCN service will work with adults (> 16yrs) living with single gene conditions (e.g. fragile X syndrome, neurofibromatosis, Huntington’s Disease, tubular sclerosis, ataxia). Its main aim is to improve the quality of families’ lives which are so often overwhelmed as a consequence of the complexity of disease impact.

The team will work in partnership with people to manage their care and needs in their communities in an anticipatory way. The project team will work in collaboration with a wide range of partners from the voluntary sector, health and social care to design, align, develop and deliver relevant services, and improve outcomes for people, embracing the Scottish Government’s health and community care initiative, ‘Shifting the Balance of Care’.

The SGCN service provides a model of service delivery which supports integrated collaborative working practices which are embedded in evidence based learning and includes a cohesive and equitable approach to service provision and encourages outcome-based self-management principles, placing people at the centre of their own care choices.

For further information on this, please contact Marie McGill, marie.mcgill@nhs.net.
Seen and not heard? Exploring the issues facing children and young people with long term conditions

The Long Term Conditions Alliance Scotland (LTCAS) recently brought together around 100 representatives from the voluntary sector, health, education and government to consider how the needs of children and young people with long term conditions can be met.

The day was chaired by Professor Nick Watson of Glasgow University and was supported by the Equality and Human Rights Commission.

The conference heard directly from children and young people through films and a ‘conversation’ style presentation. Discussions then focused on school education, mental health and wellbeing and transitions. A panel discussion considered issues such as how children and young people themselves can be involved in developing effective policy and services.

The day concluded with a keynote speech from Adam Ingram MSP, Minister for Children and Early Years. The Minister outlined the range of policy that should ensure children and young people living with long term conditions are supported effectively. In particular delegates heard how the Getting it Right for Every Child change management programme was integrating services so the child is at the centre of a “one team approach”. The Minister also highlighted a number of projects funded by the Self Management Fund for Scotland which focus on improving support for children and young people.

The conference produced a wealth of discussion, thoughts and ideas and LTCAS will seek to capture these in a report published before the end of the year. The event was not an end in itself and LTCAS looks forward to working with members, children, young people and others to develop this agenda.
Long Term Conditions Collaborative Events

We ran two hugely successful events at the end of October and November and we would like to thank all those who attended and presented at ‘The Spread Roadshow’ on the 28th October and ‘My Care My Choice’ on the 26th November. The audiences at both events were hugely enthusiastic and the national team really enjoyed seeing all the great ongoing local service improvement work.

The Spread Roadshow
The aim of the day was to promote the spreading of good practice. Jason Leitch showed how important Spread is and that there is no limit to what can be spread. This event was also a platform for Boards to promote the great long term condition specific work that they have been doing. There were a variety of breakout sessions; from developing the Health in Hand website in the Borders, to Community Nursing in Lanarkshire and everything in between! The colourful and varied storyboards also highlighted local achievements and the day culminated in a Spread related 14 Day Challenge.

My Care My Choice
This day showed how important long term condition related work is to the development of quality healthcare in Scotland. Derek Feely gave an insightful presentation into the ongoing progress of the Scottish Government’s landmark Quality Strategy whilst Carol Sinclair reminded us of the importance of capturing and learning from patient experience. There were a variety of other interesting presentations before the day concluded with two breakout sessions. Andrew Lyon discussed the Thinking Tool whilst Stewart Mercer and Audrey Taylor explored the patient measure tool.

All of the presentations from these events are available on the new LTCC Community of Practice. We will be hosting further events in 2010 so please keep an eye out for these being promoted in the LTCC Bulletin / e-mails. If you have any further questions, please contact Fraser McJannett, fraser.mcjannett@scotland.gsi.gov.uk

We also had Video3 recording this event and all presentations have now been archived. They can be viewed at http://www.video3uk.com/ltcc.
The LTCC sends out a fortnightly eBulletin that contains links and attachments to reports, initiatives and events that may be of interest to the LTCC community. If you would like to be added to the distribution list for this or would like to highlight pieces of work for inclusion, please e-mail fraser.mcjannett@scotland.gsi.gov.uk

Staff Changes

Since the last newsletter two members of the national team have left to start exciting new jobs. We would like to thank both Charlotte and Lynsey for all their hard work at the collaborative.

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Dates for your 2010 Diary:

T6 / LTC Action Plan Morning Meeting
Afternoon Learning Event
16 June—The Beardmore
23 September—Edinburgh 1st

It’s All About Me, Person Centred Event
30 April
Crown Plaza Hotel, Glasgow

NHS Annual Conference
7th & 8th June
Edinburgh International Conference Centre