Inspire, Empower, Transform

Long term conditions and end of life care

A portfolio for new PCTs that reviews and showcases practice in long term conditions and end of life care, promotes self care, and gives guidance on commissioning activities from agencies external to the NHS

Life Goes On

I often get moments of doubt and despair,
So take a few minutes and sit in my chair.
All sorts of questions go through your mind,
Sometimes the answers are quite hard to find.

So come on then now, what can you do?
The bottom line is it's all up to you.
Look after yourself, and set up a pace,
In our condition life's not a race.

Think of a plan it needn't be hard,
My first one was to walk up the yard.
Try to eat well and balance it right
Learn to relax so you rest through the night.

Life's not the same by a very long chalk,
But oh! the relief of a good long mind walk.
Help is at hand you've only to ask,
There are lots of ways to deal with a task.

I know it's not easy, but please don't give in,
Some days you lose but some days you win.
And when asked by your neighbours, how do you cope?
The gentle reply is 49 tablets and 2 spoons of hope.

Tony Allsop EPP East Midlands graduate

Dear Doctor

Over six weeks
I have learnt new techniques
To take back control of my life.
The course not begun
My life had no fun,
It was filled with nothing but strife.

Problems with the medication
Often led to more frustration,
Never time for relaxation
Feeling tired all the time.

The changes I've made
For myself, I can see,
It's a wonderful project
To do EPP.
For you learn to take hold
Of your life once again,
And become more relaxed
And can deal with your pain.

As your confidence grows
Then uselessness goes,
Helped by trainers, and friends SHAring fears.
Because with their support
And the things you are taught
The battle will not end in tears.

Clare Mogridge, East Midlands EPP graduate

Report by Roger Paffard and Janette Goodchild, independent consultants

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Aim

This report aims to be a portfolio for new PCTs that reviews and showcases practice in long term conditions and end of life care, promotes self care, and gives guidance on commissioning activities from agencies external to the NHS

Scope

The project was a time limited review commissioned by Trent Strategic Health Authority (SHA). It was part of their transitional plan to capture legacy activity and best practice for new Primary Care Trusts (PCTs), help new PCTs decide on early priorities, and to mitigate any knowledge and momentum loss. Much of the research activity therefore was conducted in the north East Midlands area however all conclusions and recommendations have been tested for their relevance to the whole new NHS East Midlands region.

The review took place between March and July 2006. During this time, a series of meetings and events were organised with deliverers of long-term and end-of-life care across NHS, social services and the third sector. Community matrons, district nurses, PCT chief executives, senior mangers in PCTs and SHA responsible for commissioning/operations/long-term conditions, long term condition leads and over 100 voluntary organisations have all contributed. We have also had exposure to a wide range of self-care practices and practitioners, patients practicing self-care across a spectrum of conditions, patient and public involvement and expert patient leads, and organisations representing people with long-term conditions.

Key Outputs

The report has essentially four outputs:

(i) A summary of self care activity and services from an online database that has potential to be expanded and developed. This has provided a baseline from which many of the conclusions and recommendations are derived

(ii) A series of nine case studies that have been selected in consultation with long term condition leads from within the region to demonstrate best practice and tangible results, and provide a benchmark for the new PCTs to review current service priorities. The case studies cover the five main long term conditions (diabetes, respiratory, end of life care, heart failure and neurological), and four generic areas (expert patients, signposting, case management and Third sector)

(iii) A comprehensive reference of relevant national guidelines and activities for executives and leads.

(iv) A series of conclusions with recommendations

Conclusions

The overwhelming impression is of a vibrant, positive and energetic culture with enough baseline activity to substantiate the widely held view that the region is in the vanguard nationally of long-term condition management. The project has been successful in starting to create the right conditions for developing and expanding best-practice in self care, cross-boundary working and the engagement of non-NHS organisations. There are 11 positive factors identified that support this position:-

From a pan regional perspective of particular relevance to the East midlands SHA:

(i) There is a strong long term condition **legacy** throughout the region with priorities established in ISIPs and dedicated resources and active networks flourishing.

(ii) The review has identified and captured encouragingly healthy levels of **self care services and activities** across the region – especially in mental health, diabetes, heart failure and non-condition specific.

(iii) There exists a mature, well-organised and constructive **Third sector** infrastructure in most if not all communities across the East Midlands with a strong motivation to engage with health & social care in the self care and wellbeing vision. The report highlights the Motor Neurone Disease Association case study model as a potential exemplar for other Third sector organisations to follow.

(iv) There are good **clinical networks** with effective clinical engagement across the main long term conditions especially with diabetes, strong cardiac networks and increasingly but more recently with COPD.

(v) One of the outcomes of this work has been the establishment of an easy to use self care questionnaire which is **internet-based** and a **database** that could provide an invaluable interactive tool for the whole region. This work has the potential to be expanded to other areas such as telemedicine.

(vi) The transitional plans are well advanced for long term conditions with the development of a **long term conditions strategic programme** proposal for the East Midlands providing a very clear commitment to self care as a strategic priority and a strong platform to engage non-NHS organisations in supporting the delivery of the white paper aspirations.

(vii) The underlying delivery infrastructure for the **transitional plan** is evolving well with long term condition and self-care networks already established involving leads from social care and the Third sector across the East Midlands. A community matron based case-finding and evaluation learning set is also actively rolling out.

(viii) This time limited review compliments and informs a number of other **transitional work streams** in commissioning; third sector engagement; balanced scorecard; model community innovation centre ; self care project which will provide natural vehicles to progress some of the recommendations to support the new organisations while they are being established.

From a community perspective of particular relevance to new PCTs:

(ix) There are some outstanding examples across all conditions but the review has identified and highlighted **5 condition specific case studies**. These are

generating tangible outcomes and attracting national attention and are exemplars for the new PCTs to benchmark current services and to prioritise for potential to roll out.

(x) There is also evidence for a strong legacy of a **patient-centred** culture and approach and this report highlights 3 generic case studies in expert patient, signposting services and case management as exemplars.

(xi) The emerging long-term conditions strategy and the national agenda will require the new PCTs to deliver significant behavioural and service delivery changes. There are a number of potential facilitating **change management resources** in the East Midlands that will connect well with this agenda e.g. the launch of the model community innovation centre, the groundwork in telemedicine and assisted technology, the education framework to support long term conditions in the workforce, the community matron and case management learning sets, the active participation of UHE in the implementation and measurement of case management.

There are also eight issues and potential barriers identified that inform the recommendations:-

From a regional perspective;

(i) There are pronounced variations in **non-NHS capacity** and resource across geographies and there is clearly an opportunity to challenge the Third sector to help identify their proven delivery strengths and capacity in some communities and how the NHS can roll this out across the East Midlands.

(ii) This review found no model in use that links long term condition outcomes with commissioning in general and practice-based commissioning in particular. There is a need to improve understanding of how the delivery of self care and long term conditions management will impact on **financial outcomes** in-year or in the longer term and a specific work stream should be commissioned.

(iii) There is widespread concern with our **non-NHS** partners and **the Third sector in particular** about the disruption, lack of long-term planning and short-term financial pressures they are currently experiencing and that are causing real difficulties. Their recent experience differs markedly from the visions and aspirations of engagement, partnership and expansion of their capacity and role articulated in the white paper and recent national third sector policy statements and pronouncements. An early programme to re-engage the sector and involve them in the plans to deliver the white/green/third sector task force agendas is needed and would be welcomed.

From both a regional and a local community perspective:

(iv) The impact of **large scale organisational change** programmes in health and social care over the last year has had a detrimental effect in stalling progress in a number of areas

partnership working with third sector;
coordination with local authority agendas and social care delivery;
key skills and knowledge management

All areas that can be positively addressed now that the new organisations are forming.

(v) The timetable for new **commissioning** framework and operational guidelines expected in December 2006 may be too late to start the dialogue needed to start addressing the four concern areas for the third sector of the impact of:

practice-based commissioning
new commissioning regimes in a financially challenged social & health care system
commissioning long term condition outcomes
proportionate monitoring & governance arrangements

Mechanisms should be explored for initiating the development of solutions now if the sector is to be engaged in time for next year's financial plans.

(vi) There is a need identified at regional and community level to develop a set of **three proportionate contracts** that are appropriate to the scale and purpose of the third sector engagement in addition to the model contract in the third sector task force recommendation.

(vii) The review also highlights a low level of service in **end of life care** generally and inconsistent and patchy geographic coverage in **neurological** and **respiratory** conditions.

(viii) Across all conditions there are significant **differences in delivery models** and whilst this is not a problem in itself the new organisations have a unique opportunity to challenge and benchmark current service models against the best. The nine case studies in this review would be a time efficient starting point.

Recommendations

There are 14 recommendations of which 9 have particular relevance at a regional level and 5 at both regional and local community levels.

At a regional level:

(i) Early approval and adoption of the NHS East Midlands long term conditions strategic programme proposal. This is a positive statement of commitment to the new direction set out in the white paper and its early adoption and publication could both provide a strong direction within the NHS and an ideal platform for engaging with both social services and the third sector.

(ii) There are a number of commissioning issues emerging from the review which need addressing across the East Midlands as part of a mainstream agenda and specifically the four issues raised by the third sector.

practice-based commissioning impact on long term conditions and joint commissioning with social services
new commissioning regimes in a financially challenged social & health care system
commissioning long term condition outcomes
proportionate monitoring & governance arrangements

Consideration should be given to a specific work stream focussing on commissioning for quality outcomes within the long term conditions programme and the development of a financial model demonstrating in-year and long term impacts.

(iii) There is also a need to develop proportionate contracts with the third sector and a specific recommendation from this report is that consideration is given to the development of four levels of contract template for use across the East Midlands

(iv) The third sector task force report published in July 2006 could provide a vehicle for constructive engagement with the third sector. The NHS East Midlands should consider whether to publicly adopt its 8 enabling principles, 16 commitments and the model contract.

(v) There is a need at regional level to define the necessary ownership and leadership across the health and social care sector to ensure that the vision for health "self care" and social "wellbeing and independent living" articulated in the white and green papers are better co-ordinated and delivered across organisational boundaries. A senior SHA executive should be nominated to lead the co-ordination across the SHA; GOEM; CSCI; Local Authorities and the third sector.

(vi) There is a real opportunity to re-engage the third sector in helping to shape and resource the health agenda in the East Midlands and a proactive programme of summits or conferences this year would be welcomed and should be implemented.

(vii) There now exists a potentially valuable baseline review for self care services and activities in the East Midlands and its adoption and development at regional and community level is recommended. The specific next steps recommended are on p25.

(viii) The constructive engagement of national and pan-regional third sector organisations in cataloguing their areas of expertise and demonstrating areas of full capacity utilisation as a basis for the planned roll-out of that capacity across the region would be a very powerful next step.

(ix) Telemedicine and assistive technology represent a significant and internationally proven untapped potential to deliver significant patient outcomes and financial returns in the medium to long-term. NHS East Midlands should consider commissioning a dedicated work stream to focus energy and priority on this area (in a similar way to this self care review)

At regional and local community level:

(x) As new organisations are formed it is timely to consider the key strategic role of non-NHS resources in the delivery of services and appoint a nominated senior executive with specific responsibility for the sector at both SHA and pct levels.

(xi) This report highlights 9 case studies of best practice within the region that are generating tangible outcomes and are exemplars for the new PCTs to benchmark current services and to prioritise for potential to roll out. The wide dissemination of these case studies via this report, TIN and their proactive use in peer reviews is recommended.

(xii) The review also highlights lower levels of service delivery across the region with end of life care and within the region in the care of neurological and respiratory conditions and this merits further investigation at a condition network and community level.

(xiii) In the review mental health has emerged as a particularly fertile area for self care and patient involvement best practice and the engagement of non-NHS partners. Consideration should be given to a more proactive involvement of mental health in the baseline review; the LTC oversight board and the learning networks for self care, community matrons and patient engagement.

(xiv) The model community innovation centre is now a valuable facilitation vehicle for developing solutions for both the long-term condition outcomes and practice based commissioning challenges. It is recommended that a programme of simulations is run across all communities and conditions over the next 6 months.

Some of these recommendations are designed to give options that will provide "quick wins" to regain momentum and send positive signals whilst the more measured planning and commissioning cycle is developed. Others are more strategic and intended to stimulate thought and debate. This report in general aims to assemble the evidence and relevant background information and guidance in one place for people to make their own judgments.

Nine of the recommendations require decisions from the SHA as they assume that some issues will need to be addressed and solutions found before national guidance is available (and before new PCT organisations have bedded in) if the imperative to achieve a significant impact on next year's outcomes and financial results is to be delivered.

Connections and Links

This time limited review complimented and informed a number of other transitional work streams in commissioning; third sector engagement; balanced scorecard; model community innovation centre; self care; community matron and case management expansion. These will provide natural vehicles to progress some of the recommendations to support the new PCTs while they are being established. The recommendations are therefore designed as inputs to these work streams.

The report also recommends consideration of further work in telemedicine and assistive technology; social care and regional public sector and third sector engagement; development of the outputs of this review where there is no obvious work stream identified to own these opportunities.

Next steps

NHS East Midlands and new PCT organisations read and consider the content of this report.
The conclusions and recommendations could be reviewed at the first East Midlands long term conditions oversight board on 28 September 2006 with a view to deciding which should be adopted.
Consideration is also needed at NHS East Midlands level on whether the 14 recommendations meet the regions strategic objectives and which actions need to be progressed and allocated to specific work streams or roles.

The format and timetable for publication of this time limited review also needs to be agreed. The earlier it can be disseminated widely the more valuable it will be to the many contributors across the region.

1.0 Introduction

1.1 Scope of project:

The project was a time limited review commissioned by Trent Strategic Health Authority (SHA) as part of a transitional plan to capture legacy activity and best practice for new PCTS, help PCTs decide on early priorities and to mitigate any knowledge and momentum loss. Much of the research activity therefore was conducted in the north East Midlands area however all conclusions and recommendations have been tested for their relevance to the whole NHS East Midlands region. The project plan is included in appendix 1. The scope is given below:

> *"The scope of the work is related to the improvement of long term conditions and in particular by commissioning and increasing the use of services external to the NHS. The key to the project is to review current practice, prepare the ground for future commissioning arrangements and deliver a portfolio to the new PCTs to promote self-management and increase use of services and agencies external to the NHS".*

The project was focused on the following conditions:

Respiratory
Heart failure
Diabetes
Neurological
End of life care

1.2 Overall Project Outcome:

The overall project outcome was to produce a portfolio (this report) for new PCTs that reviewed and showcased practice in long term conditions and end of life care, promoted self care, and gave guidance on commissioning activities from agencies external to the NHS.

In addition the project outputs can be fed into other NHS East Midlands work streams primarily:

community matron and case management
telemedicine and assistive technology
model community innovation centre – the Mill
third sector development and engagement
balanced scorecard and commissioning
self-care

1.3 Project overview

The project took place between March and July 2006. During this time, in addition to a desk top review of national context, a series of meetings and events were organised with those who deliver long-term and end-of-life care across the NHS, social services and the third sector. Community matrons, district nurses, PCT chief executives, senior mangers in PCTs and SHA (with responsibilities for commissioning/operations/long-term conditions), long-term condition leads in health communities and over 100 voluntary organisations have all contributed. We have also had exposure to a wide range of self-care practices and practitioners, patients practicing self-care across a spectrum of conditions, patient and public involvement and expert patient leads, and organisations representing people with long-term conditions.

The overwhelming impression is of a vibrant, positive and energetic culture with enough baseline activity to substantiate the widely held view that the region is in the vanguard nationally of long-term condition management, and has been successful in starting to create the right conditions for developing and expanding best practice.

This achievement was aptly captured at the long-term conditions strategy away-day on 11 July 2006 by Leigh Burns of United Health Europe (UHE)

> *"Across the patch we are finding that we are no longer being questioned on WHY (community-based long-term conditions case management) but have moved onto HOW".*

The basic pre-conditions in the East Midlands for a successful expansion of self-care and long-term conditions management have already been established. The scale of activity catalogued by the project includes:-

nine case studies (five condition specific and four generic) that are or will be receiving national recognition. All strong candidates for the new PCTs to embrace and roll-out across their geographies
examples of patient pathways, views and experiences
151 examples of current self-care activities and services with 74 of these captured through an online questionnaire
views and experiences from over 100 voluntary organisations

There is a very urgent need for the NHS East Midlands and PCTs to send out some messages of commitment and examples of positive intent to combat the widespread perceptions that;

(i) momentum has slipped backwards in the last 6 months as NHS and social services re-organisation dominates day-to-day business and opportunities for constructive long-term planning have been lost.
(ii) there is a disconnection between national vision and strategy and implementation on the ground. This is seen to be as a result of de-stabilising short-term NHS financial pressures.

(iii) there is confusion and uncertainty about the direction of the NHS, particularly about who does what and how the ideas in the white paper will be implemented especially in the areas of

- practice-based commissioning,
- new commissioning regimes in a financially challenged social & health care system,
- commissioning long term condition outcomes,
- proportionate monitoring & governance arrangements.

The recommendations in this report are aim to provide the new PCTs and NHS East Midlands with opportunities and solutions to regenerate momentum as quickly as possible.

2.0 National Context

At the same time as this project, the emerging national thinking and guidance has been particularly fertile, in the wake of the white paper *"Our health, our care, our say"* which set out clear priorities for long-term condition management, end-of-life care, the need to expand capacity for self-care, and for partnership with non –NHS organisations.

The Department of Health (DoH) Strategy *"Supporting People with long term conditions"* (Jan 2005) stated four core strategic aims:

(i) To embed into local health and social care communities an effective systematic approach to the care and management of people with long term conditions.
(ii) To reduce the reliance on secondary care services, and increase the provision of care in a primary, community or home environment.
(iii) To deliver high quality care, personalised to meet the individual requirements of people with long term conditions.
(iv) The Public Health white paper "*Choosing Health*" underpins the entire long term conditions approach. This will build on the public's growing desire for a healthier future by ensuring that self care support is in place for people, particularly those in disadvantaged groups and areas, to make healthier choices about diet, physical activity and lifestyle.

In January 2006, *"Our health, our care, our say"* reinforced these aims and Chapter 5 set out a range of new policy developments. These include:

Empowering those with long term needs to do more to care for themselves including better access to information and care plans.
Investment in training and development of skills for staff that care for people with ongoing needs.
New support for informal carers, including a helpline, short term respite, and training.
Collaboration between health and social care to create multi-disciplinary networks to support those people with the most complex needs.

Since this white paper there has been a welcome consistency of national message which provides clarity that:

improving long-term conditions management is the key to the future viability and financial stability of the NHS
supporting the expansion of self-care and of community resources "closer to home" is a core priority.
the role of non-NHS organisations in delivering this agenda is recognised as absolutely critical together with an acknowledgement that a step-change in NHS commissioning skills and practices is needed to achieve the necessary expansion of capacity required.
across government there is a recognition of the power and capacity to innovate, and the value of "the third sector". There is also recognition that "a level playing

field" is needed to truly capitalise on the potential of the Third sector in delivering public services. Sir Peter Gershon in his 2002 "*Review of Public Sector Efficiency"* and Acevo in their *"Surer Funding"* report identified four principles to achieve "a level playing field". These are:

(i) multi-year contracts
(ii) full cost recovery
(iii) streamlined monitoring, regulatory and reporting requirements
(iv) appropriate assignment of financial risk between statutory bodies and third sector providers.

Third Sector Commissioning Task Force Report "*No Excuses"* (July 2006) adds the concepts of "proportionality", engagement and involvement. The report also includes eight enabling principles, 16 commitments and a model contract which provide an excellent toolkit for PCTs to start reshaping the agenda in a positive manner with the Third sector. The report is the first of a number of national initiatives that will be aiming to define frameworks, practical tools and delivery mechanisms to help the national agenda be delivered on the ground. The full Task Force report can be found in appendix 2.

Department of Health frameworks following on from the commitments set out in *Health Reform in England; Update and next steps* (December 2005) will compliment the Third Sector Task Force report. Three draft frameworks expected as consultation documents during the summer of 2006 are:

Provider Reform framework
Commissioning framework
The management & regulation of the Healthcare system framework.

These frameworks aim to set out a health service management and delivery vision for 2008 onwards. In many cases further guidance is targeted to be published by December 2006 and these will help inform the development of new commissioning regimes for PCTs. However the extended timetable means that the development of commissioning and contractual guidance and frameworks across the East Midlands will need to proceed in advance of this timetable to deliver an impact in the next financial year. It is therefore helpful that the region has been actively engaged in the development of these frameworks as part of its balanced scorecard and long term conditions work streams.

The palliative care agenda is also active at a national level with the national cancer charities actively engaged with government on how to deliver the manifesto pledge to provide patients with the choice to die at home (by doubling investment). In July a new strategy work stream (under the leadership of Professor Mike Richards, the cancer czar) was announced. This work stream has been tasked to review:

- funding for hospices
- specialist palliative care issues,
- choice at the end of life,
- the need to improve the quality of care in hospitals and care homes,

- the need for improved coordination of services across organisational boundaries.

The target publication date is autumn 2006. It is expected to follow very similar themes to the Third sector task force report with strong support for the Delivering Choice flagship project pioneered in Lincolnshire (see case study 2). This will be showcased nationally with ministerial endorsement on 13 September 2006. However, the baseline audit findings show that end-of-life activity is the least well-developed of all the areas covered yet this was highest on the wish-list of the community matrons interviewed, especially in the provision of non-cancer care services. It would therefore appear end of life care should become a regional priority.

The scale and speed of the national work streams over the next few months at a time that new PCTs are forming would argue for some dedicated NHS East Midlands resource to ensure that the timetable allows for delivery of new commissioning impetus prior to the financial year-end

2.1 Regional Context

NHS East Midlands appears well-placed to respond to this national context and its challenging timetable. Much of the needed groundwork is already completed or underway with an active transitional plan in place.

The strategic context has been formulated with the development of a Long term conditions Strategic Programme Proposal (appendix 3) giving the opportunity for early adoption and publication. The proposal includes the following summary table:

Led By:
One cohesive strategic vision led by an East Midlands long term conditions Board and its partners

Commissioned To:
Deliver consistently high levels of quality from a range of providers
Incorporate best practice in long term conditions care pathways, from an evidence-based perspective

Managed Through:
Proactive clinical practice in the field
Patient participation & involvement
Commissioning local programmes with standards that are clinically led
Partnership working

Measured By:
Nationally and locally agreed objectives reflecting equity and minimum standards in a local framework;
Evaluation & decision driven data systems

The proposal provides a real opportunity to maintain the regional momentum behind long term conditions. With its emphasis on patient and person-centred solutions, holistic approaches and “joined-up” programmes and priorities provides the perfect platform to engage non-NHS organisations

It will also provide a very helpful vehicle (together with the Integrated Service Improvement Plans (ISIP)/Local Area Agreement (LAA) priorities to drive the long term agenda within the region and to proactively engage non-NHS partners.

The inclusion of the Self Care work stream in the NHS East Midlands core programme is also a very positive statement. The review of self care practice undertaken as part of this project provides the basis of a knowledge management environment that can inform early commissioning and practice priorities. There is also an opportunity to develop the review method into an interactive and real-time tool to support this knowledge management environment for PCTs.

A strong legacy in the East Midlands has enabled 2 pro-active pan region groups to be active already.

> A coordinating self care group involving self care leads across the region with voluntary sector and local authority participation has formed.
> A community matron based evaluation and learning set is examining case finding case loads and coding interventions to improve productivity and assist the expansion of case management into level 1 & 2 interventions.

Recommendations

- NHS East Midlands and PCTs utilise the Third Sector Task Force report principles and commitments and model contracts as a toolkit to start reshaping the agenda with the Third sector locally
- NHS East Midlands engage where practicable and possible in the development of the DoH frameworks and subsequent operational guidance
- PCTs assimilate the DoH frameworks and operational guidance as they are published
- End of Life care becomes one of the priority areas for NHS East Midlands
- NHS East Midlands dedicate resource to ensure that the timetable allows for delivery of new commissioning impetus prior to the financial year-end
- Early adoption and publication across the East Midlands of the Long term conditions Strategic Programme Proposal (appendix 3)
- The Long term conditions Strategic Programme together with the Integrated Service Improvement Plans (ISIP) and Local Area Agreement (LAA) are used to:
    - help shape the contribution of the other regional resources to aid delivery of self care and long term condition management
    - launch the engagement of other key regional partners including local authorities, regional organisations (e.g. GOEM) and the “third sector”
- The self care review method is developed into an interactive and real-time tool to support a knowledge management environment for commissioners and practitioners.

3.0 Review of practice across East Midlands

A review of practice across the East Midlands was undertaken as part of the project. The review was carried out in a number of ways

Case studies – the long term conditions leads agreed ways of working that represented best practice in each of the five priority areas (Diabetes, End of Life, Heart Failure, Neurological, and Respiratory) with a view to this practice being adopted across the East Midlands

Self care review – a review of practice was undertaken utilising an on-line questionnaire hosted on the Improvement Network website (www.tin.nhs.uk) and by linking in with two locally planned projects one in Derbyshire and the other in Ashfield and Mansfield.

Patient experience– Creating and commissioning a patient-led NHS implies a culture that is patient centred, involves stakeholders in decision-making and, which understands and aims to improve patient experience. Whilst direct feedback was not intended to be gathered from patients as part of the project plan, patients receiving the self care questionnaire were given the opportunity to feedback. The views of patients' and their experiences have also been highlighted in the case studies.

Patient and Public Involvement - Involvement of patients and the public in the planning, design, development and evaluation of services is a statutory duty of NHS organisations. The Expert Patients Programme and Bassetlaw's NHS Live project are showcased as examples of best practice in relation to involving patients in the planning, design, delivery, and evaluation of long term conditions and self care services. Case studies have also shown how patients and the public have been involved.

Community Matrons – the contribution of community matrons in informing this report has been invaluable as their role matures and four common themes have emerged that support the work of the East Midlands' evaluation and learning set. In addition a community matron has completed a case study showing how their work improves patient experience and contributes to the achievement of headline targets.

Telemedicine and assistive technology – although this area was not central to the project brief it is clear that there is significant untapped potential that would merit further investigation, particularly in the areas of non-NHS funding and scaleable multi-agency pilots.

Model community innovation centre – the "Mill" – the East Midlands has a unique resource that could provide a facilitation focus for the resolution of outstanding issues affecting the commissioning of long term condition outcomes and the roll out of best practice and learning from this report.

3.1 Case studies of best practice in relation to the 5 priority areas

Each of the following case studies is considered to be best practice within the given priority area. A short overview is given below with each study included in full as an embedded object (to access the case study documents double click on the *word* icon).

Case study 1: Diabetes –"Diabetes You and Me", Derbyshire

This case study highlights how Derbyshire are moving forward a structured education programme for people who have diabetes. It explains how after a successful pilot, the programme is rolling out across Derbyshire and how it is evolving to respond to the needs of the local community. The case study also highlights the need for a planned and systematic approach to implementation supported by a realistic apportion of resource

Structured education can have a profound impact on health and quality of life. High quality programmes have been shown to lead to improved glycaemic control, a reduction in complications and be cost effective. There is evidence that patients who never receive diabetes education showed a four-fold increased risk of a major complication. The second paper gives some background into diabetes patient education.


Diabetes & You Case Study


Diabetes Patient Education

Case study 2: End of Life – Marie Curie Delivering Choice, Lincolnshire

This case study describes the Marie Curie Cancer Care Delivering Choice Programme which aims to develop and help provide the best possible service for palliative care patients allowing them to be cared for and die in the place of their choice. The programme aims to benefit patients and their carers by designing reliable palliative care services which will provide information, support and best possible care in the place of their choice; and to benefit healthcare providers and professionals by providing service models based on better resource utilisation and through delivery of more effective ways of working. The programme has developed a model providing a single point of access with a co-ordinated approach across health, social care and the third sector.

In addition the case study shows how this model of working is already making a difference to patients. Results taken from January to June 2006 the service has received 745 referrals and prevented approximately 280 admissions to Accident and Emergency.

> ***Betty, 75, died at home in June 2006***
> *Betty had chronic obstructive pulmonary disease. She was admitted to hospital following a car accident, with multiple fractures. She was seen by a social*

worker on the ward who contacted Jo, the Discharge Community Link Nurse, for support because she felt Betty needed specialist palliative care.

Jo talked to Betty and her husband, John, who understood the prognosis and clearly wished to be cared for at home until the end of her life.

Jo liaised with all the hospital staff to assess what care Betty would need at home and also with the Palliative Care Co-ordination Centre, which arranged all the care she needed. Jo visited Betty once she was home to give extra nursing care and to provide emotional support to John.

Betty died peacefully at home two days later. Her husband John wrote to Jo to thank her for her help and support. He said:

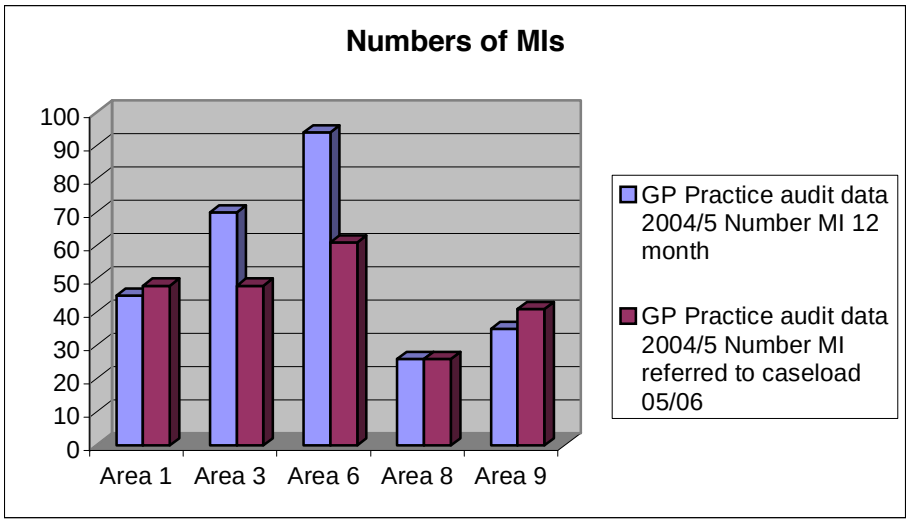
"You seemed to be the only one who made it possible for Betty to come home. If you hadn't acted I believe Betty would have died alone, in hospital."

Marie Curie Delivering Choice

Delivering choice presentation Aug

Case study 3: Heart failure – Community Cardiac Rehabilitation & Support Service, Nottingham City

This case study describes the community cardiac rehabilitation service which operates in areas of deprivation across Nottingham City. It describes how the service responds to the needs of local communities offering different approaches dependent on other services available and needs of local people. In addition to traditional health services the case study shows how the service participates in the overall community development of the areas in which it operates. Approx 83% of patients are being seen by the service in the areas it operates.



The case study shows how services can deliver strategy in an environment that is truly joined-up, informed and patient-centred, making a real difference to local people.

" Had I not taken part I would not have known that my blood pressure was high and that I needed to see my GP. It was easy to see a nurse at work whereas it is not always easy to get to the doctors".

Nottingham 4H
End of Year Repor

Case study 4: Neurological – Sapphire Epilepsy service, Derbyshire

The case study shows how services traditionally delivered in a hospital environment can be delivered in a community setting. Epilepsy is the most common serious neurological condition. It can affect anyone at any age at any time. The prevalence is 5- 10 cases per 1000 people therefore a GP with a practice population of 2000 will care for approximately 15 patients with active epilepsy. The mortality rate for people with epilepsy is 2-3 times higher than the age matched population. 1000 deaths a year occur in the UK as a result of epilepsy, 500 of these are as a result of Sudden Unexpected Death in Epilepsy (SUDEP). For some time now there has been a lack of specialist care for people with epilepsy, there is a shortfall of neurologists within the UK and not all the existing neurologists have an interest in epilepsy management. As a result you can expect to see a 20- 30% misdiagnosis rate with syncope being commonly mistaken as epilepsy.

The study highlights some of the challenges that have been encountered and how these are being overcome. The case study describes the need for effective planning from concept to implementation involving stakeholders and recipients as much as possible. The case study also describes examples of how the service is making a difference to patients and to reducing the number of A&E visits.

The case study highlights the need for resilience, flexibility and an open approach.

Epilepsy service

Double click on the word icon to read the case study.

Case study 5: Respiratory –Inspire, Lincolnshire

The case study describes how the Inspire service in Lincolnshire has evolved and is evolving. Included are statistics showing how the service is contributing to targets and making a difference to patients with COPD.

"Preliminary Results

- *There was a **23%** decrease in COPD admissions to the local hospital in 2003 compared to 2000, at a time where most hospitals saw an increase.*
- *This would equate to a cost saving of £330,000 for an investment of £116,000 for implementation of this part of the programme.*

- *Referral patterns to secondary care also showed some interesting outcomes. Although the PCT comprises **42%** of the total population of the county as a county, referrals to secondary care chest clinics only account for **22%** of the whole.*
- *The activity of the Inspire team in providing enhanced community services resulted in 183 acute exacerbations of COPD being managed over a 10 month period (April-January 2006) within the community.*
- *This would equate to a cost saving of £428,220 (LOS @ 9 days X £260 per bed day) for an investment of £212,500 (part year affect).*
- *This outcome is on track to deliver the projected benefits of reducing hospital admissions for acute COPD by 50%.*
- *Re-admissions rates are currently only 7.8% as opposed to national figures of 30%."*

The case study also shows how patients have been involved in the development of the service and describes the techniques applied.

The case study emphasises the need to work holistically and across traditional boundaries to be effective and is realistic about the challenges still to be addressed.

The service has been recognised regionally and nationally as best practice winning a number of prestigious awards.

Inspire Case study

Recommendations

PCTs consider how these examples of best practice can be applied or amended within their geographical areas
NHS East Midlands monitors the implementation of best practice and facilitates sharing of practice as it develops
Each of the best practice case studies are showcased at the model community innovation centre simulation events in the autumn and placed on The Improvement Network website (www.tin.nhs.uk)
Lessons highlighted from the case studies are developed into the appropriate work streams

3.2 Self-care review of practice

"Self care can be defined as "any action people take for themselves, their children, and their families to stay fit and to maintain good physical and mental health, meet social and psychological needs, prevent illness or accidents, care for minor illness and long term conditions, and maintain health and well being after an acute illness or discharge from hospital"

(Department of Health, Self Care - A real Choice 2005)

The aim of the self care review was to gather information on self care activity across the region helping to build a picture of what is happening and where potential gaps may be. The solution was an on-line questionnaire which is attached in appendix 4.In

addition this solution offered the opportunity to develop a database that could be used in future by practitioners and commissioners to share practice and monitor progress across the East Midlands.

The questionnaire was designed, developed and hosted utilising the EIBS software on The Improvement Network (TIN) website – www.tin.nhs.uk. The questionnaire was made as user-friendly and quick to complete as possible. The idea was to enable as many practitioners as possible to complete.

Questions included nature of self care practice, anticipated outcomes, funding, and how practice related to national priorities. Although not all questions were compulsory the majority of respondents completed every question.

The questionnaire was publicised electronically utilising the project team contacts; NHS long term conditions, patient and public involvement, and self care leads contacts; and the TIN East Midlands membership. 74 responses were received from 5th June to 24th July 2006. A summary of the responses received can be found in the document below (double click the icon to view)

Table of responses

The questionnaire remains live and responses are still being added to the database.

The self care review also linked in to other projects in the region. Two of which demonstrate how the information gathered by the on-line questionnaire can be complemented and enhanced by more detailed research at a local level.

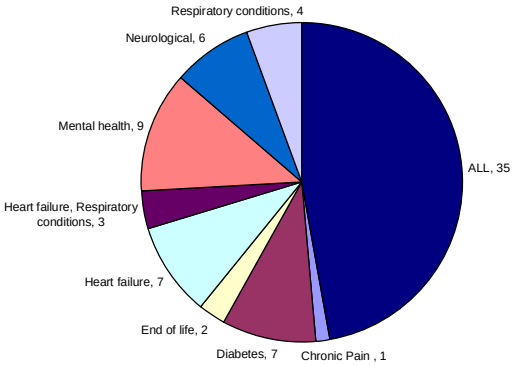
> In Derbyshire, the study was completed by a Public Health trainee. Data was gathered electronically from long term conditions condition leads across Derbyshire and by telephone interviews from the voluntary sector organisations. Results from this study can be found in appendix 5. A report is available from Derbyshire Public Health team.
>
> In Ashfield and Mansfield, the patient and public involvement manager undertook a review of self care practice across each of the PCT teams. The results can be found in appendix 5.

The third project forms part of the national Working in Partnership (WiPP) work which is due to publish its findings in October 2006. The project has been taking place in the Erewash area aimed to evaluate a health education and promotion programme aimed at challenging people's self care habits and behaviour. An insight into the project work can be found in appendix 5.

Findings from the self care review

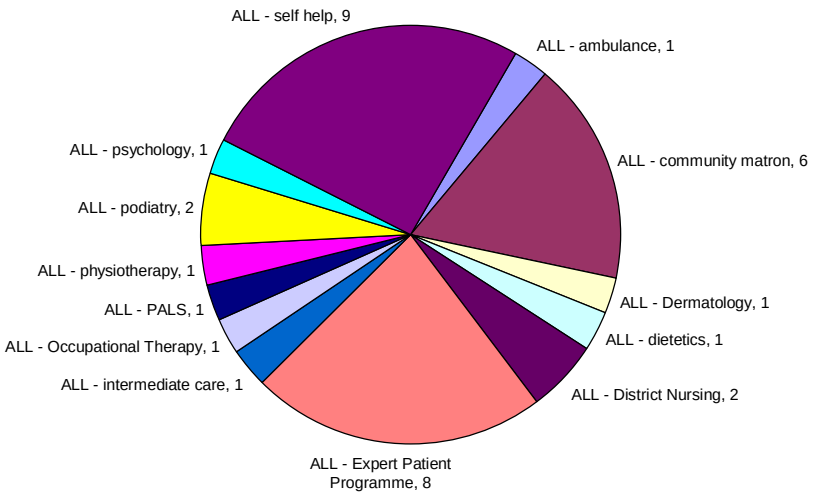
There are examples of self care activities across all of the five priority areas. Figure 1 below shows a breakdown of reported self care activity by condition. Where the activities were reported as other these have been shown as additional conditions in figure one alongside the five areas of this project.

Figure 1 Reported self care activities by condition



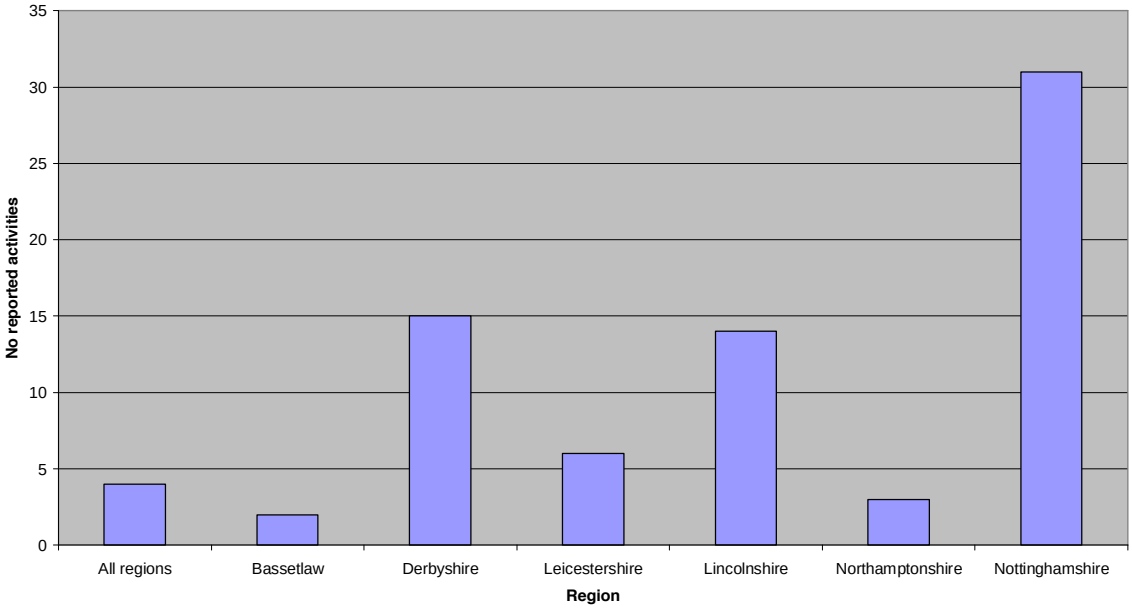
35 examples out of 75 reported are not condition specific. They aim to promote self care to anyone with a long term condition.
A significant proportion of the examples reported as “other” were for people who had a mental health condition
The 35 examples of generic practice come from a number of differing service areas see figure two below.

Figure 2 Breakdown of self care activities covering all conditions by service



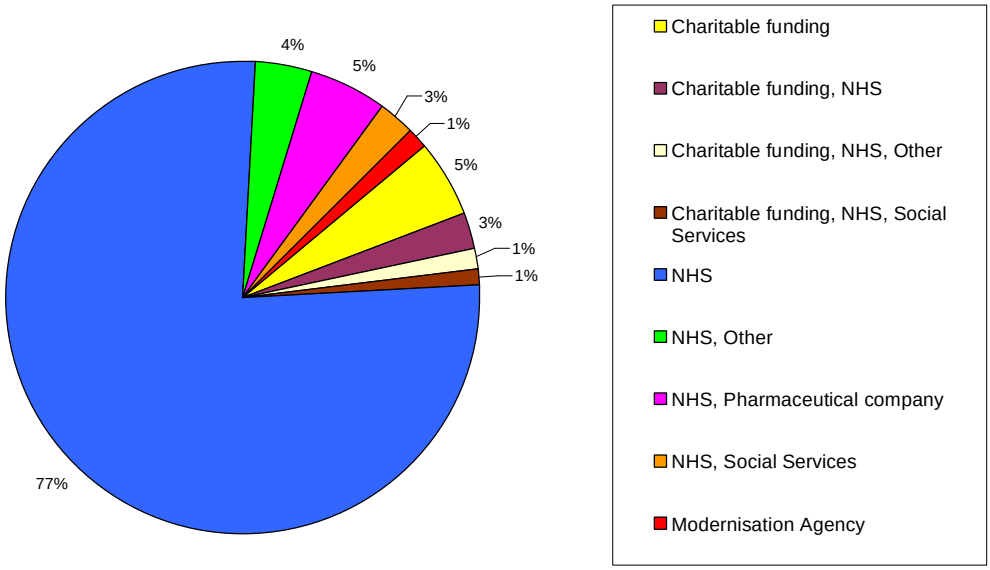
Examples of self care activities can be found across the East Midlands region. With Nottinghamshire showing twice the number of responses as other areas.

Figure 3 Self care activities by region



Examples of self care activities can be found in NHS, Social Care, Third Sector and private practice.
Funding of reported activities is primarily from the NHS although approximately a quarter of activities were at least partially funded from other sources. See figure 4 below.

Figure 4 Self care funding sources



Examples from the south East Midlands

In addition to the project work undertaken in the north East Midlands area, the following are examples of work promoting self care from the south East Midlands area:

(i) a review of practice undertaken following the Department of Health publication of *"Supporting people with long term conditions to … Self Care. A guide to developing local strategy and practice"* (February 2006). This document and the outcomes of the local review can be found in appendix 6.

(ii) A stakeholder day in response to the long term conditions national service framework which involved patients and carers alongside health professionals. The outcome has been a DVD which will be published in October 2006 along with training cards and the production of local priorities for implementing the NSF. More information about the event can be found in appendix 6.

(iii) Wise Up, an initiative to develop health professionals awareness of self care and the experiences of patients with long term conditions. Further information can be found in appendix 6.

Recommendations

The database and questionnaire from the on-line review remain live and part of the TIN website.

The self care review database is developed further for use by practitioners and commissioners to share practice and monitor progress across the East Midlands. The actions below show how this could be achieved and the ongoing support that would be required:

- On-line questionnaire is retained as a vehicle to capture practice in self care across East Midlands
- Consideration is given to broadening out the application of the questionnaire to other baseline audit activities e.g. telemedicine
- An administrator is allocated to oversee questionnaire, make any required changes to questions, and to receive completed responses. Half day training with TIN manager would be required.
- Technician is allocated and trained to manipulate data and present findings in user-friendly tables and charts for management reports
- Manager trained to manage database, oversee process, develop and refine as required, manage administrator and technician for this aspect of work, and to spot and report trends in practice.
- Database developed so it is more user friendly – enabling practitioners, commissioners and performance managers to utilise data, search and undertake comparative studies
- Training for database users on how to manipulate and extrapolate data.
- Data is tested with users to define best usage.

End of life care is given priority as the review findings show that end-of-life is the least well-developed of the areas yet this was highest on the wish-list of the community matrons interviewed (see section 3.5) especially in the provision of non-cancer care services.

Non-NHS funding potential is explored further and commissioners/practitioners made aware of external opportunities to maximise resource.

The work undertaken in both the north and the south East Midlands areas is combined to develop a joint strategy.

3.3 Patient experience - Creating a patient-led NHS

The NHS plan (2000) set out a new direction of travel for the NHS implicit within this was the involvement of patients and the public in modernising services along with a focus on understanding and improving patients' experiences. National policy and guidelines continue to reinforce the importance of this involvement and of understanding the patient's perspective to improve services. Documents such as "Getting over the wall" (October 2004) and "Now I feel Tall" (Dec 2005) give examples from across the country of how NHS organisations are improving patient experiences. Both of these documents can be found in appendix 7

"Creating a Patient-led NHS" and *"Our health, our care our say"* continue to place the patient at the centre of service planning and development. It is therefore imperative that the new NHS organisations embrace and embed this way of working at the very heart of what they do.

Patients experience was not specifically reviewed as part of this project. However, as part of the review we did receive direct feedback from patients who received the self care questionnaire about how they cope in their daily lives. Each stressed the importance of a holistic approach and the importance of their involvement in the process.

Two examples of these patient's experiences are given below, one from a health professional who found a patient education programme about their condition extremely useful and the other from an ex-teacher who has found many ways to cope with multiple conditions.


patient experience 1

patient experience 2

Recommendations

- PCTs consider the holistic needs of patients when planning and designing services
- Patients are actively encouraged to share their experiences

3.4 Involvement of patients with long term conditions in the planning, design and development, delivery and evaluation of health services

Rosie Winterton, Minister of State for Health Services has said, *"If we are to create a truly patient-led service, centred around the needs of both individuals and communities, it is essential that we create a stronger voice for patients, service users and citisens at all levels of the health and social system"*

Section 11 of the Health and Social Care Act 2001 places a duty on NHS trusts, Primary Care Trusts and Strategic Health Authorities - to make arrangements to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes.

"This is a new statutory duty, which means consulting and involving:

- *not just when a major change is proposed, but in ongoing service planning*
- *not just in the consideration of a proposal, but in the development of that proposal; and*
- *in decisions about general service delivery, not just major changes.*

The duty to involve and consult was commenced on the 1 January 2003 and guidance was issued in February - 'Strengthening Accountability'.

From Department of Health website, www.dh.gov.uk

The Department of Health has recently issued "*Stronger local voices*" which sets out the new framework for the involvement of local people in decision-making about health and social care at local and national levels. The Commission for patient and public involvement is to be abolished and local authorities are to be given the commissioning role for LINks (Local Involvement Networks). A stronger link between LINks and Overview and scrutiny committees is suggested. It is therefore imperative that the new PCTs engage with the local authority at an early stage to ensure effective working arrangements. A copy of "Stronger local voices" can be found in appendix 8

Whilst much of the practice captured in the case studies and in the self care review demonstrates that the duty to involve patients and the public is being applied across all areas of long term conditions and End of Life care, this is not universal.

Two areas of practice which are considered to be outstanding examples are the Expert Patient Programme and the Bassetlaw NHS live project.

Case study 6 - Expert Patient programme

The Expert Patient programme has been delivering patient-led self management courses for people with long term conditions across the East Midlands for the last few years. Initially Expert Patient programme began with a pilot phase controlled centrally and then it was rolled out for PCTs to manage locally. The approaches adopted by PCTs vary across the East Midlands. A baseline study of these approaches was undertaken across Trent in July 2005

The Expert Patient programme case study below aims to give an overview of how the programme is evolving nationally and across the region. It includes feedback that has been specifically compiled by Expert Patient programme graduates for this report. Double click on the word icon to read the case study.

EPP case study

Further information about the Expert Patient programme can be found on www.expertpatients.nhs.uk or from the local teams

Case study 7 - NHS Live project in Bassetlaw and Retford Action Centre

The aim of the project is to develop a programme of education and empowering opportunities for patients living with long term conditions to better self manage their condition. The programme is patient-led and designed to be a multi-agency development, using a variety of media and settings.

The vision of the project is that when a patient presents with a long term condition, they will be provided with a menu of options to support them in managing their condition and the impacts it has on their life. This menu should be available for use at times of a patient's choice from diagnosis onwards, and should include options to suit every individual regardless of their condition, preferences and abilities.

The report below gives full details of the approach and the outcomes from the work. Double click on the word icon to read the report.

Bassetlaw LIVE Project Report

As a result of this project Bassetlaw PCT has recently agreed a service level agreement with Retford Action Centre to move forward self care in the area.

SLA Retford Action Centre

Recommendations

- Across the East Midlands each organisation should ensure it is carrying out it's duty to involve and consult patients and the public
- Each PCT should consider whether they can adopt the approaches taken in the two examples into work within their organisation

3.5 Community matrons

As part of the information gathering for this report there have been a number of opportunities to talk to community matrons individually and in groups (Derbyshire and Gedling). Community matrons have also been active in populating the self care review, and have generated the attached case-study. They are a rich source of knowledge and learning for the future.

There is a strong sense that momentum is now gathering as community matron roles are becoming better understood and appreciated by the wider health and social care community, and the initial resistance and barriers are being overcome.

Community matrons view their role as exciting and rewarding. They feel they are beginning to get favourable feedback and demonstrable results.

There are some consistent themes emerging about how their roles and productivity can be improved and how lessons can be learnt from case management in general. The top four themes are given below and should be cross-referenced to other work streams where appropriate

(i) **Better Palliative care** - this is an unexpectedly significant part of the community matron role. The concerns were:

that the reluctance of clinicians in primary and secondary care to initiate proven end of life pathways was seriously impairing the quality of care for patients and their ability to be cared for appropriately at home
access to established palliative care pathways in cancer was often unnecessarily complex and bureaucratic
access for non-cancer patients was very poor.

The Marie Curie end of life Delivering Choice programme (see case study 2) are addressing many of these issues within cancer care and the active participation of BHF in the programme is starting to generate solutions and potential funding opportunities for heart condition patients that could provide a model for voluntary sector–led resources and solutions for other conditions.

(ii) **Signposting** of appropriate services - this is often something that community matrons have to learn "on the job". A menu of services such as that described in case study 7 from the Retford action Centre was viewed as something which would be useful to other areas.

(iii) **Better coordination of health and social care services** - particularly out of hours services, access to appropriate social care packages and counselling support and advice. The work being undertaken by the community matron evaluation and learning set in examining case loads and in coding interventions will prove invaluable in quantifying this issue in a way that can then be constructively shared with social services and the third sector. There are also examples within the case studies of how a single point of access for the patient for both social and health care has driven out these inefficiencies.

(iv) **Impact of practice-based commissioning** with quite widely divergent views dependent on the individuals historical experience of GP fund-holding and current relationships and dialogue. Concerns were expressed about who will employ community matrons. In the short term active participation of community matrons in the model community innovation centre simulation sessions on practice-based commissioning would both reassure them and ensure that an important voice was heard. If clarity of employer can be established early in the process then this would also help.

Case Study 8 – community matron experience

The case study has been completed by a community matron in North Derbyshire and whilst it shows the difference the community matron approach is making to both patients and to headline targets, it also illustrates some of the concerns expressed.

Derbyshire
Community matro

Recommendations

Consideration is given to the Marie Curie end of life Delivering Choice programme (see case study 2) with the active participation of British Heart Foundation (BHF) as a model for voluntary sector-led resources and solutions for other long term conditions.
PCTs look to develop a menu and directory of services along the lines of the Retford Action Centre case study to support community matrons delivery
Community matrons actively participate in the model community innovation centre simulation sessions on practice-based commissioning
Early clarification about who will employ community matrons
Outcomes from the work being undertaken by the community matron evaluation and learning set in examining case loads and in coding interventions is shared with social services and the Third sector and used to improve services and patient experience

3.6 Telemedicine and Assistive technology

This was not a core part of the project brief however there appears to be a significant missed opportunity within the region and one which has significant long term potential to help the self care agenda.

There is strong evidence internationally of the benefit of technology to assist in maintaining people's independence and to support self care regimes for people with long term conditions, palliative care needs. A literature review can be found in Appendix 9

At a community level, there are some small-scale initiatives. There appears a sense of frustration about barriers to progress in particular:

i) Access to funding to deliver scaleable projects
ii) Lack of project management skills to deliver a multi-agency solution across several stakeholders (including social services and the independent sector)
iii) Sense of being peripheral and not part of "the main agenda" of health or social services at a senior level.

There are several potential sources of financial support for technology driven solutions across organisational boundaries which would merit a pan-regional facilitation approach:

i) The Preventative Technology Grant aimed at initiating “profound” transformation in the design and delivery of health and social services. The monies are distributed through councils with social services responsibilities with an average £1m per county from 2006-8. There is a general sense in health that this funding is not delivering “profound” solutions to meet the health agenda. This may be attributed to the disruption caused by organisational and people changes in health and social care, and the money is not ring-fenced.

ii) The Partnership for Older Persons Projects (POPP) aims to enable health and social care communities to create a sustainable shift in their "whole system" toward prevention.

iii) The Department of Health has indicated willingness to fund 2/3 “scaleable” demonstration pilots where there is evidence of
    - strong project management, evaluation skills and plans
    - partnership working across health, social care, independent and voluntary sectors.

Appendix 9 highlights at least four potential ideas that could be worked up into a single East Midlands proposal - Derbyshire (“Smart” and sheltered housing), Lincolnshire (telecare interventions in chronic heart failure and stroke patients) and Nottinghamshire (Clifton telemonitoring of vulnerable elderly). This would need a burst of dedicated and focused resource along with an NHS East Midlands sponsor.

Given the potential significance of telemedicine and assistive technology, there is merit in considering a number of solutions to the challenges of funding, multi-agency project-management and mainstreaming.

Recommendations

At regional level

- Consideration should be given to commissioning a similar baseline audit for telemedicine across the region as for self-care to establish current and proposed activity levels
- Case studies of best-practice are generated for others to follow.
- There is a network or group that sponsors telemedicine across the region. Consideration is given as to whether this could be the long term conditions oversight board or the self-care or long term condition leads networks.
- The model community innovation centre is given a role in running cross-agency simulations and/or technology showcases.
- A decision on whether to mount a proposal to the Department of Health to become a pilot site is taken.

At PCT level

- Early exploration of the status of Preventative (or Assistive) Technology Grant & POPP funding in their community and the identification of a senior sponsor with some dedicated resource to ensure that the health agenda is being met.

- There is connection made between ISIP / LAA priorities and social services "wellbeing" objectives at local level to ensure that self-care initiatives in general and technology solutions in particular are "mainstreamed" and explicitly included in priorities and objectives.
- In the longer term development of high-level knowledge management in an area that is likely to provide significant financial return and engagement of non-NHS resources in delivering the self-care and independent living.

3.7 Model community innovation centre – "The Mill"

In December 2005 both LNR and Trent chief executives agreed a proposal to develop an innovation centre for the East Midlands which would:

- Meet the Connecting for Health need for a model community facility where new software could be road-tested,
- Enable local clinicians and frontline staff to participate in the development and implementation of technology supported new ways of working.
- Facilitate service improvement and the development of new and better ways of working.

The facility is to be located in Grantham from 2007, housed in a purpose-built new facility modelled on the innovation centre in Van der Bilt University, Nashville. The facility will be built with locally generated capital (largely non-NHS). An interim solution has now been successfully commissioned and launched located at "the Mill" at Barrow-on-Soar. "The Mill" is in the process of developing an active programme to address service priorities in the East Midlands region on five levels:

i) Six Facilitated Simulations of the "art of the possible" – the first two being practice-based commissioning and long term conditions in autumn 2006.
ii) Action learning sets to support service improvement and to provide a "virtual network" for service improvement and technology leads with the support of Centre for Health Improvement and Leadership at Lincoln (CHILL).
iii) Programme of monthly showcase events with national regional speakers.
iv) Regular Chief Executive and senior management briefings
v) Hosting and helping facilitate community generated workshops on service improvement.

The simulation events provide an early opportunity for communities to work through some of the issues identified in this report and in particular:

The contribution of practice-based commissioning to the achievement of long term condition outcomes.
The effective commissioning of outcomes for patients with long-term conditions
The engagement of social services and non-NHS services in delivering the self care and wellbeing agendas in a more joined up way.
The contribution to in-year and long term financial stability of long term conditions, self-care, and case management.
The opportunity to showcase (and test their relevance to different communities) the best practice and case studies illustrated in this report.

These events also appear to provide an opportunity to make significant progress in the area of commissioning (and the role of practice based commissioning within that) and long term condition management (the five priority long term conditions and mental health), with the potential to impact on future financial position with the active participation and engagement of clinical/frontline staff and non-NHS partner organisations.

There is already considerable energy within the region to deliver the simulation events through the support of CHILL and long-term condition and commissioning leads. This energy would benefit from early NHS East Midlands endorsement of the programme and the engagement of vanguard PCTs senior managers, when in post, in the programme.

In the medium term the centre could provide a focus for innovation across the East Midlands attracting sponsorship and participation nationally from government agencies as well as the independent and Third sectors, once an active programme has been established and clear signs of both clinical and non-NHS participation in events had been demonstrated.

Recommendations

NHS East Midlands early endorsement of the programme

Vanguard PCTs senior managers engage and participate in the programme

Consideration is given to the Mill providing a focus for innovation across the East Midlands

Once the programme is active with clear signs of both clinical and non-NHS participation in events demonstrated, sponsorship and participation from government agencies, independent organisations and the Third sectors is explored.

4.0 Opportunities to improve long term conditions and end of life outcomes by working more closely with the Third Sector

4.1 Emerging National Picture

> *"The Department of Health's provisional estimate is that there are currently over 26,000 third sector organisations delivering health and social care services in England, with a combined annual income in excess of £13bn.They vary considerably in sise: the largest 2% of organisations account for over a quarter of the sector's income whilst nearly half have an annual income of les than £50,000."*
>
> From the Third Sector task force document in appendix 2

The stage is set and expectations within the third sector have been raised as a result of consistent government indication that the third sector is central to public sector delivery. It started with Sir Peter Gershon's Review of Public Sector Efficiency in 2002 and has culminated in the appointment of Ed Milliband, as the first Minister for the Third Sector in May 2006.

In a recent speech (included in full in appendix 10), Ed Milliband re-iterated the government determination to engage the Third sector and to break down any barriers and resistance within the public sector in order to create a level playing field. He outlined a four point rationale

i) *the third sector is helping transform the landscape of our society and challenging both private and public sectors on a range of fronts from service delivery to campaigning for social justice.*

ii) *there are new challenges we face today which call for the skills of the third sector and to deploy those talents to the full, we need clarity about the respective contributions of private, public and third sectors*

iii) *the sector can contribute to public service improvement in three clear ways: in partnership with the public and private sector, helping mainstream lessons back into the public sector and as a source of voice demanding improvement in public services*

iv) *my role in government, in the new Office of the Third Sector, will be determinedly to break down the barriers that exist to the third sector fulfilling its potential to contribute in these three ways. This will lead to an Action Plan in the Autumn* (of 2006)

National Charities are being heavily courted by the public sector and health in particular, to engage in setting policy and directly inputting into Whitehall and No 10. This is most transparent with the impact on end-of-life care where the failure to make any progress on the manifesto commitments to make choice to die at home a reality is a major source of embarrassment and has triggered the Delivering Choice initiative pioneered in Lincolnshire and precipitated the new end-of-life strategic review led by Professor Mike Richards.

The publication of the Third Sector Commissioning Task Force Report in July 2006 is a very coherent statement of the Third sector's requirements of health and social care. It is appended in full in appendix 2.

Within the report there are 8 principles are:

(i) Systematic involvement of health and social care users at all stages of the commissioning process.
(ii) Expert knowledge and capability among health and social care commissioners.
(iii) Understanding amongst commissioners about the third sector, and its potential to add value to needs assessment, strategic planning, and to empowerment of service users and community capacity building, as well as delivery of services.
(iv) Principles and practice for commissioning and contracting that recognise and value the full range of providers, including those from the third sector, as equal partners in delivery
(v) Allowing longer term contracts, in the right circumstances, "full cost recovery" and the fair balance of financial risk between commissioner and providers.
(vi) Streamlined system management regulation that is proportionate.
(vii) Third sector providers who are able to shape their behaviour and governance to address the challenges of accountability in a regulated business environment.
(viii) Support for new providers entering the market (for example through Futurebuilders England or DoH Social Enterprise fund)

There are also 16 commitments to which NHS organisations will be expected to adhere and/or respond. These commitments include:

> *Commitment 6 "there should be strong third sector involvement in the development of PCTs and practice based commissioners"*
>
> *Commitment 8 "The Task Force will work with third sector orgs. and providers to consider how they, individually or collectively could help to improve commissioners understanding of the potential role for third sector orgs including those who choose to provide services, in improving the delivery of user experience and public health outcomes"*
>
> *Commitment 10 "the DoH will use the intelligence from its initial 3rd sector market mapping survey to demonstrate to commissioners the scale and potential of third sector capacity"*
>
> *Commitment 12 "... the DoH will review the "proposed model contract" with a view to it being made available across health and social care by December 2006 and promoted as good practice"*

The report also includes examples of model contracts between health and social care and Third sector organisation.

4.2 Views from the Third Sector Regionally

.
A consistent message from the local Third sector is to be re-engaged in understanding the commissioning regimes and objectives, and for clarity about long-term planning and financial stability to be established urgently. In an informal straw poll of approximately 100 Third sector organisations few had confidence about NHS or social service funding beyond April 2007 and some claimed to be making or considering redundancies due to lack of certainty about funding from NHS.

The most frequent requests from the third sector locally are for;

a dedicated/nominated senior person for the voluntary sector within PCTs and in social care to oversee the engagement of the sector at a confusing but potentially critical time.
an opportunity to understand the plethora of guidelines and white/green papers in health and social care and the opportunity to contribute.
a forum both locally and regionally to engage with health and understand better the contribution they can make and the commitments health are making to expand the sector and remove current barriers to growth.

There appears a need to join up at both regional and community levels the health "self care" agenda set out "*Our health, our care, our say"* with the social care "wellbeing" agenda set out in the green paper *"Wellbeing and choice"* in order to better align the public sector to focus on co-coordinated plans for individuals.

Many of the aspirations and requirements for a level playing field nationally are echoed locally. There are also other themes emerging from Third sector organisations within the region. It is important to note few organisations wished their more negative comments to be attributed as there was a high sense of nervousness about future funding stability.


emerging thoughts from voli

Local third sector organisations are feeling less assertive, less confident about their opportunity to expand capacity and more uncertain of the direction of travel than the national organisations. They are however entirely positive about the strategic intentions in the health white paper & social care wellbeing green paper. The concerns that need to be addressed centre around perceptions that:

i) Momentum has slipped backwards in the last 6 months as NHS/Social services re-organisation dominates day-to-day business and constructive long-term planning has stalled.
ii) There is a dissonance between national visions and strategies and the current real-life experience on the ground of de-stabilising short-termist financial pressures that has never felt greater, particularly to the Third sector.
iii) There is a sense of confusion and uncertainty about the direction of the NHS and how the new visions and ideas in the white paper are actually

going to work on the ground alongside the social care agenda, particularly in the four areas of practice-based commissioning; new commissioning regimes in a financially challenged social & health care system; commissioning long term condition outcomes, and monitoring & governance.

iv) There is confusion about who does what in the new world and who to contact for what now with frustration that there is no single point of entry for a Third sector organisation into the NHS nor into social care. Geographic and organisational boundaries within health and social care that are different to their own requiring different administrative and contact processes are a particular frustration.

v) A new era of professionalism in commissioning and monitoring is arriving there is also a need for proportionality in the approach to the different sizes and roles of the 30,000 plus Third sector organisations in the East Midlands that have a connection with health. The Third sector organisations providing NHS support locally broadly fall into four categories

- significant multi-year contracts (above c£20k pa) which in the future could be catered for by the model contract set out in the Taskforce report
- contracts between c£5k-£20k pa requiring a degree of formality but not sufficiently sizeable to merit major investment in processes & systems
- contracts where the financial risk is negligible under c£5k;
- non-NHS funded advocacy and support services.

There was a high level of interest in participating in shaping the solutions to these commissioning concerns.

It appears the majority of issues raised could be relatively easy to address through some planned and constructive engagement. The involvement of local third sector organisations in this project was viewed as a very positive transitional initiative.

There is considerable enthusiasm for both local and regional summits involving the third sector, health and social care that start to paint a positive picture of the opportunities in the white, green and third sector proposals and start to address the practical issues and concerns.

4.3 Non-NHS resources available to support long term conditions and end of life care

The self care review highlighted considerable potential for securing non-NHS resources and has started the process of capturing the resources available. This has identified strengths across the region in diabetes, mental health, heart and cancer. There is more variable coverage of respiratory and neurological services and a poor coverage of end-of-life services. There are some excellent examples that could be reproduced systematically across the region. There are significant differences in non-NHS capacity across the differing East Midlands geographies.

There is potential for the third sector to be mobilised in several ways to assist commissioners in developing their understanding of what is available, identifying gaps and opportunities, and participating actively in expanding the capacity of the third sector to release NHS resources.

The alignment of NHS strategies and plans to those of third sector organisations would enable opportunities for partnership working to be identified. For example, Macmillan Cancer Support in their strategy (appendix 11) state they are planning to promote and develop self management solutions for people with cancer.

Third sector participation in clinical networks has potential to expand to involvement in delivering solutions such as in the development of commissionable outcomes for long term conditions.

Case study 9 – Third sector services: Motor Neurone Disease Association

The case study from the Motor Neurone Disease Association is given as an example of the support Third Sector organisations are providing for patients. The study shows the Association's role in supporting patients and carers by providing services and in campaigning on their behalf enabling their voices to be heard – but it is also an excellent template for laying out their capabilities for commissioners and carers. It is recommended that all third sector providers be encouraged to follow this template to help the new PCTs expand third sector capacity.

Neurological MND
Case study

Recommendations

The new SHA and PCTs consider immediate public adoption of the principles and commitments in the Third Sector Task Force report as a way of re-engaging constructively with the third sector with an invitation to local & regional summits this autumn to set a positive tone for the opportunities. (link to the Third Sector workstream)

NHS East Midlands and PCTs develop a public position on the key issues of:

- multi-year contracts;
- full-cost recovery;
- fair balance of risk
- proportionate monitoring
- how the third sector can help deliver commitment 8 locally.

NHS East Midlands and PCTs allocate someone senior to be the main representative and point of contact with the third sector both to ensure that their organisations internal processes are easy to access and understand and to ensure that the third sector agenda is represented in the new organisations thinking and policy-making.

PCT's review the Third Sector Task Force report and decide how it impacts on their priorities and plans.

Consideration is given to adopt the model contract for significant contracts ahead of national timescales

The "Mill" proposed simulation events are utilised to start setting the agenda for a new commissioning environment in advance of government framework and

operational guidelines expected in December 2006.- and in particular to address the concern areas of: practice-based commissioning; new commissioning regimes in a financially challenged social & health care system; commissioning long term condition outcomes; and monitoring & governance

A community is commissioned to work on the appropriate “contracts” at the four levels identified:

- Significant multi-year commercial contracts (catered for by the model contract) - above c£20k pa;
- provider contracts requiring a degree of formality but not sufficiently siseable to merit major investment in processes & systems c£5k-£20k pa;
- infrastructure supporting services that would be missed but where the financial risk is negligible under c£5k
- non-NHS funded advocacy and support services.

North Derbyshire would appear a strong candidate for this commission as there is a combination of a mature CVS and voluntary action group, and a Third sector review already commissioned by heath and social services.

There is a follow through of the baseline self care review and to engage the third sector in making it comprehensive at 2 levels:

- the comprehensive follow-through of data collection via voluntary sector engagement in questionnaire/audit completion
- the request to the larger national and regional organisations to complete a capability review along the lines of the MND case history to help generate capacity regionally by spreading best practice.

To improve the third sector’s active participation consideration is given to reducing the number of access points, bureaucratic procedures and people to contact.

Appendices

Appendix 1 – project plan

Project plan

Appendix 2 – Third sector review

Part 1 - no excuses

Part 2 Report of third sector commissic

Appendix 3 – NHS East Midlands Strategy

East Midlands strategy

Appendix 4 – Self care review questionnaire

Self care review questionnaire

Appendix 5 – Other self care reviews

Derbyshire self care review

Ashfield and Mansfield Self care re

Erewash WiPP project

Appendix 6 – Self care in south East Midlands

Supporting Self Care

LNR SELF CARE AUDIT

LNR NSF LTC

LNR Wise UP

Appendix 7 – Now I feel tall and Getting over the wall

Now I feel tall

Getting over the wall

Appendix 8 – Stronger local voices


Stronger local voice


Recommendations for stronger voic

Appendix 9 – Telemedicine and assistive technology


Telemedicine Literature Report


Assistive technology act~chfv9f


Assistive technology Intermediate care v1

Appendix 10 – Third sector speech


Ed Milliband speech

Appendix 11 – Macmillan Cancer Support Strategy


Macmillan Cancer Support Strategy doc