

CLAHRCBITE

Brokering Innovation Through Evidence

Co-production in practice with young people in delivering a 'perfect' care pathway for diabetes



This BITE looks at the first phase of an applied health research study to co-produce knowledge about the experiences of children and young people using NHS diabetes services in London, England to achieve optimal self-care of their condition.

This applied health study was funded by the National Institute of Health Research (NIHR) in England and a local clinical commissioning group (CCG) responsible for the organization and delivery of NHS services in a socially deprived, ethnically diverse urban locality.

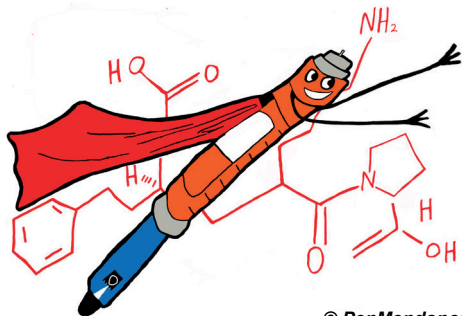
The study was undertaken by the University of East London (UEL) in collaboration with a number of other organizations, including a provider of acute hospital services and a national diabetes charity.

What was the aim of the project?

This study worked together with young patients to transform local health diabetes services.

This BITE considers how young people can help commissioners and providers better understand and address the options and barriers of delivering a 'perfect' care pathway. A mixed research team – in terms of age, ethnicity, faith-identities and backgrounds – worked together over one year to co-produce commissioning guidance. The research findings were intended for use by clinical commissioning groups to support their commissioning of health diabetes services.

Our goal was to work with young people to understand options and barriers they face when given a diagnosis of diabetes, and using NHS services. While our NHS partners can provide the latest medical and academic insights into managing diabetes, young people have first-hand experience - the highs and the lows. Young people can provide inspiration for what would make services better, now and in the future.



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The team worked with an artist to design a logo for their group

What we did

This study is primarily qualitative in orientation and employed an 'action research' approach (Carr and Kemmis, 1986) comprising of a systematic literature review, in-depth interviews and inquiry workshops. This methodology allowed for flexibility in the implementation of the research plan to accommodate the voices of multiple stakeholders. However, achieving the commendable goal of integrating Young Commissioners into the project team was not straightforward. A certain amount of capacity building needed to first take place within the participating organizations.

What we found

Key messages

- In spite of living with diabetes, young patients have been successfully involved in the co-production of knowledge to help enhance and strengthen care pathways and provisions for children and young people living with diabetes in East London.

- The project illustrates how to effectively balance an adult-centric driven agenda to authentically leverage the voices of more 'difficult to engage' or 'vulnerable' groups of children and young people in the commissioning process in order to improve the options, and reduce barriers in delivering an agile care pathway.
- This project is identified as best practice by the NIHR Central Commissioning Facility (CCF) and NHS England Patient and Public Participation team for its novel way of working with young patients and producing tangible and meaningful outcomes/impact in the field of health service design.

What next?

This study has tested the values and principles of joint working by local NHS providers and commissioners with young patients. It has involved young people as trained Young Commissioners. It has validated treatment options such as the offer of virtual appointments and piloted outpatient clinics that together demonstrate how the NHS should provide options within a care pathway that meet the different needs of young patients, who balance their condition with education, work, sports, friends and family dynamics.

In this study, access to age-appropriate, timely health services is just one feature addressed that can be strengthened further by routine intergenerational dialogue with young patients as part of the commissioning cycle, as modelled here.

Find out More

The study has positively impacted policy and practice. In policy, it has helped inform and shape guidance from NICE and the Healthy London Partnership focused on the treatment and management of diabetes in childhood and adolescence. In practice, Dudley Council's Integrated Commissioning Hub have adopted and are piloting the model with the aim of improving how they commission children and youth services.

Sharpe, D., Green, E., Harden, A., Freer, R., Moodambail, A. and Towndrow, S. (2018)

'It's my diabetes': Co-production in practice with young people in delivering a "perfect" care pathway for diabetes. Research for All, 2 (2): 289–303. DOI <https://doi.org/10.18546/R4A.02.2.07>

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Co-designing community-based diabetic services responsive to the needs of children and young people

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