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Shropshire Clinical Commissioning Group

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-  
Long Term Conditions  
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# LONG TERM CONDITIONS STRATEGY

# **Shropshire Clinical Commissioning Group Long Term Conditions Strategy**

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## **1.1 Introduction**

This strategy has been developed primarily by the patients and the member practices of Shropshire County Clinical Commissioning Group. It is offered as a first step toward the development of a shared, systems wide, vision and strategy that will genuinely improve the care experienced by individuals who live with incurable illness.

It is a description of how we plan to make and champion change in the way our society supports and delivers care to people who suffer from one or more Long Term Condition.

People who suffer from a Long Term Condition are people who have an illness that cannot be cured but who can be supported, treated and cared for in a way that minimises the impact of that illness both on the individual and on their families and carers.

One person in three suffers from a long term condition. The impact of that illness on that person is very variable and in part depends on the nature of the illness. However, in large part, the impact of the illness is also affected by what we do as individuals to care for ourselves, what we do as communities and families to care for each other and what we do as health and social care professionals when we provide care.

This strategy is a plan of how we intend to work together to ensure that those things we can improve we do improve so that every individual has every opportunity to avoid becoming unwell and if they do become unwell for it to have a minimal consequence on the quality of their lives and the lives of those close to them.

This Strategy has been developed around the needs of an individual as they live their lifetime with an illness that cannot be cured. It spans the prevention of illness and the early recognition of illness, how we support individuals and their families and carers to manage that illness and how we deliver care optimally as health and social care professionals recognising that some individuals will need more support than others as they become more unwell and older. And how, in the end, we support people in their choices for a comfortable, dignified death.

Our success in delivering such a strategy will depend upon our ability to work together as individuals, families and friends, communities and organisations so that the finite resource, skill and energy we have is directed in the right way to the right place. It will depend on leadership at all levels, a willingness to work differently, to use our resources differently and recognition that the provision of health and social care is only a small part of the solution. We need to deliver together a completely different model of care in which communities, health professionals, families and patients all have a key part to play and that all of these elements of care are effectively coordinated around the needs of the individual.

## **1.2 Executive Summary**

The document describes how, in partnership with others, The CCG will deliver the best possible outcomes and experiences for patients with one or more Long Term Condition. It

describes how we will collaborate with The Local Authority, The department of Public Health, The Voluntary Sector, practices and communities to develop a process whereby the community is empowered and supported to help individuals and where statutory, non-statutory and voluntary services are coordinated in such a way that the needs of its population are met. It describes how we encourage and support quality care delivered by our practices in which variation is minimised and individuals receive proactive, proportionate care to help them and their families minimise the impact of the illness. It describes how we commission services from other agencies so that there are no gaps and no duplication and so that care is delivered in a way that makes sense. Finally as individuals become less able to care for themselves it describes how we, together, sensitively, support them to remain independent as long as possible and to die with dignity in the manner in which they choose.

### **1.3 Background**

Developing and more importantly implementing this strategy is a priority for the Clinical Commissioning Group. This is for a number of reasons.

Firstly, as clinicians, we are hearing from our patients, our patient groups and our wider society that the support and care offered to people with long term conditions is often uncoordinated, disjointed, difficult to understand, inequitable and sometimes of very poor quality and that it falls a long way short of what is needed.

National and Local Information and research supports this view and although there is some high quality care provided there are also areas where we fall short. <http://www.apho.org.uk>

Secondly, as a new, clinically lead commissioning organisation, we have an opportunity as patients and as clinicians to shape the nature of services that provide health and social care so that they make better sense and provide a better working environment for those who work within them.

Thirdly, there is considerable evidence that by preventing illness, finding illness early and caring for people optimally the cost to society is less. The 'Nicholson Challenge' to the NHS is to save £20 billion over the next 4 years in order to address the cost of health service inflation and rapidly changing population demography. In Shropshire County this translates into a need to save £20 million per year for the next four years. Evidence is now emerging that this figure is a significant under-estimate. Shropshire and Telford & Wrekin local authorities also face a 20% *cut* in their budgets in 2012. It is only by significantly improving our care of people with Long Term Conditions, preventing illness, actively managing illness and keeping people out of hospital that we can hope to meet that challenge and create a sustainable health economy.

Fourthly, the strategy begins to make real our "CCG Principles"

*"We will strive to consistently improve the quality of the services for our patients"*

*“We will at every opportunity support the development of leadership and empower our clinicians patients and communities”*

There are many examples of good practice, innovation and development within our population. These are driven by the communities themselves, by the practices, by the voluntary sector, the local authority, the public health department and our provider organisations. The strategy seeks to provide a framework which will support close working between these bodies so that this work is encouraged and integrated to provide most benefit. The Health and Wellbeing Board will be a fundamental element of this network.

The Long Term Conditions Strategy is informed by and aligned with The Health and Wellbeing Strategy and sits alongside the CCG Unscheduled Care Strategy and Quality Strategy which together will deliver a future state in which we optimise the health and wellbeing of our communities.

## **1.4 Policy and Guidance**

### **Nationally**

One in three people suffer from a long term condition. This will rise to more than one in two over the next twenty five years. The NHS will not be able to meet this demand unless it changes. In ‘Improving the lives of people with long term conditions’, NHS Operating Framework 2011-2012;

([http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_131428.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf))

The Department of Health challenges a new, modernised NHS to improve the lives of people with long term conditions by giving them more support to self-care, helping them to remain independent for longer using new technology, simplifying who cares most for a person and training health professionals to focus on the overall health and wellbeing of a person rather than just managing one of their conditions.

The previous Health Secretary, Andrew Lansley said that ‘the average yearly cost to the NHS is about £1,000, which rises to £3,000 for someone with one long term condition and to £8,000 for people with three or more conditions’.

Current policy on long term conditions as set out in the *'Equality and Excellence: Liberating the NHS'* White Paper, published in July 2010, seeks to reduce this demand through developing services that enable people to remain living independently, and empower patients with the choice to decide their own care and support. This patient centred model engages the individual in making shared decisions about their care.

Sir John Oldham, national lead for LTC's, is promoting holistic solutions to LTC management, rather than continuing to develop the minutiae of separate disease specific pathways. He wants General Practice to get back to a team approach, to understand the needs of their population better and to maximise the contribution made by carers and volunteers.

The Department of Health is leading on the development of a Long Term Conditions Outcomes Strategy which considers how people with LTCs, their local networks, voluntary sector, local authorities and Government Departments can work together to help prevent LTCs where possible, delay their onset and provide support at appropriate times and places in their lives so that, if they do develop a LTC, they will enjoy more positive outcomes.

<http://www.dh.gov.uk/health/category/policy-areas/nhs/long-term-conditions>

The case for change has been articulated clearly in Lord Daarzi's national LTC group (2008) and Dr Vinood Patel's West Midland Strategic Health Authority LTC Group (2008) both of which described clear objectives.

- We need to develop a system that means all citizens are willing and able to take responsibility for their own health and understand how to adapt the best advice about prevention, early detection and treatment to their own circumstances.
- This relies on a single team of health and social care professionals delivering personalised care in whichever sector is most appropriate.
- This requires non-judgemental and targeted support from a myriad of health and social care professionals, working as a single team, with the right attitude, skills and motivation to adapt their services according to individual need and preference.
- It relies on providers utilising the best evidence to discuss a range of treatment options with their patients in their daily practice, and patients owning the solution.
- It requires the system to stop operating as a single assembly line in a factory and move towards a tourist information approach- citizens drop in to ask how they can make the best of their experience of living with an LTC.
- It demands an approach that seeks out the vulnerable and hard to reach groups, and includes them in this work.

*“ In organisational terms, patients will continue to need services across the piece, primary, secondary, tertiary, palliative and social care- but the current models of provision are outdated and need reviewing” -*

All of the evidence points toward a system in which:

- Prevention should be a priority.
- Early detection leads to better outcomes.
- Individuals do better if they are knowledgeable about their condition and are supported to self-care.
- Services should be evidence based, timely, closer to home and integrated.
- Services should be tailored around the needs of the patient and should reflect the degree of need. Stratifying risk can help with this.
- Patients who are less able to coordinate their care need support to do so.
- Improved quality of care leads to better health and wellbeing and a reduced cost to society.

The West Midlands Strategic Health Authority long Term Conditions Programme seeks to establish Integrated Teams, Risk Stratification and Care Coordination in all of our communities. These interventions are supported by considerable evidence but in themselves do not provide the solution. Their successful implementation depends upon a whole scale change in the way services are currently delivered and people behave.

## **1.5 Local History and Demographics**

The Joint Strategic Needs Assessment details the changing demography and needs of the Shropshire population and the challenges of delivering high quality care across our large rural county with an ageing population and pockets of disadvantage in both rural and urban communities. Mirroring the national situation, inequality and isolation play a significant role in the development and impact of LTC's in Shropshire and poor access to care and unwarranted variation in the way it is provided mean more people suffer for longer.

<http://shropshire.gov.uk/jsna.nsf/open/7FE41BF75AB70B3F8025794B0047B638>.

Of key importance for us locally is the high and growing older population particularly in the South of the county, the pockets of deprivation in both towns and remote rural areas and the difficulties incumbent with delivering services in a large rural area.

## **1.6 What are services like now?**

Shropshire County CCG consists of forty five general practices. The practices are independent contractors all of which have different ways of providing care for people with LTC's. The quality of that care is variable and the degree to which they rely on other providers is variable. Although patients see their local practice as central to providing and coordinating care some practices have become more reactive than proactive in this function. Commissioning decisions have exacerbated this trend leading to increasingly poor integration and a growing lack of clarity around roles and responsibilities. Patients perceive services to be difficult to navigate and don't understand why there are many different providers of services and many different ways to access them. As patients become less able to manage their own care so the task becomes almost impossible.

Community Services such as district nursing and schemes to avoid admission and rehabilitate after discharge vary widely across the county and do not work as closely as they might with Practices.

A recent review of district nursing services concluded that our health economy was probably not making best use of the skills of the district nurses who were spending 80% of their time on wound management. It highlighted the inequities in provision of services to avoid admission, rehabilitate and care for people at the end of life.

The journeys patients travel through hospitals are often slow, risky and difficult to understand. Records are neither shared nor patient held. Frail people with complex

problems spend far too long in emergency hospital beds and, as a result, more die or lose their independence than need to.

At a recent workshop 140 patients, clinicians and managers were asked to use their considerable knowledge and experience to identify where services are not working well. The delegates agreed that the key gaps are:

- Not enough opportunities for staying well especially in more rural areas.
- Access to practices when unwell can be difficult.
- Insufficient time to fully discuss and learn about the condition and agree a management plan with clinicians.
- Not enough information provided about the condition.
- Long delays and journeys to access specialist support.
- Care not sufficiently proactive especially where risk of admission is high.
- Not enough care in the community leading to unnecessary admission to hospitals and care homes and intolerable burdens on families and carers.
- Inadequate support to coordinate care where patients become older.

These local views are remarkably similar to those expressed by others including the Kings Fund, The Health Foundation and The Department of Health.

There has been very little progress made against the aims described by Lord Daarzi and more locally by Dr Vinood Patel and we are no nearer the implementation of the SHAs goals: Risk stratification, integrated teams and case management.

## **1.7 What is our vision?**

There are many visions described by eminent clinical and non-clinical leaders. They all share common themes and build on evidence, common sense and consensus.

Shropshire County CCG holds a vision in which traditional health and social care forms only a part of a much broader range of activities and networks which, as a carefully integrated whole, provide the support and care needed to help people within the community stay well. Within that vision the community is both empowered and supported by the practices to play a fundamental role, not just as individuals taking better care of themselves, but as individuals supporting others. Within that vision there are a myriad of opportunities, close to home, to stay healthy both physically and emotionally. There is support from volunteers if for some reason it is hard for an individual to access these opportunities. There is support from neighbours, family and friends who are themselves supported and valued. People understand better how to keep themselves healthy and how to recognise when they might be unwell. Within that vision statutory services, voluntary services and the community's essential contribution work together, seamlessly, with no gaps or duplication, coordinated



around each individual so that throughout their journey, from prevention to end of life, their illness has as small a negative impact as possible.

The vision looks to the practices to re-establish themselves as the first line of contact for patients. To develop themselves as the hub in the community to which other voluntary and statutory services link closely. To bring leadership in the development of the community as a vehicle through which people with long term conditions can be better supported. It looks to the practices to excel in the care they provide, to use risk stratification and other local intelligence and to tailor care to the particular needs of the patients registered with the practice. It looks to the practices to champion self-care and support the patient in the coordination of care where that individual is less able to do so for themselves. It looks to the practice to effectively sign post and link other services to the patients' needs in a way that leaves no gaps and causes no duplication. It looks to practices to take back the overall responsibility for the patient's journey in partnership with them

The vision includes the development of integrated community teams, called Frail and Complex Teams. These teams will work alongside the practices bringing expertise in assessment of complex patients, admission avoidance schemes, rehabilitation and end of life care. The teams will demonstrate genuine integration of those different elements provided by different organisations. The practices will be able to seek the support of the Frail and Complex Team in the care of their patients along agreed pathways of care.

The vision includes a change in the way we work with hospitals in which the specialist nurses work more closely with the practices sharing their expertise with the practice team raising standards and knowledge amongst practice staff. They will work closely with the Frail and complex team to support those who might otherwise need admission in their homes and to help support people who are discharged from hospital. The consultants will work in a different way where responsibility is clear, where clinicians can communicate together and effectively share the care of patients who need that specialist knowledge. Telehealth and IT supporting the specialist to provide their expertise closer to a patient's home.

The vision includes people who live in care homes, nursing homes and in sheltered accommodation. The care and the services that are available to people who live in their own homes must be available in an equitable manner to those who do not. This means that patients in care homes should receive the same support in managing their long term conditions and the same support to avoid unnecessary admissions as those that do not.

Finally the vision includes end of life care delivered in a way that is responsive to the needs and wishes of the individual and their families. An integrated service available at all times so that individuals are assured that they can die in their own homes if that is what they choose.

## **1.8 Where do the challenges lie and how do we meet them?**

### **Prevention**

*“My mother smoked all of her life. She was also housebound toward the end because she was massively overweight. She spent the last 8 years of her life in a chair. She died at 44 of heart failure”*

For most individuals with a Long Term Condition there was an opportunity to prevent or delay the onset of that condition. People need to be aware of the risks they are subjecting themselves to through unsafe behaviours or unsafe work practices and they need to have opportunities to reduce those risks. Some of these opportunities might be provided by communities within communities for example opportunities for weight reduction, exercising, some might be provided through the work place, occupational health practices and some might be provided through the commissioning of statutory services such as smoking cessation services.

Although there are many initiatives through the Public Health Department, The Local Authority, The Voluntary Sector, The Communities and The Practices to provide opportunities to live healthy lives there is no clear picture of what might be achieved in a community and how that community can be supported by the statutory sector in achieving their vision. Opportunities differ between communities, for example, in rural areas there may be ready access to walking but no access to swimming. In some communities there are opportunities for social inclusion in others those opportunities are limited, for example in more remote communities. The ability of individuals to access these opportunities is also variable particularly where individuals are less well or where travel is more difficult.

Developments in the past have not always reflected the particular need of the population. New initiatives have often led to the development of a pilot scheme that is poorly evaluated and even where providing positive outcomes it is not provided across the population in a way that reflects the need equitably. Also practices vary in the extent to which and way in which they support public health initiatives.

The challenge is to support the development of an equitable range of opportunities that reflect the particular needs of the population and that take into account the ability of an individual to access them.

### **Early Detection of illness**

*“My doctor is very busy. I didn’t like to trouble him”* - a person with chest pain for many months before collapsing with a heart attack

The negative impact of the illness on an individual’s quality of life can be reduced or delayed if the diagnosis is made earlier in the course of the illness. An example of that might be the earlier diagnosis of dementia. There is considerable variation between communities in the effectiveness of early identification. This variability reflects a number of factors.

- The effectiveness of screening programmes.

- The behaviours and knowledge of individuals some of whom do not seek help despite very significant symptoms
- The quality of care provided in practices.
- The quality of care provided by other providers of health care

The challenge is to reduce this inequality by optimising the effectiveness of screening programmes, improving the knowledge of illness amongst our communities and by improving the quality of the care provided by the practices and other health providers.

### **Confirming a diagnosis**

*“My optician referred me to the eye specialist because he thought I might have some ageing at the back of my eye. By the time I was seen at the hospital my sight had deteriorated ...irrevocably”*

Where a diagnosis is not clear traditionally a patient is referred to an acute hospital for a test or to see a specialist in an outpatient appointment. There can be delays, difficulty for the individual attending a distant appointment, repeated appointments, unnecessary follow up appointments, poor communication between specialist and GP, lack of clarity around responsibility, patients getting lost in the system with inequity of access across the CCG. There is no recognised system for receiving advice and guidance, inequitable access to more local appointments with specialists and very little innovation around telehealth.

There are particular problems in Shropshire where the demand for outpatient appointments outweighs the capacity of the hospitals to deliver. This is leading to long waiting times and delayed diagnoses.

The challenge is to develop effective alternatives to the traditional model so that the specialist opinion or test is available at a reasonable time and place in a way that makes best use of his or her time.

### **Self-Care, Education and Empowerment**

*“My doctor referred me to the special diabetic nurses who taught me all about my diabetes. I met other people with diabetes and we meet to talk about things. My new friends know more about diabetes than my doctor! They are a big help to me.”*

At present there is a good programme of education offered to diabetic patients. GPs do not routinely sign post to it. There is some patchy education for patients with COPD but there is no similar provision of education for patients with other Long Term Conditions. There are multiple providers of the generic expert patient programme. The quality of that programme is in question and it is variably accessed. Within the communities there are self-help networks

some arranged locally and some by the voluntary sector. These are inconsistent and variably supported. They do not integrate well with statutory services.

The practices and hospital specialities vary in the degree to which they provide education, training, support, care planning and sign posting. There is no consistency across organisations so that individuals know who is responsible at any one time. It is usually unclear who an individual should contact with concerns.

The challenge is to support the patients and the practices so that everyone with a Long Term Condition can access education and support networks within their own community and be empowered and supported to manage their own condition where possible.

### **Good Quality Care**

*“At my last practice I had a letter from the nurse reminding me I needed a check-up. I don’t think they do check-ups at this practice”*

The care provided by clinicians to patients is often inconsistent. Inconsistent between individuals inconsistent between organisations and inconsistent between professions. Clinicians vary in the quality of their diagnosis, their prescribing, in their referral habits and in the pathways they use. Sometimes they adhere to guidance sometimes not. The extent to which clinicians are proactive rather than reactive also varies. Some practices have rigorous processes for reviewing individuals with Long Term Conditions and some don’t. Some conditions are managed proactively and others not. The time allowed within consultations, enabling shared decision making between clinician and patient, with sufficient time for understanding also varies. This raises issues of appointment length and consultation style.

The challenge is to find the right balance of support, education, and incentive and performance management to improve the quality of services in primary and secondary care

### **Accessing help when help is needed**

*“I have emphysema. I did try to get an appointment when my chest was bad but they were busy. I ended up with double pneumonia and was in hospital for weeks”*

It is often confusing for patients to know who to contact if they become unwell. The majority of patients with Long Term Conditions do not have a written plan describing appropriate steps to take under these circumstances. Access to the practice, access to Out of Hours support, availability of community staff, access to urgent specialist opinion and tests are all variably problematic.

The challenge is to support patients through care plans so that they know how to access help and when that help is needed. The second challenge is to commission and deliver services that respond in an appropriate way to the needs of the individual recognising that failing to do so could lead to significant deterioration.

## **Co-ordinating Care or Case Management**

*“My friend was getting on a bit, her memory not so good. Her daughter lived in America and didn't really bother. I did what I could but I'm 92. She went into hospital a dozen times. Eventually she didn't come out.”*

Some patients need more support in coordinating their care than others either because of complex physical illness or because of an intellectual inability to coordinate and manage care particularly as an individual gets older. Most patients with a Long Term Condition coordinate and manage their own care. Some are supported by a practice nurse and some by GPs. In some areas of the county Community Matrons or Specialist Nurses provide some coordination of care and some Case Management. This is inequitable with lack of clarity around thresholds for referral and length of follow up. There is considerable evidence that targeted case management and coordination can reduce dependency and admission.

The challenge is to recognise when someone is not managing or at increased risk of admission to hospital and provide the right sort of support so that they do not deteriorate unnecessarily.

## **End of Life Care**

*“Mum died at home last year. She was so peaceful. It actually went to plan. Everyone was great. We were so grateful”*

People would on the whole choose to die at home. Many do not. They are admitted to hospital unnecessarily for a number of reasons. Lack of care in the community, fear amongst family members or the individual, lack of preparation for the end of life, no end of life plan, difficulty judging how near the end of life has become, fear of retribution amongst professionals and carers for not admitting when a crisis ensues, inability of professionals to provide a sufficiently urgent response.

Issues within the community include lack of clarity around clinical and organisational responsibility, inadequate carer and nursing support in the community, variable quality of diagnosis and end of life planning by practices, variable responsiveness of hospice and changing capacity amongst Macmillan Teams.

The challenge is to get over our fear of talking about death. We need to do our best to predict it and we need to plan for it well in advance. The second challenge is to develop the right sort of support in the community so that there is never a need for someone to die where they do not wish.

The West Midlands Strategic Health Authority long Term Conditions programme seeks to establish Integrated Teams, Risk Stratification and Care Coordination in all of our communities. These interventions are supported by considerable evidence but in themselves do not provide the whole solution. Their successful implementation depends upon a whole scale change in the way services are currently delivered. Widespread cultural and behavioural change. The gaps and issues summarised above all contribute to unnecessary admissions, physical deterioration, distress and cost.

The CCG strategy seeks to both develop an understanding of and address these issues through this LTC Strategy.

### **1.9 How will we develop and implement our vision?**

If we are agreed that a Long Term Condition Strategy encompasses prevention through to end of life then by necessity it needs to be a strategy shared by patients, families, carers, communities, practices, health provider organisations, the local authority and the voluntary sector. It will require cultural and behaviour change in every individual involved from the patient themselves to the doctors and nurses that treat them.

This strategy is a work in progress. It has been developed primarily by the patients and the member practices of the CCG. It is offered as a first step toward the development of a systems wide vision and strategy that will include the perspective of other health and care professionals. It offers a framework on which to build a shared Health and Wellbeing strategy for patients who suffer from a Long Term Condition.

The methods used have been developed in recognition of the need to deliver large scale, whole systems and transformational change by combining the best available evidence with a strong stakeholder consensus of what works, based on the combined experience of patients, clinicians, front line workers, managers and commissioners.

### **Developing Consensus**

#### **Practice Involvement**

The process of gaining stakeholder engagement and perspective began in April 2011 through a series of practice workshops held by The Practice Support Team. The workshops sought views from the practices around what works well and what works less well in their communities. They also began the process of exploring with the practices how they might improve their care of patients with Long Term Conditions and how that might impact on the activity they generate in other organizations. Through the Quality and Productivity elements of the Quality Outcomes Framework all 45 of the practices are improving the quality of their own care and influencing the commissioning of new pathways to better support the care others provide. They were also asked for ideas for improvement and change. Their perspective has been a key driver for the development of this strategy.

A third round of visits has begun in which this LTC vision and strategy is being further considered and influenced.

The 45 practices meet as three locality boards, subgroups of the CCG Board. Conversations have regularly been held at the locality board meetings examining elements of the strategy

in some detail. These discussions have in turn been fed into the development of this strategy. They are minuted and recorded.

A steering group has been established with practice manager and GP representation from nine practices who are working alongside four CCG managers to further develop elements of the strategy and create a link between the practices, the locality boards and the strategy.

This is called **The LTC Steering Group**.

## **Patient Involvement**

The strategy has been developed with leadership from patients and communities. Very early work with the locality patient groups established the care of patients with long term conditions especially when frail and vulnerable as a priority. Concern for the growing elderly population and a recognition that services are poorly integrated and hard to navigate was the starting point for the work.

Forty one of the practices have a patient participation group. The groups are working collaboratively to develop an understanding of how they might support their wider communities and practices in the care of vulnerable people and how the community might become more involved in helping itself stay healthy. Their discussions are contributing to this strategy through the practice meetings and through meetings with the Practice Support Team.

The individual patient groups come together in the locality patient groups. Discussions have been held within these groups exploring views and stories expressed by the members. The strategy has been developed as a result of these discussions and shared with these groups as it develops.

In February 2011 The Shropshire County CCG Long Term Conditions Conference saw the coming together of 140 health professionals, patients and managers who were asked to use a life time of experience and knowledge to define "*What do we want to see for ourselves, our patients and our families with a long term condition?*"

They were asked to consider the question in the light of a patient journey they had heard. That journey carried an individual through his early healthy years in the army, through marriage and civilian life, through the onset of one long term condition and how it affected him, through the onset of two further long term conditions with the inevitable decline in independence and finally his death.

The thinking that emerged from that event was captured and refined further at a second smaller event into what the group describe as "*The Twelve Stages of Care*". These are simple statements that define the ideal circumstances at each of twelve places within this journey. They represent the outcomes we would like to achieve through the implementation of this strategy.

## STAGE 1

We would like to see an NHS and Social Service that fully understands the needs of its population and how illness and the effect of illness varies in different populations.

We would like to see services developed that take into account this variability.

## STAGE 2

We would like to see a wide range of opportunities to support people in living healthy lives and where people find it difficult for whatever reason to take advantage of these opportunities that they are helped to do so.

## STAGE 3

We would like to see a world class range of evidence based tests offered to people that are designed to pick up illness before it is noticeable in other ways.

Where people do not take advantage of these tests for whatever reason we would like to see systems in place that help them to understand fully the benefits.

## STAGE 4

We would like to see people provided with the right sort of information that would help them recognise that they are becoming unwell.

We would like to see services in the community that encourage and respond promptly to the first signs of illness.

## STAGE 5

Where the possibility of a long term condition has been identified and clarification is required, we would like to see an effective process for accessing tests or a specialist opinion, which is sensitive to the individual's circumstances

## STAGE 6

Where a diagnosis of a long term condition has been made, we would like to see routinely offered a programme of education and support that enables the person to, as far as is reasonable, manage his or her own condition so that there is minimum impact on their lives.

## STAGE 7

In circumstances where the individual needs help from a health professional, it is made absolutely clear at all stages of their illness who they should contact and how.

## STAGE 8

Where treatment is required this should be wherever possible supported by evidence and fully explained to the individual including the pros and the cons. Where the individual is unsure further opportunities for discussion should be made available

## STAGE 9



We would like to see services react promptly and effectively where a person's health is deteriorating.

#### STAGE 10

Where a person is becoming older and more affected by their long term condition, we would like to see services change seamlessly to meet the individual's needs.

#### STAGE 11

Throughout the process of caring for a patient with long term conditions, opportunities for discussions about planning for the end of life should be offered and a changeable plan in place.

As a person reaches the end of their life we would like to see that, as far as is possible, their needs are met according to their wishes.

#### STAGE 12

Finally, we would like to see an NHS and Social Service that listens to the experiences of people with long term conditions and the clinicians and families who care for them.

A reference group of thirty patients has been empowered by this forum to come forward, contribute to and steer the further development of The LTC Strategy alongside the CCG Board and LTC Steering Group. This is called the **LTC Patient Reference Group**

### **Stakeholder Involvement**

#### **Specialist Care**

To date the CCG have been working in partnership with clinical teams in Robert Jones and Agnes Hunt, Shrewsbury and Telford NHS Trust and the Community Trust. These teams have reviewed the way services are currently provided within individual specialities and have been asked to reflect upon current evidence and whether they believe they are delivering their element of Long Term Conditions Care in line with the evidence and in the way that they would like.

Each team has contributed to that aspect of The Strategy that will deliver effective, integrated specialist care and diagnostics.

#### **The Voluntary Assembly**

The Chair of the voluntary assembly has been closely involved in the development of this strategy. Several events are planned to extend this involvement to members of the assembly as the strategy is further refined. The CEO of Severn Hospice has been closely involved in the end of life and frail and vulnerable elements of the strategy and is a close partner in going forward

## 1.10 Further Development and implementation of the Strategy

The further development of this strategy document, the development of The Shropshire Clinical Commissioning Group Vision, the engagement of hearts and minds across the health economy and the early implementation of The Strategy are proceeding simultaneously. The “Long Term Conditions; Work to Date and Planned” document describes the work that has already been accomplished and makes proposals for the next steps.

It is recommended in that paper that the work moves forward from here in five modules and that the modules are steered by five suitable teams as shown.

- **Module 1** Promotion, prevention and early diagnosis
- CCG and Public Health Partnership
- **Module 2** Community Development
- Community Development Steering Group
- **Module 3** Practice Development and Quality
- Practice Quality and LTC Steering Group
- **Module 4** Care Coordination and Case Management
- Care Coordination and Active Case Management Group\*
- **Module 5** Specialist and Diagnostic Support
- Long Term Conditions Specialist and Diagnostics Support Group.\*
- **Module 6** Optimising Care for Patients with Long Term Conditions in Care Homes
- The End of Life Group\*
- **Module 7** End of Life Care

*\*These groups are operating within the Unscheduled Care governance arrangements*

## 1.11 Conclusion

Since completion of the first draft of this strategy the working groups are established with clear purpose and reporting mechanisms. The implementation of The Strategy is making good progress.

This is detailed in The LTC Strategy Work plan Update September 2012.

Alignment with the Health and Wellbeing Strategy and a clear idea of how disinvestment in acute care can translate into investment in this strategy is becoming increasingly important as the work develops.

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