

Commissioning for long-term conditions: hearing the voice of and engaging users – a qualitative multiple case study

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Plain English summary

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It is estimated that some 15 million people have a long-term condition (LTC) in England and, while the number of people with LTCs is increasing, there have been concerns for a number of years about whether or not the NHS meets their needs. In order to improve the way that the NHS provides services to people with LTCs, successive governments have developed policies to improve the way that NHS plans and organises services and also to strengthen the involvement of patients and the public in decisions about local services. This project examined these developments in three areas of the country focusing on the experience of people with diabetes, rheumatoid arthritis and neurological conditions. We found few good examples of instances where NHS organisations involved patients and the public, but where there was involvement and developments started by patients, these were beneficial for them. The main problems were that the way people were involved was often tokenistic or good ideas were not followed through. Many initiatives started by patients were short term and not sustained. Recent changes in the NHS also meant that existing relationships between NHS organisations and patients were disrupted and people were frustrated at having to start again to develop new relationships with NHS organisations. Essentially, we found that involvement was more successful in places where it was supported and maintained, and where patients could see that it made a difference. However, the process of involvement can be seen as a delicate circle that might be easily broken, leading to people feeling frustrated and disconnected.

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