



East Staffordshire Clinical Commissioning Group

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Improving care for people with long term conditions

Report of patient listening event 7.11.13

Background

East Staffordshire Clinical Commissioning Group (CCG) is currently looking at ways in which services for people with long term conditions and those requiring short interventions of intermediate care [short stays in specialist units to ensure recovery after ill health] can be delivered differently to improve outcomes for patients. This work will enable the CCG to ensure the services it buys from local health providers meet the needs of more people in the local community as their health needs change and demand for services continues to grow. At the same time, the CCG is seeking to establish new standards in service delivery to support more effective monitoring of services and continual improvement in service delivery year-on-year.

The CCG wants to bring care for people with long term conditions and those needing intermediate care closer to home. The aim is to support and empower patients and their carers to have greater personal control in the management of their long term condition, embracing proven new ways of delivering health care support and advice, enabling people to stay at the lowest point of dependency for longer. The CCG has embarked on a series of public engagement activities to find out whether local people generally share this vision for health care. The CCG want to hear the views of service users, carers and others already involved in delivering services about what ‘change for the better’ really means to them when it comes to effective and high quality care. Feedback from these activities and events is being used to develop a strategy for future care and determine services informed by people’s expressed needs and preferences.

The national perspective

Doing things differently is widely acknowledged as the way forward for the health service in relation to the development of services for people with long term conditions. East Staffordshire CCG’s work in this area. is being undertaken against the backdrop of national directives and a wider national public discussion on health care known as the ‘Call to Action’. Driven by NHS England the discussion involves everyone with an interest in NHS healthcare. It sets out to establish the best way forward in tackling the pressures on health services as a result of the growing number of older people who are living longer with a range of long term conditions such as diabetes, heart failure, hypertension and chronic bronchitis (known as COPD). It is estimated that if nothing is done to deliver long term condition services differently we could face a national health service funding gap of £30 billion by 2021-22. The position in terms of the local health population in East Staffordshire is the same as that nationally. So in East Staffordshire, as in the rest of the country, doing nothing to address the issues involved in maintaining effective healthcare for people with long term conditions is not an option.

The Growing Elderly Population in East Staffordshire

Table 1. Population projections for East locality

	2013	2021	Additional people	Percentage increase
40 and over	157,500	169,300	11,800	7%
65 and over	55,300	66,600	11,300	20%

75 and over	23,400	32,200	8,800	37%
All ages	297,800	316,000	18,200	6%

[East Staffordshire and South East Staffordshire and Seisdon CCGs]

Listening event Burton upon Trent 7 November 2013

The public engagement event held at Burton upon Trent library on the evening of 7 November 2013 was part of wider East Staffordshire public engagement activity on the future of long term conditions care.

The event was attended by a broad range of people including service users, community leaders, local councillors, public and patient group representatives from local GP practices, carers, patient advocates, and some people working for providers of services.

The aim of the CCG was to establish what people thought good health care should look like, how service could be improved in line with this vision and how people viewed latest innovations in health care in terms of 'good care and change for the better'. Those who attended the meeting were first given a presentation by CCG commissioning managers which set out the need for change in the way long term conditions services were delivered, the CCG's current thinking on change and some of the opportunities for change the CCG was considering. Everyone then split into five groups to discuss three central questions on what 'change for the better' meant to them. The questions were:

- *What do you have to do on a day to day basis to manage your condition?*
- *What is the 'best' day and what is a 'worst' day in the life of your condition?*
- *What influences your decision to confidently manage your condition on a daily basis?*

A CCG facilitator led discussions around these questions in each group. Each facilitator recorded people's views on services; their concerns; their experiences and their perceptions.

Group sessions: feedback

The three key questions were used as springboards to develop wider thinking on service change and stimulate discussion. Generally group discussion around the questions evolved into a much more broad ranging exploration of change than immediate answers to the questions themselves. The feedback across all groups fell into four main themes:

- **Support and condition management**
- **Peer support and clinical expertise**
- **Availability of quality communications, advice and guidance**
- **Changes to existing services for diabetes, heart failure, pulmonary rehabilitation and cardiac rehabilitation.**

Support and condition management

The overarching response was that an improvement in support and management could be made. People expressed concern about isolation and lack of peer support. They were appreciative of the healthcare provided by their specialist nurses, GPs and others working with them in the community. However, people also expressed concern about a lack of timely support and guidance. Taking tablets was part of the day-to-day routine and the availability of robust advice on managing their medicines and any side effects was highlighted. People described relying on information from informed relatives and friends in the first instance. Health professionals [including pharmacy, GP and A&E] were not always able to provide timely advice. People agreed that telephone support was useful and that support from their clinician gave reassurance and helped to build confidence. One attendee said, “a friendly voice at the end of the phone, who knows what they are talking about” was essential.

Better communication between health professionals was a necessary part of good patient support and condition management. A patient said that she had not been able to access pulmonary rehabilitation until two years after leaving hospital because she had not been made aware that the service existed.

Psychological support was important to help people develop coping strategies to deal with difficult times – stress and anxiety management, meditation and depression courses.

Peer support and availability of clinical expertise

People emphasised the importance of support groups both for people suffering from long term conditions and for their family and carers. These groups offered the opportunity to meet and talk to others with similar experiences which is invaluable as having a long term condition can be very isolating. People felt uncomfortable in receiving support and guidance predominantly from voluntary or peer support or accessing information from the internet. People said they had felt lost and worried after operations and the fact they had a nurse or someone with clinical expertise available at the end of a phone who could be contacted relatively easily, and by text in some cases, provided them with reassurance and support in the early stages of their recovery. One patient who had had a non-malignant brain tumour said no support services existed for that condition and the small brain tumour peer support group which existed in their area was very helpful.

Some patients described their doctors as very helpful and were able to see their doctor quite quickly on request. Others said having consistency in seeing the same GP or nurse was important in improving care.

Patients thought that telehealth could be a useful way of supporting people with long term conditions alongside other clinical services. Patients were concerned that there were too few people to come into home settings to look at need and assess what people wanted. Some people struggled with aftercare following hospital discharge saying basic support was poor.

Availability of quality communications, advice and guidance

People indicated that consistency of service delivery was key to good patient experience. Seeing or dealing with the same GP or nurse was important in improving the nature and standard of care. They described how in some circumstances direct contact with health service professionals failed to provide the information they needed to manage complications with their medication effectively. In other circumstances, they described how they had received medical equipment [blood pressure monitors] without proper instruction and when they had asked their GP surgery for advice, no one knew how the monitors worked.

People talked about sometimes feeling 'stuck' on a particular type of medication without any proper explanation of the drug. Quality of information was central to a good experience of local health care particularly at milestones in a patient's journey such as diagnosis or hospital discharge, and on the correct use of medication.

A key factor in a good patient experience was the ability to get feedback quickly and from someone who you knew and who knew you. "Sometimes what I need is to be able to go to a nurse saying this is what happened yesterday, what do I do today," one patient said. Another said they would like to see a more proactive approach taken by doctors and nurses working with people in their own homes or in the community.

The internet provided opportunities for improving information and guidance but this needed to be backed up with timely clinical expertise. The amount of support available in home settings determined whether patients had good or bad days. People said they had struggled with aftercare following discharge from hospital. In some circumstances aftercare was poor and too little information was provided with prescriptions.

There was concern that systems of care in the community were not robust enough to support more vulnerable people unable to represent themselves or 'fight their own corner'. People said poor social care led to more problems for patients including incontinence, bed sores and other difficulties.

Changes to existing services for diabetes, heart failure, pulmonary rehabilitation and cardiac rehabilitation.

While the event on 7 November had been arranged as a general discussion about shaping new provision for long term condition services for the future, a proportion of the people attending the event had specific concerns about commissioning arrangements for services for diabetes, heart failure, pulmonary rehabilitation and cardiac rehabilitation. East Staffordshire CCG had been looking at the commissioning of these services to ensure they reached as many people needing care as possible. Some of those attending presented a written submission about cardiac rehabilitation services to members of the CCG.

Written submission

Cardiac Rehabilitation Services

- 1) *More access to rehab nurses, perhaps with sessions in GP surgeries to reach more people who have need. More services are needed rather than less, maybe GPs can get help to do this from charities too.*
- 2) *Can GP surgeries perhaps have more services supplied to the communities around them?*

People generally agreed that other services such as telehealth could be beneficial but this needed to be underscored with professional help as and when needed. They spoke of their high regard for specialist nurses who were often on the end of the phone when needed and who offered reassurance in the management of specific conditions.

Conclusions

The Burton Library listening event was very successful in exploring a range of issues in the development of long term conditions services. The feedback from patients and public has already been used to inform commissioning activities in the day-to-day work of the CCG and has informed and directly influenced the commissioning of new contracts for **community diabetes, community heart failure,** cardiac rehabilitation and pulmonary rehabilitation which are due to begin on from 1 April 2014. At the time of the listening event on 7 November, notification had been given to the provider organisation that the existing contracts for these services would not be renewed after 31st March 2014 and services would be recommissioned.

Feedback from this event will be also be used in the development of the CCG's wider long term conditions strategy. It will be used alongside feedback from other engagement work which is currently being held to discuss the need for change and influence the development of long term conditions and intermediate care services for the future.

East Staffordshire CCG would like to thank all those who attended Burton Library on 7 November and welcomes the continued input from our local people to help shape and develop long term conditions services for the future.