

Young People's access to decision Making - Scoping Paper April 2021

The issue

Access to decision making for children and young people (CYP).

What are CYP experiences of accessing the information they need to enable them to have control over their own health and care? Do the basic things happen to enable this? Are young people aware of the choices they have? What impact may we have in prioritising this?

The Department of Health sets out a quality-criteria for youth friendly services in the 'You're Welcome' document. This links into the NHS long term plan and work being done by the NHS England Youth Forum. The Forum have produced posters and leaflets aimed at CYP to let them know of their rights. In compiling this report it seems that the relevant information is out there but it may not be obvious or easily accessed, especially to CYP. Much of the information is aimed at parents or carers rather than the CYP themselves.

Several other Healthwatch have carried out research into young people's experiences of healthcare but not specifically into decision making. Generally there has been a lot of work done into mental health services for CYP but much less work into services in general. The findings of the mental health work show that taking a more person-centred approach helps CYP feel involved and more engaged with their care, so they are more likely to continue.

The VCS sector are of the opinion that people will struggle with systems regardless. CYP are often caught up in systems and don't feel listened to or are not aware that they have rights. Bad experiences with health and social care services mean that CYP become passive allowing others to take responsibility, care is done to them rather than with them. One area of interest is whether social or financial background has a bearing on how much individuals become involved in their own care.

Providers can struggle to get messages across to CYP. This could be because they are not engaged, or parents/carers take responsibility for information and decision making so the young person does not feel they have any autonomy. But there is evidence that changing the methods of engagement can make a difference, for example not sending letters or asking people to call departments instead developing an App which allows CYP to do everything on their device (but this has obvious implications for the digitally excluded).

Gateshead Council are implementing a new way of communicating with CYP. Letters or communications will be addressed directly to the CYP using understandable language advising them of why something needs to happen rather than just telling them. They also encourage CYP to be fully involved with their care plan and be aware of who else has access to it.

Public Health Gateshead and Newcastle/Gateshead CCG are currently conducting a survey to find out how CYP and professionals feel about information being provided. This is a national survey and will help design future provision. The survey results could influence the format and design of any work undertaken by Healthwatch as we need to ensure we don't duplicate. ([survey link](#))

Pros of undertaking the work

- Healthwatch struggles to engage with young people, this work would help build and cement connections, which will lead to ongoing work.
- Healthwatch would be able to show providers the current feeling and experiences of young people with their services.

Cons of undertaking the work

- As already started Healthwatch has difficulty engaging young people. We may struggle if the research topics or methods are not appropriate.
- It may be difficult to drill down and find specific issues as many people switch off from all engagement after one bad experience.

Our goal

To identify what systems, organisations have in place for allowing and encouraging CYP to be involved. To find out how much young people know, use and feel about these arrangements. To identify areas for improvement.

Desired outcomes

- For providers to understand better the needs of CYP and to identify areas where they have made changes.
- CYP who want to be more involved in the decision-making process to be able to do that.

Type of work required

- An initial exercise should be carried out to identify what information and procedures organisations already have in place. This would take the form of a mapping exercise and a survey.
- Understand the experiences and expectations of CYP. We can use existing VCS connections to access groups
- Healthwatch collate the findings and share this information

Resources available/required

- The Healthwatch Gateshead 'Don't Box me in' survey, September 2020, this project used the 'You're Welcome' document as a starting point. Reports and websites listed at the end of this document
- Healthwatch Champions can be involved in the initial information collation exercise, focus groups and data analysis
- Focus groups to engage with young people. It may be appropriate to incentivise participation, for example a £5 Amazon voucher
- Young people are very used to digital platforms, it would be appropriate to use these to gather information, for example Facebook private groups, video diaries/experiences. Ongoing online forums will be a new and useful way for us to collect feedback and encourage participation, several platforms are available at varying costs.
- Healthwatch staff time will be required to oversee the project.

Who will we collaborate with?

VCS organisations and community groups working with young people both for input and access. Service providers to give us information and feedback.

Demonstrating the impact

The impact will be CYP being aware of what their rights are and being able to access the information required to make decisions. We can demonstrate this by providers giving us examples of changes they have made to information and procedures. CYP can take part in

follow up research, survey, or verbal diaries, to find out how they feel improvements have been made.

Recommendations

This work has the potential to engage a group of people we struggle to engage with. It would also give us an overview of CYP services across Gateshead which can be used for signposting. Work still needs to be done to define the parameters of the work but it is recommended to the committee.

Organisations contacted as part of this scoping process:

Children North East	Jigsaw
North East Youth	The Key
Gateshead Youth Council	Humankind
Young Women's Outreach project	Gateshead Council CYP service
Streetwise	

The following websites/publications have been used when compiling this report:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216350/dh_127632.pdf

<https://www.health.org.uk/improvement-projects/shared-decision-making-in-child-and-adolescent-mental-health-care>

<http://www.youngpeopleshealth.org.uk/wp-content/uploads/2017/03/Young-Peoples-Health-Update-2017-final.pdf>

<https://www.nhs.uk/conditions/consent-to-treatment/children/>

<https://adc.bmj.com/content/83/4/286>

[Under 18? Your healthcare rights - NHS Newcastle Gateshead Clinical Commissioning Group \(newcastlegatesheadccg.nhs.uk\)](http://newcastlegatesheadccg.nhs.uk)

<https://www.rcpch.ac.uk/sites/default/files/RCPCH-involving-cyp-in-health-services-2012.pdf>

https://gatesheadcs.proceduresonline.com/chapters/p_child_consult_part.html

GMC 0-18 years; guidance for all Doctors 2018