

Involving Children & Young People in Health & Care



Healthwatch Leeds is here to help local people get the best out of their local health and care services and to bring that voice to those who plan and deliver services in Leeds.



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Introduction

This report provides a snapshot of children and young people's involvement in health and care services in Leeds. It highlights some local examples of good practice in children and young people's involvement.

Why we did it?

The Leeds Health and Wellbeing Board wanted to understand how children and young people (CYP) are involved individually and collectively in decisions about health and care services they use. A steering group, led by Leeds Beckett University was set up to take this work forward.

Following advice from Leeds City Council Children's Services Voice, Influence and Change Team, CYP were defined as anyone from birth to 25 years.

What we did

Health Together at Leeds Beckett University did a brief scoping of published literature and local and national policy. A questionnaire was developed and sent out via Healthwatch Leeds to local health and care organisations about their experience of involving CYP.

As all Leeds providers did not complete the survey, telephone interviews were scheduled as a follow up. In total, there were 18 responses from services in Leeds.

The Leeds City Council Voice, Influence and Change team contributed by talking to five CYP groups in Leeds that have broadly a health and/or care focus. The focus of the conversations were to identify how the CYP became involved in the group or activity, what works, gaps and best practice examples.

Headline findings from the survey and conversations are described in this report.



What we learned

Survey respondents indicated that involving CYP in decisions about their health and care improves services; for CYP as consumers of care, and for clinicians as service providers.

There was a strong view that involvement was key to putting CYP at the centre of their care. This is because involving CYP in their health and wellbeing can help “keep the services they receive relevant”, “more applicable” and “better tailored to children’s needs”.

Involved in what?

In Leeds, CYP were involved a range of decisions about health and care, including:

- ideas for changing existing policy or services
- commenting on proposed new policies and services
- delivering services
- monitoring or evaluating services or policies
- promotion and campaigning
- staff recruitment

Most examples were of CYP being directly involved in decisions about their own health and care.

What works and what doesn't?

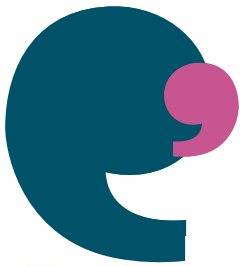
Good examples of involvement were:

- consultations with nurses,
- student led sessions in schools
- being involved in a Youth Forum.

Some staff spoke negatively about online surveys. Respondents stated that even with incentives they can fail to engage CYP particularly those described as “hard to reach”. Organisation have been more successful when they have completed surveys with young people face to face or worked with partner organisations to do so.

Other problems around engagement included:

- not all CYP want to engage
- some CYP can be obstructive during an involvement process (i.e. asking inappropriate questions, defacing questionnaires)



Respondents recognised that CYP need appropriate and accessible engagement. They spoke of the strengths of involving CYP through digital media, including websites, video, social media, virtual worlds, online-gaming and ‘apps’.

“I firmly believe if we used technology better, we could capture a much wider audience with children and young people and their families”.



Examples of Good Practice

YouthWatch Leeds

Healthwatch Leeds has been running YouthWatch Leeds since 2014. YouthWatch Leeds is for 14 to 25 year olds and currently has 20 active members. The aims of the group are to:

- listen to and represent the views of children and youth people make health and social care services friendly and accessible to young people
- use unique and creative ways to engage and involvement youth people
- inform young people about health and social care services available.

What they do

When YouthWatch Leeds launched young people were instrumental in choosing the name ‘YouthWatch’ and developed their own logo and branding. They have created videos about their work to promote what they do to other young people.

The group have been involved in



the creation of digital badges for young people, in particular, the ‘NHS Inspector, Your Views’ badge which is linked up to local HealthWatch to encourage young people to share their views.

Working with the Healthwatch Leeds Board they have helped to ensure it is more young person friendly, and that young people feel more able to participate and have their say during board meetings.

The young people planned and hosted a YouthWatch Showcase Evening to showcase their work and develop potential partnership working with other health organisations.

Members of the group undertook Facilitation Skills training, resulting in 18 young people being trained as young facilitators. All of YouthWatch Leeds’ reports and meeting notes are published online and promoted via social media (facebook, twitter and Instagram).

Why it works

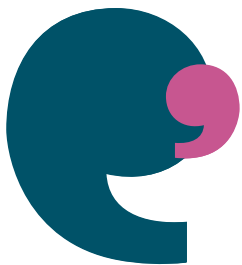
YouthWatch Leeds were involved in producing a report about children and young people’s mental health services.

This report ‘strongly influenced’ the recommendations of the 2015 review of children and young people’s emotional wellbeing and mental health services in Leeds, which was carried out by commissioners.

YouthWatch Leeds directly influenced the design of a school nurse led school health drop in service,. This is a great achievement of the group.

An important aspect of YouthWatch Leeds is the difference it makes to the young people involved, whether it is developing confidence, helping with job applications etc.

The presence of YouthWatch Leeds continually challenges Healthwatch Leeds as an organisation to reflect on how it can be more young people friendly.



A young person's perspective

14 young people shared their experiences of being involved in YouthWatch Leeds. For some young people this was their start of their journey with YouthWatch whilst others have been attending for 18 months.

YouthWatch Leeds is advertised as a volunteering opportunity for young people on different websites such as V-Involve and Dolt.org. Some young people heard about the group via social media and picking up a flyer from an event.

“YouthWatch Leeds provides you with lots of opportunities to get involved, you can give as little or as much time as you like, however after 30 hours of volunteering you are able to use the staff as references which is great for your CV!”

“The group provides us with the chance to have our opinions heard and increase our knowledge and skills.”

“We have had so many opportunities to get involved in, our favourites have been creating short films to promote services (Doctors, Talk to me), learning new skills in the office, attending events to promote YouthWatch Leeds and taking part in radio interviews!”

“The skills you learn from being part of YouthWatch are transferrable which is great for job applications.”

Since joining the group young people feel they have gained confidence and improved skills such as public speaking, interview techniques, team work, evaluation, organization skills and problem solving.

“workers make it really easy to participate”



Challenges faced

The main challenges for YouthWatch Leeds is the diversity of the young people in the group. Healthwatch Leeds continues to face challenges with engaging with young men, young people with physical disabilities and those from hard to reach communities.

More recently the age range was lowered from 16 to 14 years old, however at present there has been no interest from younger volunteers.

Kicking on

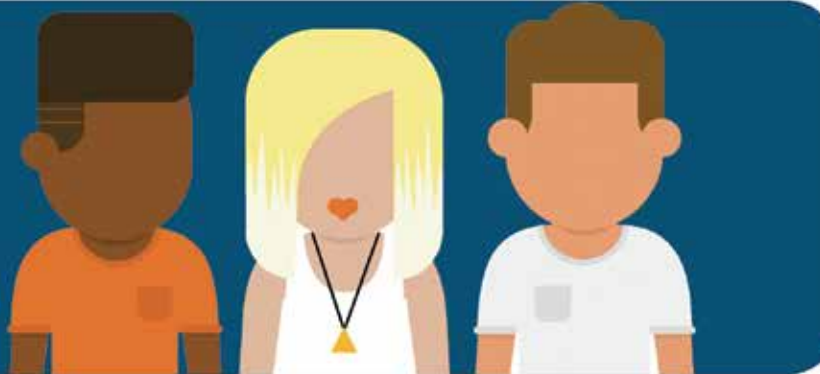
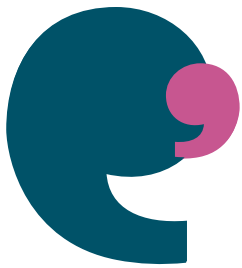
YouthWatch Leeds recently worked in partnership with a local learning disability organisations Paperworks and Fixers and continue to publicise the 'Doctors, Talk to Me' film they have developed.

They are working with Common Room and Clinical Commissioning Groups to consult with young people, parents / carers and professionals on their views of mental health services in Leeds with the aim to see if things

have improved as a result of their recommendations.

YouthWatch Leeds members are moving towards co-facilitating their meetings with staff, so they have more control and ownership of the meetings.





Mindmate Young People's Panel

The MindMate young people's panel has been running since January 2016 and currently has 9 active members.

"I have been involved in MindMate for nearly two years, I first learnt about MindMate from a worker at YoungMinds. It sounded like the ideal opportunity for me as I had already been volunteering for 8 years and this would give me something new to be involved in where I could use my passion and strive to improve society for other young people."

"MindMate has given me the opportunity to voice my opinions about services, and also share the opinions of other young people who don't have the confidence to do so."

"The group has increased my knowledge and given me skills to enable me to speak confidently to other young people and professionals."

"I would recommend everyone to

get involved with MindMate as you can meet new people, gain confidence and learn about your strengths and weaknesses"

Why it works

The MindMate website is primarily aimed at young people, and the group provides the function to ensure the content is endorsed by young people for young people.

Challenges faced

Young people who are on the panel may find the approval process a bit dry, however there is scope for the group to evolve over time and the activities of the group are likely to become more varied. For example, a workshop is planned for April to test and improve the new games on the site.

Kicking on

It is hoped there will be other opportunities for the group to be more involved with developing new content for MindMate, potentially working with the design team on new developments such as interactive tools



Leeds Hospitals Youth Forum

The Leeds Hospitals Youth Forum was formed in October 2014 and is aimed at 12 to 20 year olds. There are currently 15 active members, with an additional 25 virtual members. The young people are from a variety of backgrounds; and include young people who are being/have been treated in one of the Leeds Teaching Hospitals Trust hospitals, as well as young people who have never been in hospital.

Since forming they have developed terms of reference for the group, a set of ground rules as well as a constitution, and elected two chairs. The aims of the group are to:

- be the voice for children and young people in their healthcare and surroundings
- to raise the profile of young people in a positive way.

The group promotes and encourages activities, events and opportunities for young people in Leeds, and encourages and initiates communication between young people and the Senior Management teams in the Trust.

What they do

The forum has set up a facebook page to communicate with young people, as well as via email and text. They have consulted with young people and fed back to the hospital on the three things that need to change in hospitals for young people (food, Wi-Fi and safe space).

The group have been involved in:

- Influencing the Children's menu, and assisted in creating a separate young people's menu with a take-away themed evening menu once a month
- Arranged for patients who are in hospital for a long time to have Wi-Fi
- After robust lobbying, a teenage space has been identified and funding has been found to furnish it
- Influenced how the new Leeds Teaching Hospital Trust website looks and rebranding of the Children's Hospital
- Presented at the Children's Hospital Conference, Leeds Hospital Conference, NHS

England patient engagement event and the Children's Research event

- Attended and opened a day for professionals who work with young people
- Held a Facilitation training day for members of the Youth Forum and YouthWatch Leeds (Part of Healthwatch Leeds)
- NHS digital badges are being piloted with the youth forum before being rolled out to the children's hospital

Why it works

The Youth Forum were awarded 'Highly Commended' in the Leeds Teaching Hospitals Trust Shine Awards 2015.

Many professionals now seek the views of the Leeds Hospitals Youth Forum when making decisions around changes to the service.

"I have been involved in the Leeds Hospital Youth Forum for over a year now, and have recently been elected as Chair which is a great achievement."



"I was told about the forum by a play specialist on the children's wards as I was in the middle of my transition and it was something I could get involved in to help improve other young people's experiences whilst in hospital by sharing my own experience."

"Being part of the forum has increased my confidence and enabled me to help other young people have the confidence to voice their opinion."

"As a group we have improved the food provided on the children's ward and also secure a safe room within the hospital for young people as well as somewhere for the forum to meet."

"I would advise anyone to join, we have fun and you get to see parts of the hospitals you wouldn't normally see"

Challenges faced

Travel for some young people is difficult although there is a small fund to pay expenses when needed.



Funding was also a challenge but they have now secured some funds to provide refreshments and travel.

Kicking on

The Leeds Hospital Youth Forum will continue to grow, advise, innovate and raise their profile as the voice of young people. They need to standardise the way in which they are consulted by professionals.

The forum have secured a teenage space and are now looking at funding for Youth Workers to help to run it. It is anticipated that these Youth Workers will report to the Youth Forum.

HYPE

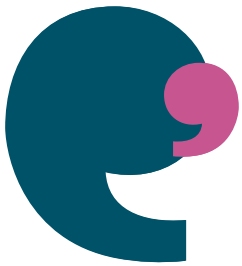
The Market Place in Leeds have been running the HYPE (helping young people through experience) group for 13 to 25 year olds for the past 10 years. There are currently 11 active members. The group meets regularly, and their aim is to help shape the delivery of the services at the Market Place and other organisations, by giving their views on different issues that affect young people.

Young people involved in the HYPE group have been involved for as little as 6 months and as long as 5 years. Young people who have accessed one of the services at the Market Place are informed by staff about the group and are able to join, after their involvement with the service.

HYPE provides young people with the opportunity to learn new skills and build on their confidence. The group provides a safe place where vulnerable young people can meet socially and be involved in activities they would not normally get an opportunity to be part of.

What they do

Young people from the HYPE group have



been involved in decision making and shaping services for The Market Place. They have designed the look and feel of the place from choosing décor to designing young people friendly counselling rooms. They have also helped shape how the staff work with young people by running inductions for staff, and interviewing all paid and volunteer staff.

Young people have been involved in numerous consultation and workshops with the Police and Crime Commissioner, Mindmate, Leeds Safeguarding board, Leeds sexual health, Leeds City Council, NHS, MP's and Leeds Mind.

Young people facilitated a workshop with social work students at Bradford College about their approach to working with young people. They helped to and influence how social workers can be more effective in working with many of the most vulnerable children and young people in West Yorkshire. They created a 'stay safe' pack in December to make young people more aware of the dangers and

risks during winter, especially over Christmas when services are more limited and people are often left isolated. These included top 'stay safe' tips and contacts of available services in Leeds.

Young people worked with a coalition of organisations who are creating a 'single point of access' (SPA) for young people seeking help and support. HYPE helped design the SPA leaflet and looked at ways to effectively communicate this new service with young people across Leeds.

Why it works

Young people have helped to create a more young people friendly space, service and staff team at The Market Place making the service more relevant and accessible for young people across Leeds.

HYPE members have also given their time to getting the voices of young people heard about the issues that affect them most; particularly raising awareness about mental health and making



sure it is high on the agenda of children's, youth and health services. Members of the group have also developed confidence, learnt social skills and built supportive peer relationships.

"The staff told us about the group and it sounded like a really good place to meet new people, experience new things, gets you out of the house and gives you the opportunity to help other people."

"The HYPE group have had so many opportunities to get involved in; some of these include talking at conferences about mental health, being part of interviews for the Volunteer Youth Worker posts, as part of the takeover challenge we were given the opportunity to be Youth Workers for the day and we attended a big awards ceremony in London for an award we had been nominated for" (came 3rd out of 600 nominations!)

"The group has given me confidence in delivering presentation and is a great place to meet new people and make friends for life and the staff are great."

"It saved me - made me more mature, helped me handle my temper and different situations"

"It's really nice to have a separate place and new set of friends and so all the things we do."

Challenges faced

The uncertainty of funding has made long term planning difficult and young people have found holding on to those unknowns hard to cope with at times. The nature of the group also means young people join and leave regularly which has been both a challenge and an opportunity.

Kicking on

The HYPE group plans to continue in its current format and there are plans to interview new potential volunteers, hold consultations with Mindmate and induct new counselling staff.



CAMHS

CAMHS have been working with service users for a number of years to improve the quality of service provision. Children and young people have been offered the opportunity to be involved in short term task and finish groups. In the last 12 months over 150 children and young people have been involved in projects and consultations delivered by CAMHS.

What they do

CAMHS offer opportunities to children and young people who are primarily service users. Young people have been involved in recruitment panels for new staff, creating a patient held record app, consulted on issues relating to CAMHS, improving the webpage, producing documents / films to promote the work of CAMHS and reviewing different processes across the service.

Why it works

Young people are given the opportunity to get involved in short term projects that they find appealing to them. This ensures

commitment to the project and the young people can see a start and finish. The voice of young people has been held central to the changes CAMHS have made over the last 12 months.

Creating an App

“I was given a flyer about joining a focus group in CAMHS to design an app, the flyer made the focus groups sound really fun and gave me a clear way of giving my opinions.”

“I was part of the group for 6 months, we meet on a regular basis to help design the new app.”

“Being part of the CAMHS focus group for this project has improved my ICT skills, given me more confidence in larger groups and best of all I made new friends that I still stay in touch with.”

Film Making

“The director at the youth theatre I attended asked me



if I would like to be involved in making films for CAMHS, I jumped at the chance as an amateur actor this would be my first experience acting in front on the camera, although this was daunting at the time the lessons I learnt were unquestionable.

“My favourite part of getting involved in the film making project has to be the friends I have met. Meeting and getting to know so many people who have and are still battling with their mental health was incredibly eye opening.”

“Being part of this group I learnt all sorts of information about the film making industry but also about the structure of the NHS’ mental health support it also opened up the possibility of paediatric psychology to me because I am now hoping to go to medical school to become a paediatrician, but mental health work wasn’t something I’d ever really considered before.”

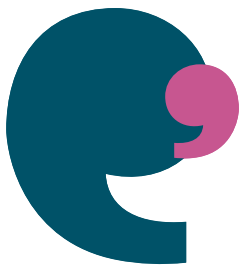
Challenges faced

Going forward the main thing that the service would like to improve is the provisions of the ‘you said, we did’ feedback to our service users as whole. This is important to the service because they want all the children and young people they work with to know that their opinions can and will make a difference. While the short task and finish group approach works very well, it does mean those involved often just see a snapshot of what has been achieved.

Kicking on

The CAMHS service plans to continue working with children and young people on a number of projects these include:

- continued development of CO-OP a patient held record app.
- developing a new CAMHS microsite, and recruitment of staff.
- The recruitment of a Participation Worker develops the role of service users in service development and improvement.



Leeds and York Partnership Foundation Trust (LYPFT)

There is a 16 bed unit for patients between 12 and 18 years old, although it is unusual to have children at the younger end of this range.

Patients come from all over England but primarily Yorkshire and Humber with a significant proportion from Leeds. There is a similar service in Leeds, Littlewood House Hall which is provided by Leeds Community Health Care Trust (LCH). Recently LCH have had significant problems with their building which has meant that LYPFT has been taking more young people from across Leeds.

What they do.

They have regular community meetings with the young. They bring issues and suggestions such as:
Going on trips
Issues with cleanliness of rooms
Other areas of discussion may be around concerns of wellbeing or vulnerability.

Why it works

The unit has agreed that 2 young people could attend part of the Clinical Governance meetings and bring any issues for discussion there. The young people raise issues such as anxiousness during the night, some were worried about temporary staff -they would like to know in advance which staff were coming in.

The unit has started a young people's council to look at specific issues facing young people in the unit. For example, use of smart phones, internet access and social media. The discussions are fed back to the Clinical Governance meetings.

Challenges faced

The unit had wanted to involve young people in the interviewing of new staff but due to the changes to how interviews are carried out by the Trust this has now stopped.



Kicking on

They would like to include young people in the multi-disciplinary meetings that happen twice a week.

Moving Forward in Leeds

Involving CYP in decisions about health and care is well established in Leeds; in policies and statements towards the 'child friendly city' goal, and amongst health and care practitioners.

CYP are more likely to be involved in personal decisions about their own healthcare rather than strategic decisions about health and wellbeing services.

Challenges with both are numerous, including practical and psychological barriers experienced by health professionals, policy makers, CYP themselves and their families. 'Seldom heard groups' remain at risk of being ignored without specific interventions.

Emerging digital technologies, as common platforms in the lives of

many CYP, offer new opportunities to creatively involve CYP in decisions about, and control over their health and wellbeing.



This report was created by Mark Gamsu, Dex Hannon, Harriet Wright, Hannah Lamplugh and Kayleigh Thompson. Many thanks to the children and young people and organisations that shared their views or fed back to create it.



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