

# JOINING UP CARE

for people with long term conditions



## BACKGROUND

“We need a birth to death pathway for people living with Long Term Conditions, and it needs to be a seamless pathway with all involved, in a partnership; between patients, carers and health professionals..... To know what care they (patients) can expect to receive, and also what part they can play in keeping themselves well to remain as independent for as long as possible”.

### Patient with Long Term Conditions in North West

This document is the result of the work of the Adults and Elderly Care Pathway Group (CPG) for NHS North West during 2009/10. It recommends the next key actions that Commissioners and Providers in collaboration with Clinical Networks, Operational Leads and front line Clinicians, should take towards achieving the 10 year vision for people with Long Term Conditions (LTC) set out in Healthier Horizons. These recommendations are given in the setting of the need to increase quality, innovation, productivity and prevention (QIPP) so that the challenges of increasing need within limited resources can be met.

Joining up care between health and social care, between generalists and specialists, and when patients move between healthcare settings or teams are priorities for people with all long term conditions, and particularly for the increasing number with multiple conditions. All services should use common measurement sets to evaluate their impact



People with Long Term Conditions are the highest users of healthcare services

## EXECUTIVE SUMMARY

People with Long Term Conditions are the highest users of healthcare services, and often require social care in addition. They try and manage their condition on a daily basis with their families and carers, but only too often their experience is that the support and care they need is fragmented or difficult to access to meet their need. Health and care professionals also recognise that there are significant opportunities to improve care for people with long term conditions, in particular by clarifying who should be delivering and supporting care when. There is significant duplication of care, and when care fails the resulting outcome is at a high cost to patients and the health and care system. The increasing age of the population in the North West in addition to the significant deprivation means that the number of people with long term conditions, and with multiple long term conditions will continue to rise, and that rise will accelerate over the next decade.

The Adults and Elderly Clinical Pathways Group of NHS North West considers that closer integration of care for people with long term conditions is the next step in achieving the vision that was set out in Healthier Horizons'. The redesign and transformation of care for people with long term conditions set out in Healthier Horizons is essential if we are to meet the increasing need within the resources available.

This document recommends that actions are taken by commissioners and providers of health and social care that move towards closer integration of care for people with long term conditions. These actions are in three linked and complementary areas. They are integration of health and social care, developing a stepped model for long term conditions care that integrates the role for generalists and specialists, and planning and implementing transitional care. In addition we propose a series of measures that should be used to assess the quality of services for people with long term conditions, and that should be developed to be comparative across the North West.

To integrate health and social care requires executive agreement across local health and care economies. Once this is achieved then areas where partnership already exists can be further developed to integrated locality teams with a single access point, a single assessment and care planning process, and shared care delivery roles across health and social care. These will inform the joint commissioning of services across local footprints for care.

We describe a generic stepped care model that enables the clarification of professional roles and competencies for those caring for people with long term conditions, and moves care towards a more supportive framework for patients, families and carers. Independence and Autonomy is the core level that gives patients and families the ability to live as full lives as possible with their conditions, it is enabled by supported self management that is primarily delivered in general practices. These are the fundamental elements of care. Some patients will require enhanced care or specialist care at times with their conditions. These must be integrated and enable supported self management with the aim of achieving independence and autonomy. Local models of care for individual long term conditions and for multiple conditions should be developed in line with this stepped care approach.

Transitional care describes an active process of care as people with long term conditions move between care settings and teams. It requires the development of processes that deliver collaborative care planning and coordination, define accountability and responsibility, involve patients and families at all stages, and are supported by timely and appropriate communication.

The quality of care for people with long term conditions is seldom measured effectively in the North West at present. Comparable measures should be used that demonstrate safe care through completeness of care, coordination and planning of care, and reduced readmissions to hospital, effective care through disease related outcome measures, patient reported outcomes and hospitalisation rates, and patient experience through measuring importance, involvement, confidence, support, and joined up care.

## INTRODUCTION

Approximately 1.5 million people in the North West are living with one or more long term conditions (LTC)<sup>2</sup>. This number will grow considerably over the next few years. In 2031 an estimated 36% of the population will be aged over 50, an increase of 2% from 2010, and the percentage of people aged 85 plus is expected to rise from 2.1% to 3.4%. With the growing numbers of people living with a long term condition along with an ageing population, the North West will continue to experience an ever greater pressure on its health and social care services if we continue to ignore the need to redesign and reform services. Radical changes to the delivery of care were recommended in Healthier Horizons by the Long Term Conditions Clinical Pathway Group. The recommendations taken from the original reports<sup>3</sup> are summarised below:

- Personalise Care and put the person with the long-term condition and / or their carers “in charge”
- A generic patient pathway with a greater focus on self-care and recognising the inter-relationships between diseases
- A collaborative care plan as the central component to all care, a true collaboration between the person with a long-term condition, family, and professional carers.
- Virtual care campus- should be focused around general practice/ primary care, and incorporate all the skills and expertise that the person with a long term condition and their family require
- Skills and roles- the role of the advocate and care coordinator in the care team is seen as key, with the need to redefine roles within the care campus
- The development of the care passport, using the patients’ own health record and care plan
- The concept of personalised budgets should be developed for health care based on need and the current social care models, with indicative budgets at patient level
- Population stratification for risk of disease, morbidity, hospitalisation and so on should underpin all strategies for improving health outcomes and care pathways
- NHS organisations need to have mechanisms to invest in long-term prevention and broader outcomes of care.

The Adults and Elderly CPG makes generic recommendations for people with LTC, we believe that approaches to care are shared across conditions.

These recommendations can be used for individual conditions and particularly apply to people with multiple conditions. The original recommendations were a 10 year vision, and therefore the essential next steps on this journey need to be clarified. We believe that there are many examples of care within the North West that go some way to achieving individual components of the proposed future model of care, and by exploring these examples we can learn how best to implement the necessary changes to current care. We also believe that integrating care is the essential next step that all areas must take to improve patient outcomes, experience and efficiency. Evaluation of examples of best practice for people with LTC in the North West is very limited, an evaluation and measurement framework for current and future services is essential so that their relative success can be understood, and real evidence gained for what works for patients, families and the NHS.

Throughout 2009/10 the North West Adult and Elderly CPG has explored current practice and evidence of integration of care and makes recommendations for 3 elements of integration:

- Health and Social Care Organisations are actively integrated across both strategic and clinical levels to deliver joined up services to people with LTCs.
- Stepped Care models for LTCs are developed at locality levels to maximise the best use of generalist and specialist health care provision, and clarify the roles of each component of the health and care system for patients and families.
- Transitional Care is planned for people with LTC as they move between care teams and care settings.

Recommendations for evaluation of services are also made to ensure that services are safe, effective and personalised.

Throughout this paper we have used the term patients and families to represent people who are receiving or in need of care from the health and care system for their long term conditions, and those who are close to them, or have a significant supportive relationship that will influence their care. We have used the term carers to represent people who give a significant component of care to support the individual to live with the condition, they are often family members of the person with a long term condition, or may be a person nominated by the patient as their representative. Professionals refers to people who are employed to deliver care for people with long term conditions, they may or may not have professional qualifications.

## INTEGRATION OF HEALTH AND SOCIAL CARE

Moving from the current fragmentation of services to integration removes a significant barrier to more effective care. A simpler more continuous and user friendly service is necessary with a single point of access wherever possible.

In 2000, the NHS Plan<sup>4</sup> called for radical redesign of the whole care system and integration of services to eliminate the fragmented experience of service users. Whilst everyone agrees with this, it has not happened despite 10 years of multiple further policy documents including NSF for Long Term Conditions<sup>5</sup> and most recently the Next Stage Review, From Good to Great<sup>6</sup>, and even the revised operating framework for 2010-11<sup>7</sup>.

There are however examples across the North West where some considerable progress has been made. These recommendations draw on that experience and suggest next steps in implementing integration of health and social care.

“In its most complete form, integration refers to a single system of needs assessment, service commissioning and /or service provision”.

-These are managed together by partners from health and social care, remaining legally independent. Working alongside service users, carers and the third sector.<sup>8</sup>

In order to move towards integration the first step is to develop partnerships. Where partnerships exist then integration can begin. This requires a level of commitment from organisations, workforce and the inclusion of service users in the decisions and designs of services. Evidence shows that integration is best established and most valuable when initially focused on a specific group of people with complex needs<sup>8, 9, 13</sup>, this has often been with patients nearing the end of life.



adapted from 8, 9,13

It is important to recognise that the third sector are and will be increasingly key providers of social care. Partnerships of traditional provider organisations with the third sector are fundamental to the development of integrated care and can be the first step to integration of health and social care.

### What is working well in the North West?

In collaboration with the SHA Transforming Community Services<sup>14</sup> work stream and North West Joint Improvement Programme (JIP) a consultation using semi structured interviews was undertaken with 8 areas who had made some progress in the integration of health and social care for their local communities, but who were at different stages or had developed different or innovative approaches.

### Key principles involved in providing and delivering effective integrated services

These arrangements were consistently needed to deliver integrated health and social care

1. Co-located integrated teams of health and social care professionals for older people, working within specific localities, supported by integrated health and social care management arrangements.
2. Incorporating crisis response, intermediate care and re-ablement services into a single coordinated system with agreed pathways. Co location also helps.
3. Use a common assessment framework for health and social care workers, for initial assessment and ongoing collaborative care plans, thereby reducing duplications.

Where this is working well the following enabling features were also noted

- Strong leadership and high level commitment to integrated health and social care
- Commitment of management to integrated working within teams and problem solving when challenges arise
- System and cultural change evolved, and changed by continuous reflection
- Formal staff development programmes commonly joint between health and social care
- Co terminosity of organisations for a defined population
- Co location
- Agreed common aims
- Single point of access to care for referrers
- Strong professional leadership arrangements
- Involvement of wider services (e.g. housing, community pharmacy, voluntary organisations) with the team.

Duplication of work is reduced and can be particularly helped with the role of generic worker / assistant practitioners who possess both social care skills (NVQ Level 3) and health care assistant skills within one role. These work in some areas within intermediate care services, and also as a direct resource to the community matron/ active case manager services and/or palliative care teams. They are commonly employed by Social Care with Health (PCTs) supporting training in health components of role. Waiting times for assessments and for services to be put in place are also reduced.

A number of areas have reported a reduction of unplanned admissions to hospitals and reduced length of stays following the establishment of integrated teams as well as improvements in patient experience and increased job satisfaction demonstrated in staff surveys.

### Integrating Health and Social Care Key Findings- Evidence of Good Practice from around the Region

The following case studies illustrate key features of some of the areas we visited highlighting good practice and development of innovative service delivery.

#### Ashton, Wigan and Leigh- Solutions for Integrated Communication Systems

Ashton, Leigh and Wigan locality developed their LTC strategy service delivery plan, which aims to deliver services from 3 locality hubs with rotating outreach clinics providing equity of access and promoting integration. Joint assessment processes are used within case management services and due to geographic and accommodation constraints, models for virtual and co-located teams have been adopted. To maximise the benefits of integrated teams, a web based system for patient records that can be accessed by both Health and Social care, including a case finding approach through GP systems, is used across organisations.

- The Golborne Project used project management principles to deliver specific aims to a specified locality of need involving PBC consortia; networks of teams with relationship managers, clinical leads, public health and finance to deliver integrated care for their area; irrespective of boundaries, demonstrating key principles required for effective integrated service delivery.

### Cumbria - Strategic Overview

Cumbria's Care Closer to Home, an example of strategy informing service delivery, in which the organisational partnership comprising Cumbria, Lancashire County Councils and 3 PCTs, has provided an established framework for collaboration, working across differing spatial levels.

### Halton- Clinical Leadership

GPs and clinicians are leading service development as active stakeholders with clear clinical leadership and have demonstrated a reduction of people entering care homes through reorganisation of services and prioritising community services through an integrated approach; which has also shown reduced unplanned admissions to A&E at times of pressure.

Existing partnerships have been utilised along with expertise outside of health and social care to commission CVS (Voluntary Action) to review their overall voluntary services strategy locally.

### Salford- Single Management Structures

Integrated community teams for older people set within the context of an integrated health and social care whole system has provided strong evidence of key indicators of partnership, and was the driver to move towards integration.

Integrated line management and professional supervision structures within integrated community teams for older people was adopted along with single assessment processes which are integral to service delivery.

This has provided evidence for their business case illustrating reduced admissions through increased access and rapid response rates, crisis management, and maintaining patients in their home.

### Stockport- Wider Stakeholder Engagement including Communities

Senior organisational commitment is evident as SMT meetings held with PCT, LA and FT and Health and Well Being boards are linked to community plans to address wider public health issues linked to LTC. Strengthening links with the voluntary sector and enabling access to information for both workforce and communities was evident e.g. Stockport Synergy, an online information hub hosted by LA called FLAG. [www.stockport.gov.uk/FLAG](http://www.stockport.gov.uk/FLAG)

The aging population means that the number of people with multiple LTCs is increasing rapidly in the North West



## THE CHALLENGES OF INTERGRATING CARE: THE VIEWS OF STAFF

### PLATFORM FOR INTEGRATION

A wide shared understanding has emerged about what the 'platform' for integrated care should look like, with the following components



#### Supporting Evidence

The work carried out on behalf of DH examining the Integrated Care Organisation Pilots summarises many of the findings we elicited from our focus groups and presents in a clear, concise model.<sup>15</sup>

#### Recommended Actions for Commissioners and Providers - Moving Closer Towards Integration of Health and Social Care

##### STAGE 1

- Establish agreement of senior leaders within partner organisations to move towards integrated delivery of care for people with LTC in a local population
- Use the RAND Platform for Integration as a framework to develop a shared vision and implementation plans
- Develop a local vision for integrated care delivery for people with LTC by:
  - o Wide stakeholder involvement including clinicians, patients and families, voluntary and independent sector, providers
  - o Use patient journeys and experience to understand how care can be improved through integration
  - o Use the Stepped Care Model to clarify the roles of organisations, teams and patients and families
  - o Communicate the shared vision and actions to clinical teams and patient groups

##### STAGE 2

- Identify areas of delivery where partnership working is established or emerging and with the potential for innovation
- Identify support (project management) to these teams to plan steps towards integrated delivery for their "patients and families"
  - o Establish measures of quality of care
  - o Involve clinicians, patients and families and other agencies in redesign of care processes.
  - o Use Stepped Care Model to clarify the role of the members of the team, and links to others involved in care
- Develop single management arrangements for integrated teams of health and social care professionals for older people, with co-located community matrons within specific localities
- Agree the single assessment process for the team

- Establish a single referral point and communicate to referrers and patients
- Implement single assessment process
- Develop a workforce plan, to include
  - o Shared skills
  - o Collaborative care planning
  - o Joint health and social care roles, including the potential for generic working at all competency levels

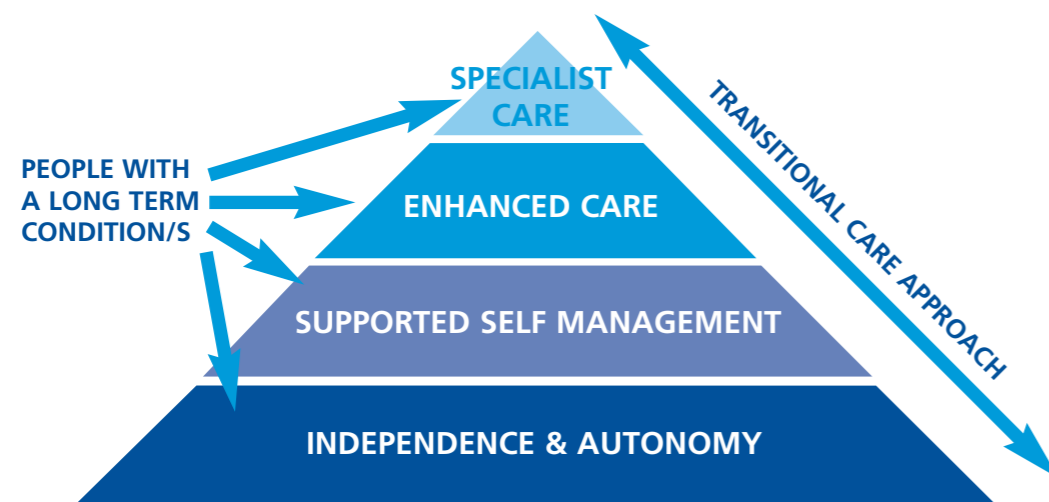
##### STAGE 3

- Identify opportunities for joint commissioning across health and social care economies- for example re-ablement services, self management support services
- Use the evidence base already available to develop business cases.
  - o Partnership of older peoples projects evaluation16 [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_111222.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_111222.pdf)
  - o NW JIP/CSED efficiency model for reablement programmes for older people. For further details contact David.fish@dh.gsi.gov.uk
- Use learning from the progress which has been made in certain sectors of the health service, e.g. Childrens, Learning Disabilities and Mental Health Services
- Spread integration to other teams and localities and adapt the approach to individual settings and teams

## STEPPED CARE MODEL

The stepped care model aims to address one of the commonest issues for those who are responsible for organising and delivering care for people with LTC. How do we integrate care across the continuum of complexity for people with one or multiple LTCs, so that we maximise the appropriate skills of patients and carers, generalist clinicians, and specialists? In developing the stepped care model we have reflected on best practice on integrating care across the North West to build a common model that can be applied to all LTCs, including people with multiple conditions. We believe that implementing a stepped care model for a local population will ensure complete care for people with LTCs, rather than the common occurrence where elements of care are missed because the patient is in the “wrong place”.

We describe 4 steps in the care model, independence and autonomy, supported self management, enhanced care, and specialist care. We have focussed on the competencies required for each of these. Independence and autonomy and supported self care are fundamental for all people with LTC, enhanced care and specialist care may be required for some people with more complex conditions or at times of increased need and are supplements to the fundamental elements of care. The model aims to move us away from the common confusion and sometime conflict between the role of the specialist or generalist in care for people with LTC. It also gives a framework that is not based on organisations or institutions, but focuses on need and how that can best be met.



Underpinning the model is the focus on supporting people with LTCs and their carers to most effectively self care and self manage their LTCs at every stage.

It is important to note that when a patient is diagnosed with a LTC condition they may enter the model at any level, e.g. a person who is involved in a road traffic accident and diagnosed with an acquired brain injury who was previously fit and well, would enter the model at the specialist level requiring intensive specialist support initially as well as support for family and carers. As individual needs changed, and the medical condition improved the transition through the model would be towards independence and autonomy wherever possible. It is accepted that for some people this may not be possible and supported self management with planned transitions between the other levels would be the optimum.

Conversely an older person who participated in a community screening programme and was diagnosed with Type 2 diabetes and additional CVD risk factors would commonly be appropriately managed by the fundamental elements of supported self management that will enable independence and autonomy.

The information provided to patients and families must be consistent with need and appropriate for the level of care within the model required at that time.

The competencies required for each stage of the stepped care model are described. The principles described for transitional care should be applied to facilitate a smooth seamless transition through the levels.

### Independence and Autonomy

This is the underpinning stage that aims to promote independent living for people with LTCs. Wherever the patient enters the model, and whether cared for by specialists or generalists, this is the aim, and will need to be supported by other elements of the model. The skills gained by patients and carers in this stage enable collaborative care planning to occur at all other stages and the skills to deliver key elements of the plan. The use of patient held or accessed records is a key enabler of independence and autonomy. Skills based group education such as the Expert Patient Programme, and similar disease based programmes are key methods for patients and carers to develop the competencies for this stage and need to be widely used.

#### Patient and Carer Competencies for Independence and Autonomy

- Understanding of own condition and self care and self management principles for the condition
- Understanding of early warning signs of deterioration or exacerbation and what to do when this occurs.
- Awareness of local services, their role in supporting the individual and family, and how to access them when necessary
- Awareness of access to psychological support for living with their condition.
- Skills to maximise the benefit of consultations with health and care professionals
- Understanding of where and how to access local patient and carer support groups
- Awareness of and access to local patient and carer education programmes
- Where applicable, awareness of how to access personalised budgets and support
- Knowledge of where and how to access carers assessment and support
- Knowledge of how to access additional support to live with their condition in their local community including housing, environmental services, education services, employment and support from the voluntary sector

### Supported Self Management

In order to live well with their long term conditions patients and families need support from health and care professionals. This is what we term Supported Self Management. Whilst many of the activities that take place at this level are traditional healthcare

activities often within general medical practices for common conditions or multiple conditions, there is a need to change the emphasis to acknowledge that their purpose is to support self management, and thereby enable autonomy and independence.

Supported self management is delivered by multidisciplinary teams. The teams require the skills and competencies to support and educate patients, families and carers to manage and monitor the impact of having a long term condition. They must have the skills of patient centred consultation, collaborative care planning and behavioural change support. These skills will ensure that holistic support is given. The ability to assess co-morbidities and therefore inform priority setting in care planning makes general practice the best location for this in the majority of cases. Many patients will be on multiple medications for their LTC and co morbidities, medicines review to maximise effectiveness, minimise adverse effects and enable self management through a patient centred approach to medicines use is required. Psychological assessment and support are also key to supporting self management, and these skills commonly need development within multidisciplinary teams.

Collaborative care planning is the cornerstone of support for self management. These skills and competencies need to be developed in the team, as well as by patients, family members and carers. The processes of care at this level must also support collaborative care planning, and the development of a written and accessible care plan. (The Diabetes Year of Care provides additional resources on this aspect and collaborative care planning, [www.diabetes.org.uk](http://www.diabetes.org.uk) 17)

Some of the aspects of disease monitoring will need to be performed by the multidisciplinary team, rather than the patient. Specific knowledge of individual diseases and their management will be needed. Changes to care required at times of exacerbation are a vital component of the care plan. Easy access by patients and families for continuing support is vital, and multiple formats should be used. In a number of disease areas and for people with multiple conditions group consultation and education has been shown to be particularly effective, and the skills to facilitate patient groups should be within the team.

Whilst support for self management is primarily related to support for the individual, there is also a need to consider the local population at this level. Therefore the skills for case finding, register management and population stratification are also required so that the management can be targeted appropriately for population needs.

### Workforce Competencies within the multidisciplinary team for Supported Self Management

- Clinical diagnosis of long term conditions
- Clinical Management of LTC in line with evidence based guidelines and pathways
- Identification and management of exacerbations of LTC, including access to enhanced and specialist care
- Condition specific physical examination/ investigation
- Psychological assessment and support
- Medicines review
- Patient centred consultation and collaborative care planning skills
- Adult education skills, including group facilitation skills
- Population register management, stratification and case finding
- Ability to monitor outcome data for the population
- Coordination and follow up of care plans, linking with other agencies and with enhanced or specialist care when appropriate

### Enhanced Care

Some patients will require Enhanced Care in addition to the fundamental elements of care previously described. This may be because of the complexity of their condition or the interventions required, the number of co-morbidities and how they interact or their level of dependency and therefore support needed. For the majority of patients this should be a transient need because of a new complication or co morbidity, exacerbation or progression of conditions, or other change that increases their care and support needs. It requires a level of skill, intensity of support or coordination that cannot be achieved within the multidisciplinary team providing supported self care. This may be for physical, psychological or social needs. This is supplementary to the basic elements of supported self care, and will therefore change the composition of the care team. The team is likely to comprise a mixture of generalists and specialists when need reaches this level. The individual professional coordinating care may or may not change, but must be identified. It could remain one of the generalist team, or someone with enhanced skills may need to take on this role during this phase of care. As the patients care needs are increased the ability to interact in a more

intensive way with other agencies for health, social care and support for living will be required.

Technological developments may be a support to care with patients at this level of dependency, and telehealth and telecare may be helpful.

The competencies required to support self management will generally also be required for enhanced care. The skills of patient centred consultation and care planning are key, as well as those of adult education. With certain conditions education of patients and families by staff working at this level will be appropriate.

Enhanced care should be provided in community settings or peoples' homes wherever possible. This is commonly done by community based professionals with enhanced skills, and particularly by those with case or care management responsibilities for patients with complex needs e.g. case or care managers, psychologists, specialist nurses etc.

### Workforce Competencies for Enhanced Care

- The competencies of supported self management
- Assessment and management of complications or exacerbations of LTCs – may require additional diagnostic and treatment skills
- Complex care coordination for health and social care needs
- Assess and review need for telehealth and telecare, including the use of additional assistive technology
- Enhanced psychological assessment and support skills
- Skills to support reablement of people with LTC
- Assess, review and plan needs of carers for those with more complicated conditions or more complex needs
- Ability to link with multidisciplinary teams providing supported self management to identify and support patients with increased need or dependency.
- Ability to link with specialist teams
- Ability to link with other agencies outside healthcare and commission their involvement

### Specialist Care

Specialist care is a costly and limited resource for people with LTC and must be used optimally for those requiring this level of skills. Specialists also have a vital role in educating, supporting and enabling those delivering enhanced care and supported self management. This is best illustrated in the joint Royal Colleges document "Teams without walls"<sup>18</sup>.

Specialist care is delivered in multidisciplinary teams to meet the complex multifaceted needs of the individual requiring specialist support for their LTC. Traditionally specialist care has been delivered from hospitals. This will be necessary when patients are inpatients because of the severity of their condition or co morbidity at that time, or specialist equipment is needed that is only available at a hospital. However for "ambulatory" care, specialists are increasingly working across the community and are not limited by hospital boundaries. They will require a base for their multidisciplinary team which may be on the hospital site or in a community setting.

Specialist care is required when patients with LTC have a degree of complexity in their conditions or co morbidities that cannot be met by supported self management in primary care settings or by enhanced care. The number of patients with a condition requiring specialist care will depend on the nature of the condition and how common it is. Less common conditions are more likely to require specialist skills because knowledge is limited within the rest of health and care professionals.

The clinical and educational skills and competencies required for supported self care are also required for specialist care.

As the patient has increased need and complexity care should be intensive and time limited whenever possible at the specialist level, and aim for the patient to stabilise so that they can enter enhanced care, supported self care and move towards autonomy and independence.

### Workforce Competencies in Specialist Care

- The clinical and educational competencies of supported self management
- High level condition-specific clinical knowledge and skills
- High level multidisciplinary team working skills to support others with extended role within the specialist multidisciplinary team
- Technical skills required for interventions for specialist patients
- High level of cross-agency working skills, linking with those providing enhanced care and supported self management
- Professional education skills to develop others to deliver care for specific conditions
- Ability to work with others on strategic needs for the patient population with specific conditions
- Ability to work with others to develop the wider workforce, model of care delivery, and procurement and development of services
- Ability to be a champion for the care of people with specific conditions
- Ability to manage and balance risk
- Research and evaluation skills to develop new knowledge or translate new findings into local practice
- Advanced communication and negotiating skills

Specialist care is a costly and limited resource for people with LTC and must be used optimally for those requiring this level of skills.



### Case Study Examples

The following examples are taken from condition specific specialities, demonstrating the transitions through a stepped care model.

#### Diabetes- Supported Self Management- Independence and Autonomy – Enhanced and Specialist care

A patient with Type 2 diabetes, diagnosed for a number of years and manages relatively well maintaining autonomy and independence. She receives care at supported self management level with her general practice team. She accesses them with pain and swelling in her foot and is diagnosed with a foot ulcer. The nurse contacts the specialist foot team for urgent multidisciplinary assessment. Once the foot ulcer is healing and risk factors are managed follow up of the ulcer until healed is with the community podiatrist with an interest in diabetes (enhanced care). The patient returns to autonomy and independence within weeks.

#### Neurological- supported self management to enhanced and specialist care and back to supported self management

A patient with Motor Neurone Disease (MND) has been living as independently as possible for a number of years with his family. His wife is his main carer and they receive support from social care for disability living aids and holistic advice about living with a LTC (enhanced care). His GP and Specialist manage his health care with active input from the patient and family. His care is coordinated by the specialist nurse for MND. His family contacted the nurse about recent weight loss and progression of swallowing difficulties as they were aware this was a marker of progression. After discussion with the specialist videofluoroscopy was arranged. At a collaborative consultation it was agreed to initiate enteral feeding. The patient was admitted to the specialist centre and had a PEG feeding tube fitted. The patient and family received education and support from the multi-professional team as to initial use and ongoing use. On discharge back home equipment was arranged and delivered with ongoing support, initially by the community nursing and social care team. With continuing support and training this enabled the patient to live at home and live as independently as possible with his family.

#### Mental Health – Transitional Care through a Stepped Care Model

The following example is taken from a mental health case study. Mental Health services have used stepped care models for many years.

A 19 year old well educated man and strong sportsman lives at home with his mother. His mother made several help-seeking contacts with the GP over 8 months with concerns about changes in her son's behaviour/mood. He then presented to the GP with a full psychotic episode. He was referred for acute assessment to the secondary care multidisciplinary access service (Specialist), and was admitted to hospital. He was referred to the community mental health team (enhanced) on admission who started to plan and coordinate his transition home with all other agencies. On discharge a community support worker worked with him and his care coordinator (an occupational therapist within the team). Psychological therapies for educational/therapy were delivered for and with the patient and his family, with particular emphasis on how to recognise early warning signs, how to manage symptoms, how to manage stress (triggers symptoms) and medication management. After 6 months the patient 'stepped down' into the Review and Recovery team, with annual reviews (supported self management).



People living with long-term conditions are the greatest users of the health and social care services, especially hospital services.

#### Recommended actions for commissioners and providers in implementing a stepped care model

Close collaboration between commissioners and providers in primary, community, and specialist health and social care for a local population is necessary to develop and implement a stepped care model.

Our experience from across North West demonstrates more effective clinical and experience outcomes for people with LTCs, their families and the workforce, when there are cohesive and integrated strategies for commissioning and providing. The areas in the region with the most strikingly significant outcomes are those where health, social care and the third sector share a common vision informed by patients, families and the workforce

#### Commissioners should:

1. Develop or engage with local clinical networks of clinicians, patients and carers
2. Develop a shared vision with stakeholders of a local stepped care model for some common LTCs or for people with multiple LTCs, based on an understanding of local population need and current services
3. Develop a more detailed stepped care model, and associated clinical pathways using resources such as Map or Medicine, NICE guidance and NSFs. Include planned measurement of performance including patient experience and outcomes

### TRANSITIONAL CARE

People living with long-term conditions are the greatest users of the health and social care services, especially hospital services. The aging population means that the number of people with multiple LTCs is increasing rapidly in the North West. The complexity of care increases with the number of conditions the person is living with. This will require care in different settings, and with different teams at various times in their lives with these LTCs. Movement between these "locations" of care is termed a transition. This requires an active process that we term Transitional Care

We were only able to find limited examples of transitions being managed well in the North West. In addition the understanding of the term "transitions" was variable and inconsistent. Most work on this has been undertaken in the USA<sup>19-22</sup> and the recommendations of the American Geriatrics Society 'One patient, Many places: managing health transitions' has greatly informed our recommendations<sup>19, 20</sup>.

The case studies used illustrate the concepts though do not fully demonstrate the model, as it is not delivered as a whole within the North West.

This approach is strongly supported by patient groups and was concept-tested with representatives from the Greater Manchester Patients Council, Bury.

4. Consider how the stepped model will address the following scenarios, to inform workforce planning and also service provision:
  - o When the person with a Long Term Condition is coping well with treatment and can participate in day to day life.
  - o When the person with a Long Term Condition struggles with the condition in terms of daily living skills.
  - o When the person with a Long Term Condition develops complications or an exacerbation of the condition.
  - o When the person with a Long Term Condition becomes acutely unwell.

#### Providers should:

1. Be clear of their role in the stepped care model and how they work with and support other levels of the model
2. Identify the job roles that best meet the required competencies at each step of the model, ensure team working and commence implementation
3. Assess the current skills of the workforce within each component of the stepped care model
4. Develop local workforce by sharing skills across the care continuum and commission workforce development to meet the need identified

#### Defining Transitional Care

Transitional care is a planned and managed process where a person with long term conditions is actively and collaboratively managed as they move between care settings or teams.

The process should be centred on the individual's needs, values, skills and relationships through a collaborative care plan.

The key components of transitional care are:

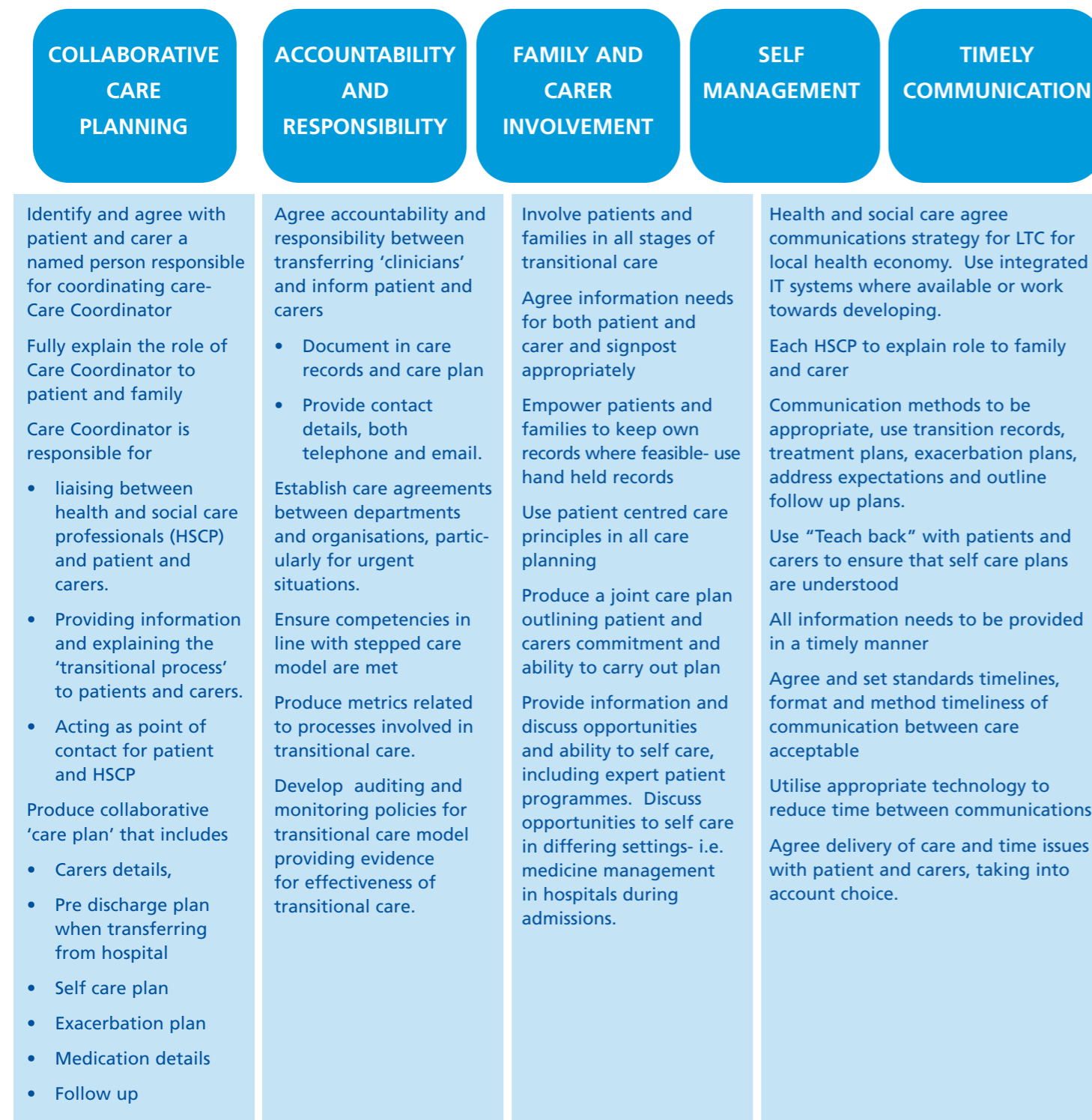
- collaborative care planning and care coordination,
- agreed clinical accountability and responsibility,
- family and carer involvement,
- empowering towards self management
- timely and appropriate communication

NW NHS Adult and Elderly CPG, 2010

The Transitional Care approach should be used as patients move between stages of the Stepped Care Model

## TRANSITIONAL CARE

### Underlying Principles for Effective Transitional Care



### PATIENT CENTRED- BUILDING RELATIONSHIPS AND TRUST

Transitional care transcends pathways, across timelines; traditional age/ generational milestones (paediatrics-adolescents-adults-elderly-end of life)

Transitional care is multi directional and complex, but aim towards self management and independence

### Collaborative care planning

A true partnership approach between patients, families, carers and professionals is fundamental to all LTC care, but is exemplified in transitional care planning. This means that all aspects of care are agreed between the patient/carer and professional, based on the patients' needs, values, beliefs and preferences. This approach, whilst understood by most professionals involved in LTC care, is difficult to do within the constraints of current care processes and environments. It requires the development of patient centred consultation skills in professionals and patients, and a change in culture from dependency to partnership. These changes will take time as these skills are developed by professionals and patients, and the processes of care are changed to enable collaborative care planning to take place, and the plans to be delivered. The elements that we recommend within the transitional care model will enable care to move to a more collaborative approach

The formal identification of a care coordinator for transitional care is essential for anyone with 2 or more LTCs, and preferable for all. This may be a professional already directly involved in their care, such as practice nurse, community matron or AHP, specialist nurse, ward nurse or their GP. It may also be a role that is taken on by a family member or patient advocate.

NHS Sefton Community Health Services introduced the named nurse concept within their District Nurse service for older people and people with LTC. Patients and nursing home staff have a named nurse and contact number. Patient benefits cited as, "better to know the nurse as they have a better insight into the family, and I (Patient), feel more confident". Also has improved continuity of care, staff morale, and resulted in manageable case loads. The concept has been rolled out to Cardiac and Heart Failure Teams, and is being considered for respiratory conditions. Contact Bernie.Connell@sefton.nhs.uk, LTC Lead, NHS Sefton Community Health Services.

The use of Common Assessment Framework coordinators in childrens' services as a care coordinator can be learned from for adult care. This named individual is involved in the care of the patient and family, responsible for liaising between services, acting as point of contact for the family and health and social care individuals involved in the care and ensuring communication remains consistent, up to date and relevant.

The Productive Ward Programme also improves patient centred care planning. "I had an excellent experience during a hospital admission, the ward used Productive Ward principles in which I was valued and respected. They respected everyone as individuals and planned care based on the individuals needs".

### Accountability and Responsibility

Lack of clarity about accountability and responsibility of individual clinicians and other staff during transitional care is a common cause of delayed, inefficient, poor experience, unsafe or unsuccessful transitions. For common transitions this may require formal care agreements between different departments or parts of the care system. Each task that is required for a safe and effective transition needs assigning to a key individual. This must be communicated clearly to patients and families. The care coordinators role is key here in ensuring all tasks are coordinated, completed and communicated. Within the care plan, it will be clear who the patient or carer contacts for certain issues, and at times of need, with the care coordinator as the central contact for many situations, and when the patient and family are uncertain.

Many aspects of accountability and responsibility are those of the patient and family in self management

All organisations and teams involved in the care around the transition should have joint ownership for transitional care. The quality of transitional care, should be measured, and fed back to all involved for continuous review and improvement. Patient experience is a key component in this measurement<sup>23, 24</sup>.

"My GP and consultant involve each other, and me and my wife (carer) in the management of my LTC. Both the GP and I have contact numbers for the specialist nurses to contact them if we are unsure of things, this makes it easier for my wife and I as we feel confident in managing at home".

There are a number of examples of patients having "joint appointments" with more than one specialist when they have more than one condition. These are used to agree responsibilities for care of each component of the conditions, and who coordinates care

A true partnership approach between patients, families, carers and professionals is fundamental to all LTC care,

### Self Management and Family and Carer Involvement

Many aspects of transitional care correctly fall to the patient, family and carers. Their involvement in care planning is a fundamental principle of patient centred care. This should begin when a care transition is envisaged, and continue throughout. The ability of patient, family and carers to deliver certain aspects of care must be established, and will change over time. Skill development of patients, families and carers may be needed, and formal training should be available<sup>25</sup>. Clarifying, agreeing and documenting their roles in the care plan is necessary. This care plan should be held by the patient, family and carer, and supported with other relevant written information.

In Heywood, Middleton and Rochdale, patient education programmes have evolved to provide ongoing support and sustainability, and are being delivered in general practices by partnerships of patients and professionals. Contact Julie.Dawson@hmr.nhs.uk Expert Patient Programme Coordinator and Assessor.

A patient with intestinal failure was encouraged and supported to self manage, was provided with training to undertake dressings and procedures himself, that enabled him to remain independent and take control. The alternative was daily visits from District Nursing teams and having to 'wait in' for them every day. " I now appreciate the opportunity to self manage as this means I have independence, and increases my quality of life, I don't feel dependent and it means I can still go on holidays and live my life with a LTC". He believed strongly that EPP helped his confidence.

### Timely communication

Without good and timely communication transitional care is unsafe, and often inefficient. This applies to verbal and written communication between patients, families, carers and professionals, and between professionals.

Written communication between professionals must be accessible to all involved in care, this can be greatly improved by integrating IT systems across healthcare boundaries and between health and social care. Even without full integration the ability to view electronic records or documents, or transmit them by secure electronic methods markedly improves availability and timeliness.

Verbal communication between professionals and patients, families and carers must be appropriate to culture and understanding. The use of "teach back" is vital to ensure that the information and actions are understood<sup>26</sup>.

Access to the electronic record by patients, greatly improves communication, understanding and involvement in care.

"Whilst I was in hospital I asked my nurse for some information about going home, she gave me some written information for me and also gave me a copy of the letter that was to go to my GP. This was good because I had the information to refer back to, because often when you get told things you often don't remember them, unless its written down, you may be confused or in trauma about what's happening. The written information explained what needs to be done, expectations, and what I needed to do, and gave me the chance to ask questions.- I would say this should happen at every step including GP visits".

### Managing Transition of Adolescent to Adult LTC Services

The existing evidence on the transitions from adolescent to adult services can inform the implementation of transitional care<sup>27</sup>. Management of this age-determined transition is commonly holistic involving patients and families in a collaborative process. There is recognition that there should be agreement of which practitioner takes overall care co-ordination responsibility until the transition is signed off. There are working examples of how technology is being utilised with this particular age group of patients, utilising text messaging to remind/ inform of appointments, use of social networking sites to sign post to additional support services/ health pages, encouraging self management. The principles of transitional care should be applied to this situation.


### Recommended Actions for commissioners and providers in implementing transitional care

#### Commissioners should:

1. Agree with all local providers to move towards a transitional care approach
2. Work with providers to agree a programme of implementation for transitional care
3. Agree with providers a high volume high risk transition in which to develop the approach
4. Involve clinicians, patients and carers in redesign to address this
5. Commission a programme to develop skills of collaborative care planning for patients and professional
6. Agree standards for timeliness of communication between providers, and other performance metrics including measures of patient centred care
7. Facilitate the development of care agreements where necessary
8. Work with providers to integrate information systems

#### Providers should:

1. Work with commissioners on all the above actions
2. Assess current approach to care and measure patient centred care and assessment
3. Review current processes for a high volume high risk transition
4. Develop transitional care for this transition including
  - o Review and modify documentation
  - o Development of care coordinator role
  - o Development of collaborative care planning skills
  - o Develop care agreements between departments or with other providers if necessary
  - o Develop supportive tools for staff and patients/families/carers for transitional care
5. Measure the quality of care transitions



Health and care professionals also recognise that there are significant opportunities to improve care for people with long term conditions,

## MEASURING THE QUALITY OF CARE FOR PEOPLE WITH LTC

We could find little evidence of services for people with LTC in the North West that were systematically measuring the quality of services.

We recommend measurement of services using the quality domains of Safety, Effectiveness and Patient Experience. In the context of QIPP many of these are key measures of productivity of the healthcare system, as poor quality of care for people with LTC results in unnecessary use of high cost resources. In addition preventive measures should also be included.

**NOTE:** Many measures can only be accurately assessed when reported by patients and carers

**We recommend that AQUA supports the development of comparative measurement in NHS North West in the following areas for people with LTC**

### Safety

1. The completeness of disease based registers: numbers vs expected for population, as identification and registration for recall and review is a fundamental building block for all LTC care.
2. The percentage of patients with LTC with a named care coordinator. (% of patients who can name care coordinator – this would need to be by sample audit as systematic measurement is not currently in place)
3. The percentage of patients with an exacerbation plan with key conditions (% of patients with exacerbation plan they can follow)
4. The percentage of patients who have had medications reconciled within 72 hours of transfer between care settings.
5. Hospital Readmission rates for people with LTC measured at 72 hours and 28 days post discharge.

### Effectiveness

1. Disease related outcomes and intermediate outcomes as quantified in the Quality and Outcomes Framework.
2. A measure of functional ability within certain patient groups e.g. EQ5D – 5F. This is being used in pilots of Patient Reported Outcome Measures (PROMs). These are currently being piloted in the North West for specific long term conditions.
3. A measure of self management, and supported self management e.g. the Patient Activation Measure<sup>28</sup>. Patient assessment of chronic illness care<sup>29</sup>.
4. Standardised Admission Ratios for certain LTC, currently collected by NHS Information, and available through NHS choices.



## Patient Experience of Care Measures

The following questions have been proposed by the 10 SHA Long Term Conditions Clinical Leads for inclusion in the GP MORI survey to assess the 5 key components of patient centred care for people with LTC; importance, involvement, confidence, support, and joined up care.

1. Have you had discussions in the past 12 months with a doctor or nurse about how best to manage your health?  
Options: Yes, No  
If Yes go to Q2  
If No go to Q3
2. In these discussions...  
... did you discuss what is most important to you in managing your health?  
Options: Almost always, Some of the time, Rarely, Not at all, or Don't know  
..... were you involved as much as you wanted to be in decisions about your care and treatment?  
Options: Yes definitely, To some extent, No  
.....were you offered a plan to record the discussions you had about managing your health?  
Options: Yes, No, Don't know, Can't remember
3. Thinking about the overall care over the past 12 months...  
... How confident are you that you can control or manage your health?  
Options: 'Very confident', 'Somewhat confident', 'Not too/Not at all confident'  
... Have you had enough support from local services or organisations to help you to manage your health? (Please think about all services and organisations, not just health services)  
Options: Yes, Always; Yes, Sometimes; No  
... Do you think the support and care you receive is joined up and working for you?  
When you think about your health care in general, how often do you receive the health care YOU need WHEN you need it?  
Options: Always, Often, Sometimes, Rarely or Never



closer integration of care for people with long term conditions is the next step in achieving the vision that was set out in Healthier Horizons

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NAME	JOB TITLE
Anand Rajasekaran	Consultant in Anaesthesia and Pain Management
Glenn Russell	Medical Director LHCH
Jeff Seneviratne	Clinical Lead, Gtr Manchester Pathology Network
Jeremy Wilkinson	Clinical Implementation Specialist
Jerry Martin	Commissioning Board (PEC) Chair
Jim O'Connor	Medical Director Provider Services, Liverpool PCT Vice Chair of CPG
Joanne Greenwood*	North West Leadership Fellow Adult and Elderly CPG <a href="mailto:Joanne.Greenwood@nhs.net">Joanne.Greenwood@nhs.net</a>
John Dean*	Medical Director Bolton PCT Chair of Adult and Elderly CPG <a href="mailto:John.dean@bolton.nhs.uk">John.dean@bolton.nhs.uk</a>
Julie Rigby	Gtr Manchester Neurorehab Network Lead
Karen Clancy	Nurse Consultant LTC (respiratory)
Krystyna Walton	Consultant Neurorehabilitation SRFT
Michaela Toms	Community Matron
Neil Snowdon	Clinical Director of Scheduled Care, Pennine Acute Hospitals NHS Trust
Paula Mays	PA Support to CPG
Phil Morley	CEO Mid Cheshire Hospitals Foundation Trust Sponsor of Adult and Elderly CPG
Sarah Collins*	North West Leadership Fellow Adult and Elderly CPG <a href="mailto:Sarah.collins@bolton.nhs.uk">Sarah.collins@bolton.nhs.uk</a>
Sharon Lloyd	LTC DH North West network Lead
Simon Hardy	Clinical Director General/Vascular Surgery
Susan Ramprogus	North West JIP Programme Manager
Vaikom Mahadevan	Consultant Cardiologist and Honorary Lecturer

\*Principle authors of the report

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