

Carers Focus Group Event

Thursday 9 June 2016

Introduction

It is a statutory requirement that the CCG involves patients and the public in service reviews to gain their views and listen to their ideas. This input will influence CCG decision making and help to shape services that people want and need.

Carers have an important part to play in planning healthcare services; they have a unique view of services from a different perspective to the patient. It would be easy to forget the importance of the carer in a patient's care and the CCG need to seek their views when planning redesigned and new services.

West Hampshire Clinical Commissioning Group hosted a carer's focus group event for carers across West Hampshire. We worked with Carers Together, the Princess Royal Trust for Carers, One Community and Young Carers to invite carers from across west Hampshire. The event was attended by 14 people including 8 carers and 6 carers' representatives, 10 returned an evaluation form.

The meeting was chaired by Dr Nick Arney, GP and Clinical Director supported by Dr Katrina Webster, GP and Clinical Director.

The meeting was divided into mental health commissioning, long term conditions, acute commissioning and primary care commissioning

Mental Health Commissioning

Jason Hope, Senior Commissioning Manager for Mental Health and Learning Disabilities

There was some discussion around what local services are available and how to access them. Carers raised concerns around signposting for carers who look after patients with Dementia.

There were issues regarding a lot of management responsibility for the carers as well as the continuity of care particularly for people who do not have carers. A carer also highlighted that if he was not proactive in he's responsibility as a carer, he would not have known about the support services available.

Dr Katrina Webster summarised by saying we need to work on GPs referring to Dementia advisors, which should be used as a resource for signposting. Secondly, secondary care which should be part of diagnostics.

It was agreed that services are available, including a vast amount of localised help it's just a matter of signposting them. For example, signposting well-being centres for adult mental health commissioned jointly with the Hampshire County Council. Organisations like One

Community hold the responsibility of signposting therefore it was recommended that carers contact them if they are looking for support services.

It was agreed that the way information is put out in regards to primary care needs to be reviewed. It was further highlighted that there is a need for directories of services. However directories are often difficult to keep up to date.

A carer highlighted following an initial 6-week physical care package, she received no support as a carer for an individual with Vascular Dementia. No one listened to her concerns as a carer.

A carer highlighted that there is no support to set up sports for young people with learning disabilities and mental health issues. Beverley Meeson stated that there is a national push for personal health budgets which is a great opportunity to use for things that might benefit your health such as sport related causes.

One carer raised issues with CAMHS. He suggested that young people are being put out of placement as quickly as they join. For example, he was offered Cognitive Behavioural Therapy however as soon as he turned 18, the offer was withdrawn.

There were some issues with CAMHS particularly around waiting times which was deemed unacceptable. This was particularly significant to individuals suffering from mental health conditions, waiting could cause them to deteriorate further.

A carer representative highlighted cases of people going private as a result of desperately needing a diagnosis.

It was agreed that there is a need to improve links between CAMHS services and schools and colleges.

A carer worries that that her son who has autism is socially isolated. She said there has been a lack of social support for her son who fears leaving the house and interacting with strangers. The group identified there is a gap that needs to address social health and wellbeing and providing support for individuals with autism who struggle to interact with others.

A representative from Young Carers said the main concern for young carers and their families in terms of mental health is CAMHS and the lack of capacity. We hear time and time again professionals asking how deep they are cutting – and if it isn't that severe the young people are written off until it is. What are the CCG doing to support young carers in terms of their mental health, can they commission more services to hold those who are on waiting lists or don't meet thresholds.

As a project we have not had one referral to young carers for a GP in five years and doctors need to be aware of our services in the same way there is the push for them to refer to dementia services. GPs should be using the REED code for young carers.

Long term conditions

Beverley Meeson, Deputy Director Service development

A carer with long term conditions highlighted the health and wellbeing of carers is also significantly important. As well as life skills for things that must be done on a daily basis for long term conditions such as Diabetes. For instance, there is a lack of insight into dieticians, dietary advice and day to day support. Furthermore, a lot of advice online needs to be

filtered. On the other hand, NHS Choices is a legitimate source of health information, accredited by health professionals.

A carer representative pointed out that young carers are not able to pick up their parents prescriptions on their behalf. Young carers are often overlooked by health care professionals as they assume they do not know very much or they are not recognised as carers. Also, young carers have not been offered an assessment to be identified as carers.

In addition to this, there is an opportunity to identify the carers from the point of view of patients.

Another point that was raised was what happens when the carer gets ill, particularly for a multi-carer.

ACTION: It would be helpful for carers if the next carers' meeting is conducted jointly with Hampshire County Council so that they can understand the connectivity between commissioning services and adult services.

The group agreed that there is a failure of discharge planning and a failure to coordinate services to meet patient needs.

Another carer suggested carers need psychological support for when times get tough. Carers would also appreciate attention to physical health needs. Services need to talk and work with each other for clarification.

Acute Commissioning

Sara Owen, Commissioning Manager, Urgent and Emergency Care

Carers pointed out that it is a regular occurrence that belongings get lost in transition between A&E and AMU and the ward. Moreover, there is no form of a lost property system. Carers shared the concern that they are not informed of the movement of patients in their care or have not given consent for their movement as a carer.

A carer suggested that this should be embedded in contracts when commissioning hospitals as a duty of care. There needs to be more assurance from providers.

ACTION: Commissioners should review service contracts with providers to ensure a duty of care.

Hospitals hold multiple databases of patient records in various departments for multiple reasons. Carers recommend that hospitals hold one database which is consistently updated. Moreover, health professionals should already have notes on patients which should pass on in advance of appointment with patients.

It was pointed out that patients should not have to wait hours for their needs to be met. There are instances where patients might not be seen because they are perceived to display high levels of aggression. However, what might be determined as aggression might actually be high levels of anxiety or agitation.

Primary Care Commissioning

Andrew Gaff, Primary Care Development Manager.

One carer suggested there needs to be standardised levels of services with performance indicators against them. This can be done through contractual obligations.

The group agreed that carers should highlight they are carers to GPs or practice managers so this can be noted and they can get the entitlement to meet their needs as a carer.

One carer raised issues she was having with continuing healthcare. Providers and commissioners should relieve administrative burdens that carers have taken so they can concentrate on caring.

Carers need flexibility when booking GP appointments for themselves so they can make appropriate arrangements for the people they are caring for.

A carer highlighted that often you have to wait months for a routine appointment, particularly if you wish to see the same person each time.

Feedback evaluation

All attendees who completed the evaluation form indicated that the focus group was either good or excellent, with just one person rating it average.

Overall, attendees felt they had a chance to put views forward as well as being listened to and taken seriously. Attendees also found the focus group interesting and useful.

All attendees apart from one said they would be interested in attending further focus groups and would like a copy of the minutes following this meeting.

Some suggestions for further improvement included holding focus groups outside of school hours so that young carers can attend. One attendee suggested she would like more time for discussion and she would also like the agenda to be grouped into issues, not commissioning areas.

One attendee said it would give the group more confidence to see the professionals taking notes of what people were saying.

Wider audience

By using social media we increased the audience for the event. We tweeted about the meeting, others tweeted about the meeting, and retweeted. The potential reach of this social media activity is 19,000 people, taking into account the number of followers each account has. We also have nearly 5000 followers, making a potential audience of more than 24,000 people or organisations.

The report of the meeting was included in our Health Matters stakeholder newsletter, which has a circulation of more than 800 people and organisations. It was included in Team Talk for staff.

Next steps

Commissioning managers will take the feedback to their teams and discuss how they can implement some of the suggestions. The group will be kept informed of developments by email and may be contacted in the future to help with further input.

Recommendation	Actions to address
There should be better signposting for carers to support services	The Hampshire County Council resource Connect to Support is a directory of service which carers can access via the internet, help can be found in local libraries
GPs need to have access to a directory of services, including support services for carers	Hampshire County Council has created Connect to Support, an online signposting service to support and information
GP practices should be aware of carers, who may need flexible appointments to allow them to take time away from caring duties	We are planning education for GPs and practice staff
There is an issue with young people accessing mental health services around the time they transition to adult services, services need to be more joined up	We are working with Child and Adolescent Mental Health Services to improve pathways for young people in transition
There should be better links between CAMHS and schools and colleges	We are working with Barton Peveril College, other local colleges and Winchester University to improve links
There should be more support for those with autism or caring for someone with autism	The Transforming Care Partnership is addressing issues of support for learning disabilities and autism. Autism ambassadors will be working in GP practices.
GPs need to be made more aware of Young Carers services and how they can support young carers. It would be useful if GPs could code their records to highlight young carers.	We are engaging with the Young Carers group with a view to working together to address this issue
The CCG should hold joint carers groups with HCC so services can be more joined up	This is now happening
Carers should be given support for their mental and physical health needs, not just be seen as a carer	We will educate GPs and practice staff and we are looking to enhance our psychological support offer to carers in west Hampshire through a dedicated service such as a carer's helpline
Commissioners should review service contracts to ensure a duty of care to carers as well as patients	Commissioning managers are now asking providers to factor carers into their service specifications when agreeing contracts
Providers and commissioners should relieve administrative burdens for carers so they can concentrate on caring	Care navigators are now in GP surgeries to signpost to support services