

PARTICIPATION REPORT

NHS Sussex

*A collection of children and young people's participation activity
to address Sussex-wide mental health and emotional wellbeing
improvements*



NHS SUSSEX YOUTH CONSULTANTS OUR MESSAGE

"Involving us is key to getting things right!"





We are a group of mental health champions from across Sussex who have come together to help improve children and young people's mental health and emotional wellbeing (MHEW) support.

It is so important to include the experiences and expertise of children and young people to ensure health and care services meet their needs and save resources.

In just under a year, we have reached a diverse number of children and young people to better understand their views and experiences of MHEW services in Sussex through creative engagement, and have seen how this influences change and our role in supporting this.

It has been so rewarding to share children and young peoples feedback with service leads, clinicians and commissioners, to help them better understand children and young peoples priorities, and spark action to improve access MHEW support.

For us, this has only been possible by having a dedicated staff member supporting us, and decision-makers investing time and resource in spaces that respect and validate children and young people's opinions. It allows us to feel brave whilst sharing what can be very difficult lived experiences.

Involving children and young people in improving the Integrated Care System is an opportunity to build a better future. Involving young people is key to getting things right the first time and ensuring that strategies and services meet the needs of local young people.

This collection of Sussex-wide participation activity to address mental health and emotional wellbeing improvements aims to help the system see the different approaches taken and showcase some of the work we and other young people have been involved in, with co-designed recommendations for the future .



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Important Information

Register to the NHS Sussex Insight Bank to access resources that
are hyperlinked from this document.

<https://int.sussex.ics.nhs.uk/register>

Foundations for our Future

Driving real improvement in mental health and wellbeing services
for children and young people across Sussex

The review

NHS Sussex and the local authorities commissioned an independent review, in partnership with the voluntary and community sector, to better understand what works well, and what could be improved on, in order to provide the right mental health and emotional wellbeing care and support to children and young people and their families.

Review findings and recommendations


The review findings gave a greater understanding of what needs to change, and enabled organisations to work together to take bold and ambitious action to make change happen.

20 recommendations were developed from the findings as the priority areas of focus to take forward. Involving children and young people in the approach to and delivery of these recommendations has helped to ensure that their voice has influenced at an individual, operational and strategic level.

Call for involvement

Central to the review findings was the call to better involve children and young people and parents and carers in how services are designed, planned, delivered and evaluated, from the outset.

Co-production is recognised as the best way to achieve success and a key enabler to improve services, health and wellbeing outcomes and reduce health inequalities across the 'system'; *this includes the NHS, local authorities, providers, voluntary and community sector, and our people and communities.*



Foundations for our
Future in the words of
young people

[Click here](#)

Recommendation 17 called for a survey to better understand how flexible the current MHEW services are; specifically when they would like to attend routine mental and emotional wellbeing services, and where they would like to be seen.

Young people co-designed a survey with system leads and parents and carers. The findings show us that children and young people want to be attend appointments at 'school, college or university', where as parents and carers chose 'at home'.

Both parents and carers and young people favoured appointments between 3pm and 9pm, with Monday's, Wednesday's, Friday's and Saturdays as the most favoured days.

Contact the [Public Involvement Team](#) for full report.

Recommendation 19 called for children and young people to have a greater say in how resources are spent, by a proportion of financial resources delegated to them to prioritise for their own communities and neighbourhoods.

It was not possible to provide dedicated budget to young people to allocate to projects / services of their choice given the current financial challenge. However, involvement in wider Foundations for our Future programme decision-making has included young people and families.

Recommendation 20 called for the scoping of a children and young people's panel to ensure youth voice influenced the FfoF programme implementation.

This recommendation was debated at a youth engagement session where it was felt that given the programme was time limited, and that the delivery team was small, there were ample opportunities to work in partnership in the local areas and engage with young people through planned activity with partners supported by NHS Youth Consultant expertise.

Beyond the FfoF programme, a new framework to embed children and young people voice is to be developed in collaboration with all stakeholders.

Rights, legislation and guidance

Our population - children and young people

0-25 year olds make up 20-25 % of the population in Sussex. It is vital that they have the space to express themselves, feel actively involved, are listened to and can influence the decisions that affect their health and care.

International rights

The above is endorsed by the United Nations Convention on the Rights of the Child (UNCRC) that states their right to influence decisions that affect them (article 12) and their right to the best healthcare possible (article 24).

National legislation and the duty of Integrated Care Boards

Nationally, the Health and Care Act (2021) states that health and care organisations must work together to make improvements. To make this happen Integrated Care Boards (ICBs) were established with new responsibilities including a duty to consult with people and communities that use services ICB's commission.

The Sussex-wide 'Working with People and Communities Strategy' aligns to the national guidance and provides a framework for how ICS' are to work with and involve people and communities.

The strategic approach aims to...

1. Drive a system shaped by insight from our people and communities
2. Utilise community strengths and skills, and remove barriers to empowerment
3. Use insight capture and involvement to address health inequalities

A framework for involving children and young people's voice utilising the above is being developed with stakeholders.



**NHS Youth
Consultants leading
the Thrive
Framework
discussions**



System strategies embedding voice

Integrated Care Systems are required to build new and existing partnerships to improve services, health and care outcomes, and reduce health inequalities.

The three Sussex-wide children and young people's strategies below aim to guide us to reach our combined aims and highlight participation, and specifically co-production, as key enablers to achieving this.

Our Sussex Mental Health and Emotional Wellbeing Strategy, states that we will...

"Ensure shared decision-making with the voice of children, young people and families being central. This includes co-production and co-design with children, young people and families at the heart of all we do".

Our 'Working with People and Communities Strategy' supports the public involvement activity for each strategy

Our Learning Difficulties and Autism Strategy states that we will...

"Use the talent, knowledge, and skills of experts by experience to design better services"

...as one of the three high level objectives to achieve success.

Our Physical Health Strategy states that we will deliver accessible services that offer consistent, compassionate and high-quality care by...

"embedding children and young people voice and empowering communities".

This report outlines some of the participation work with children and young people between 2022-2023, through the Foundations for our Future programme and Mental Health Collaborative with recommendations for next steps.

All three strategies are accountable to the Sussex-wide Children's Board and other local governance structures

What is participation?

Participation is the umbrella term for any activity where the public are involved in the decisions that affect them. The term is interchangeable and can often be described as "involvement" and "engagement".

Useful models to help us embed participation

There are many models that could be used based on who you are engaging with and the purpose of the engagement.

However, participation is often explained by using a ladder of participation, where children and young people are involved in equal decision-making with adults from the very start of a project at the 'top' - co-production. The bottom of the ladder represents manipulation, tokenism which should be avoided.

Lundy's model (2008) is a way of explaining Article 12 and is what's called a rights-based model of participation. The model breaks Article 12 down into four elements which follow each other in order to deliver successful participation activities.

Space: Children must be given safe, inclusive opportunities to form and express their view.

Voice: Children must be facilitated to express their view.

Influence: The view must be acted upon, as appropriate.

Audience: The view must be listened to.

Levels of participation

Participation can be visualised and organised at an individual, service/operational or strategic level within organisations.

For example:

- **Individual** - meaningful involvement in a support plan
- **Service/operational** - delivering training, interviewing professionals, telling us how our services do or don't work
- **Strategic** – meeting with and influencing elected members, contributing to commissioning activities, having a seat on partnership boards

Commitment to participation

In addition to the statutory duty placed on Integrated Care Boards to deliver public involvement, if children and young people's participation is to be effective, meaningful and long-lasting, it must be an ongoing whole system approach, resourced well.

A culture of participation with all staff, policy and practice is the ambition, as opposed to one-off isolated events or led by one person, team or organisation.

Involving children and young people supports their citizenship, social inclusion and personal development, in addition to the many benefits to organisations.

Benefits for the Integrated Care System (ICS)...

Creates services that are better at meeting children and young people's needs and aspirations

Contributes to building more effective, relevant and long-lasting services

Reduces risks of legal challenges and improves safety, experience and performance

Addresses health inequalities by understanding communities' needs and developing solutions

Improves decisions about service changes and how money is spent

Challenges us to be more inclusive

Strengthens accountability and being clear about what can and cannot be achieved



Click [here](#) to read the full report from Stephen Lightfoot's, NHS Sussex ICB Chair, consultation

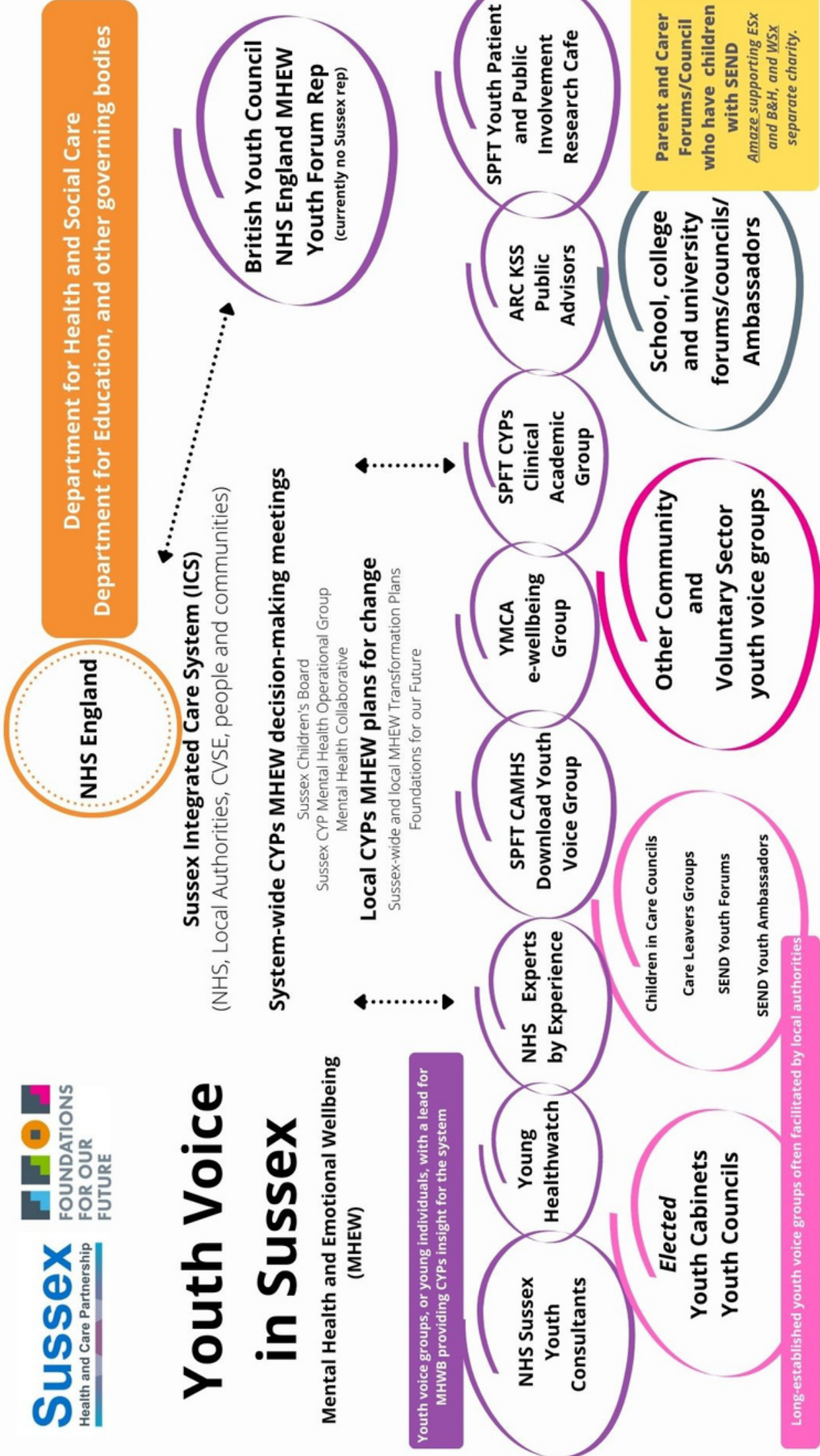
What youth voice looks like in Sussex



Youth Voice in Sussex

Mental Health and Emotional Wellbeing (MHEW)

Youth voice groups, or young individuals, with a lead for MHEWB providing CYPs insight for the system



Children and young people's participation activity at a glance

Strategic level

Participation level

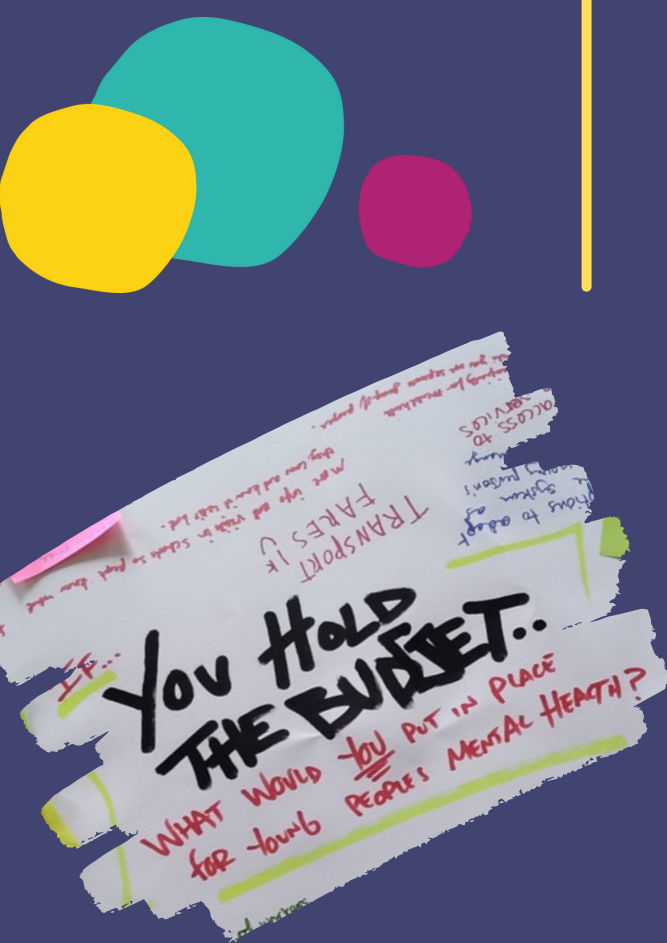
- Decisions relate to long-term planning.
- The activity includes meaningful roles in priority setting, monitoring and designing services.
- Outcomes influence policy and practice.

Activity - Supported by a Participation Lead

Team of NHS Youth Consultants recruited and supported by a Participation Lead to co-design Integrated Care System (ICS) participation activity

- Under 25 Co-chair supported to be involved in the Foundations for our Future (FfoF) Oversight Board meeting
- NHS Youth Consultants and local young people recruited to influence the Sussex-wide FfoF and placed-based meetings - local Partnership Groups and sub-groups
- Young people from voluntary and community sector organisations commissioned to:
 - develop recommendations on FfoF strategy language, content, and delivery (Concordia)
 - be involved in an Eating Difficulties (ED) Steering Group to influence the all-age ED pathway development (Priority 1-54)
 - inform the NHS Sussex and health and care partnership MHEW priorities

- NHS Youth Consultants influenced the FfoF report 'strategy on a page' and 'vision statement'
- Concordia's young people informed the FfoF report design concepts
- NHS Youth Consultants contributed to the FfoF launch activity - film, radio podcasts, Facebook takeover



Children and young people's participation activity at a glance

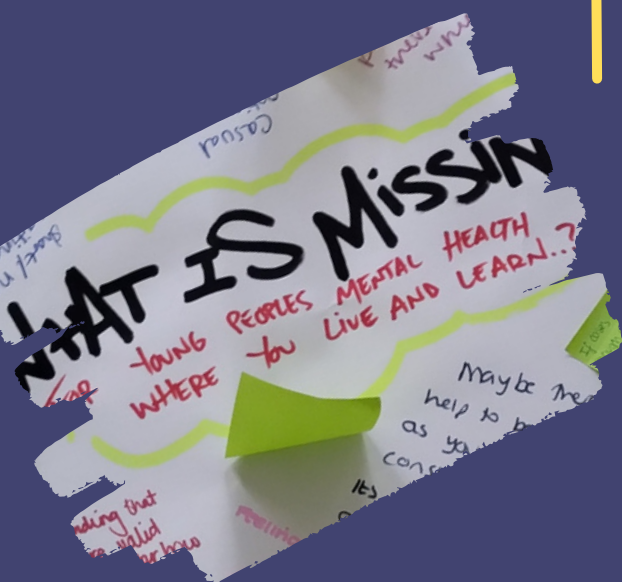
Service / operational level

Participation level

- Decisions relate to planning, delivery and evaluation.
- The activity aims to improve the quality of service provision.
- Outcomes affect the individual and other service users.

Activity - Supported by a Participation Lead

- Children and Young People's Clinical Academic Group co-designed the Single Point of Access/Advice core principles terminology
- NHS Youth Consultants co-designed engagement to support the development of the Single Point of Access/Advice in Brighton and Hove
- NHS Youth Consultants and system partners co-produced the Sussex-wide 'Accessibility of Routine Mental Health and Emotional Wellbeing Services' survey
- NHS Youth Consultants co-produced and delivered a series of eight additionally resourced engagement workshops in East Sussex, in Partnership with Priority 1-54
- YMCA DLG co-designed stage one of the redesign of an outcomes framework for children and young people's mental health services (led by Jo Robertson, MH Transformation Team)
- Young people consulted to inform the Sussex-wide Physical Health Strategy
-



Children and young people's participation activity at a glance

Individual level

Participation level

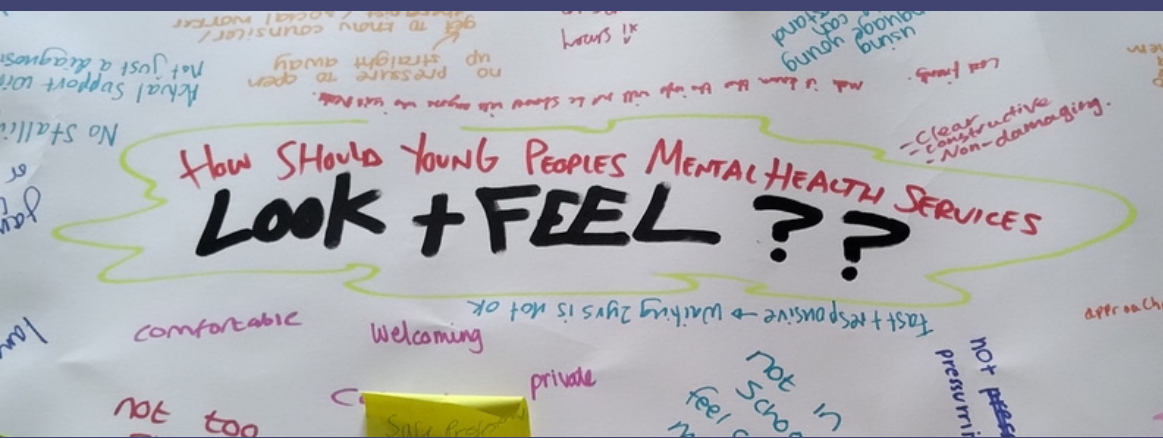
- Decisions relate directly to the participants' own lives.
- Decisions are made about day to day activities.
- Outcomes primarily impact the individual.

Activity

- NHS Sussex Youth Consultant personal and skills development
- YMCA DLG co-designed resources to support children and young people's concerns around privacy and confidentiality for online appointments
- YMCA DLG produced a film to support young people's mental health and emotional wellbeing when transitioning from higher education into the workplace
- Two care experienced young people recruited by NHS Sussex, Safeguarding Team through Kickstart funding to work with ICB and partners. The young people influenced all levels of participation, as highlighted throughout the report below, however on an individual level the young people redesigned the pre-birth assessment policy for care leavers



Click [here](#) to view full report



**MEN'S
EATING
ISSUES
MATTER**



That one thing...
Funding support for recreational activities / groups.
Gym memberships on prescription.
Personal Trainers for Mental Health

NHS Youth Consultants

The need

The Foundations for our Future review called for children and young people to be embedded with the programme and involved in the co-production of service design and delivery, supported by a specialist children and young people's participation lead.

Focus of work

A group of NHS Youth Consultants were recruited with lived experience and/or specialised in youth voice participation and were supported to lead Sussex-wide activity to progress the aims of the programme and local transformation plans.

Their impact

Improved governance by

- co-chairing and influencing strategic FfoF meetings that manage the delivery of the Sussex-wide plans and recommendations of the FfoF review
- influencing the local MHEW partnership groups, their local transformation plans and engagement

Supported greater social cohesion and partnership working by

- co-designing inclusive creative workshops to consult with local authority and voluntary and community sector youth voice groups to support the development of children and young people's mental health and emotional wellbeing priorities for Sussex
- co-designing and delivering a conversation with the NHS Sussex Chair and Sussex-wide youth voice groups about 'what matters to them in health and care.' to inform the ongoing work across the health and care partnership

Improved quality of services, projects and programmes by

- co-designing a survey to understand the accessibility and flexibility of routine MHEW services to inform commissioners and heads of service
- redesigning the language used in the FfoF strategy and vision statement
- supported the business case for a Single Point of Access – a single route so that children, young people, families, carers and staff can be directed to the right service
- influencing the development of key clinical mental health and emotional wellbeing pathways and priorities - social prescribing, Information Advice and Guidance (IAG), Comms, whole school approach, workforce

Supported capacity building and learning by

- co-designing and delivering a leadership mentoring programme to support the aim to embed a culture of CYPs participation

My experience

"Co-chairing the Foundations for our Future (FfoF) Oversight Board was incredibly positive and I feel like I've both learnt a lot about the health and care system and also had opportunities to influence and change the system for the better.

Working with senior officers has enabled me to have strategic conversations on key issues within children's health, care and education.

I have been involved in mentoring leadership to better understand the importance of participation, explored ways to embed it, and advised on engagement activity locally.

Supporting FfoF has informed my East Sussex County Council role where I continue to apply creative approaches to champion youth voice and collaborate with young people to improve services.

A key challenge has been that change takes time and it can be viewed as tricky to embed participation when it is new to lots of people, resources are limited and system pressures take priority."

Ed Peasgood, Participation Consultant



Long-term involvement of children and young people as Youth Consultants: Impacts for the Integrated Care System...

strengthened system workforce by youth consultants representing participation across the three local areas with their acquired system knowledge

kept young people at the centre of discussions

greater awareness of participation helped to widen the ambition to create a culture of participation across the system

system received perspectives, and ideas through a young person's lens who are confident to challenge

able to swiftly co-design and test out system priorities with young people in the local areas that use services

better engagement with their peers by embedding youth consultants with system knowledge in the leadership of events and workshops

Concordia Youth Action

Influencing the Sussex-wide strategy

The need

Co-production with children and young people, and their families, has been central to Foundations for our Future (FfoF) programme and highlighted as a key enabler.

To ensure lived experience helped to shape the Sussex-wide Mental Health and Emotional Wellbeing Strategy development, international charity Concordia brought together service users and clinical staff in a series of workshops.

Focus of work

The group met three times online to :

1. Identify from the strategy what should be drawn out, highlighted what was missing
2. Develop recommendations on strategy delivery

Generate recommendations on how to develop the most effective written product

Strategy Delivery

- Written product should always be available in audio and video format that can be engaged with
- Social media is key to reaching children and young people if they are to own the strategy

What do you hope the impact of this strategy would be?



“For all young people to feel less alone”
“That more young people know about and can access the services already in existence”
“Hearing young people say they benefit from it”

Key insight

Strategy content

- View recovery as a journey, not end point
- Less clinical, unclear and provoking language
- 100% school attendance should not always be a Key Performance Indicator
- Avoid acronyms
- See resilience as something to develop
- Recognise that a 'Families approach' might not fit all families
- Address digital poverty
- More emphasis on social prescribing

Impact

All recommendations and comments were discussed and amendments were agreed in the final strategy.

The feedback showed how important it is to youth proof public facing documents, as 'system speak' is so easily used.

Concordia's young people recommended a [film to communicate the FfoF strategy ambitions.](#)

Why my opinion matters

This is to help young people, so it's great to co-produce a strategy moving forward

because i'm a young person who has struggled with mental health, so as good as it is that adults try to improve mental health services for young people, i experience it

because I am a young person who is not that aware of the services available

we can get other young peoples opinions as well as our own

We can spread the word to the target audience

What is one skill you have gained from this process?

I've gained confidence to articulate my thoughts

What do you think would be the best result of this strategy being implemented?

for all young people to feel less alone

How do you think young people should be involved so that they can keep "owning" it going forward?

That more young people know about and access the services already in existence in Brighton

social media updates and polls that are accessible to everyone

regular reviews with new opinions and updates to the resources

+1

A review mechanism on the website

Communication considering the wording to make it accessible to all

Putting my experience to good use to hopefully help in some way.

hearing young people say they are benefitting

listening to other opinions, compromising to find middle ground and wide outreach

CYPs Clinical Academic Group (CAG)

Influencing Single Point of Access/Advice Principles

The need

The Foundations for our Future (FfoF) review highlighted how difficult it is to access mental health and emotional wellbeing help and support.

In response, Single Points of Access/Advice (SPoAs) were developed in East and West Sussex, with aspirations for a similar model in Brighton and Hove.

SPoAs aim to be the first point of referral that will triage professionals to a service that meets a child's needs. In West Sussex this service can also be used by the public.

Focus of work

A set of core principles were developed to ensure each locality had guidance on how to deliver a good SPoA offer.

Sussex Partnership Foundation Trust's Children and Young People's CAG were involved in a series of online workshops to review the language - grammar, clarity, sentence structure, and flow.

Examples of co-designing the language...

From...

"Needs-led appropriate access to services, pathways and advice"

To...

"Easy access to the right service, pathway, and advice to meet the needs of young people, parents and carers"

*"Front door means nothing to me"
CAG member*

From...

"One front door with a clear point of contact for parents, carers and professionals who are concerned about a child or young person."

To...

"One clear access point for parents, carers and professionals to be able to get support and advice if they are concerned about a child or young person."

Key insight and impact

Young people were able to analyse the formal, clinical and often complex 'system speak' and provide alternative text that could be understood by a wider audience. They also shared their views on how the language may be interpreted and helped to bring a different perspective on what questions should be asked behind the principles, what adults missed or did not prioritise.

The CAG's revision to the text was adopted in the final SPoA Principles document.

Improving the accessibility of routine mental health and emotional wellbeing services

Survey

The need

The Foundations for our Future (FfoF) review highlighted that the accessibility of routine mental health and emotional wellbeing (MHEW) services may not align with the needs of service users.

The review recommended that to improve accessibility, services must operate more flexibly and beyond usual working/ school hours of 9-5.

In addition, services should be offered in a broader range of locations and where appropriate in non-statutory sector buildings.

Focus of this work

Two surveys were co-designed with young people, parents and carers, service leads and commissioners to better understand what 11-25 year olds and parents and carers want from services and what their experiences have been.

There were up to 20 questions in each survey that focused on views and experiences before, during and after appointments.

Observation

The majority of responses were from those that had a negative experience of services



Demographic Overview

- **288 survey responses collected**
 - 203 parents-carers and
 - 85 children and young young people
- **Where respondents were from**
 - Parent-carers
 - West Sussex 68%. Followed by East Sussex 19% and Brighton and Hove 13%.
 - Children and young people (CYP)
 - West Sussex 79%. Followed jointly by East Sussex and Brighton and Hove 10%
- **Majority of respondents were female** - 68% CYP; 90% of parents and carers
- **Those that did not identify as assigned birth gender** 15% CYP; 2% parent-carer
- **Majority of respondents were White** 87% CYP; 90% parents-carers
- **Those with a physical disability** 13% CYP; 26% parents-carers
- **Those with caring responsibilities** 62% CYP; 55% parents-carers
- **Those with a long-term disability** 68% CYP; 34% parents-carers
- **LGBTQ+ respondents** 34% CYP; 9% parents-carers
- **Majority of CYP (53%) were aged 14-15;** parent-carers were aged 40-50

Survey Findings

Where would you like to receive mental health or wellbeing services?

Parents and carers

34% At home
32% Fine where it currently is
21% at GP or clinic

Children and young people

48% At school, college or uni
30% At home
29% at GP or clinic

- Least favoured by young people and parents and carers were community settings
- 'Outdoor spaces' were young people's next favourite choice over 'online' by a margin

What appointment days and times are better for you?

Parents and carers

3pm-6pm received the most responses (376) with Monday and Saturday as the preferred days

Followed by

6pm-9pm (368) with Monday, Wednesday and Friday as the preferred days

Children and young people

6pm-9pm received the most responses (209) with Monday, Wednesday and Friday as the preferred days

Followed by

3pm-6pm (198) with Wednesday and weekends as the preferred days

- Both parents and carers and children and young people choose the same day preferences for appointments between 6pm-9pm
- Sunday's were least favoured by parents and carers
- Early morning appointments (6am-9am) were least favoured by children and young people, and later slots (9pm-12am) were least favoured by parents and carers

Other findings:

- **% of respondents that were not asked for feedback** on how to improve the services they use: children and young people 45%, parents-carers 63%
- When asked **what would help respondents to use the service** children and young people chose knowing more about the staff (52%), followed by staff with similar lived experience, appointment reminders via email/text and in-person appointments (all at 26%). Parents-carers chose clearer information about what the service offers (45%), followed by in-person appointments (33%), staff with lived experience (32%) and home visits (31%).
- When asked **what helped while waiting for a referral or appointment** children and young people's top four were friend (top) and family support, school, college and university staff support and taking part in positive activities. Parents-carers chose family support (top), not receiving any support was highlighted as the second, friend support, education staff fourth

Local youth voice collaboration

Different approaches across Sussex involved a mixture of collaboration at a local level with local authorities, and community and voluntary sector, and engaging with system-wide activity

East Sussex

The need

'Improve mental health' was voted as the third priority concern for children and young people in East Sussex through the 'Make Your Mark' Ballot.

However, given that children and young people's mental health and emotional wellbeing (MHEW) is a priority concern for the council, additional investment enabled the local authority, NHS and partners to collaborate on a series of eight engagement sessions to improve (MHEW) concerns, aligned to the Children and Young People's MHEW Local Transformation Plan that sets out the strategic approach to improve, measure progress, develop plans and address health inequalities.

Focus of work

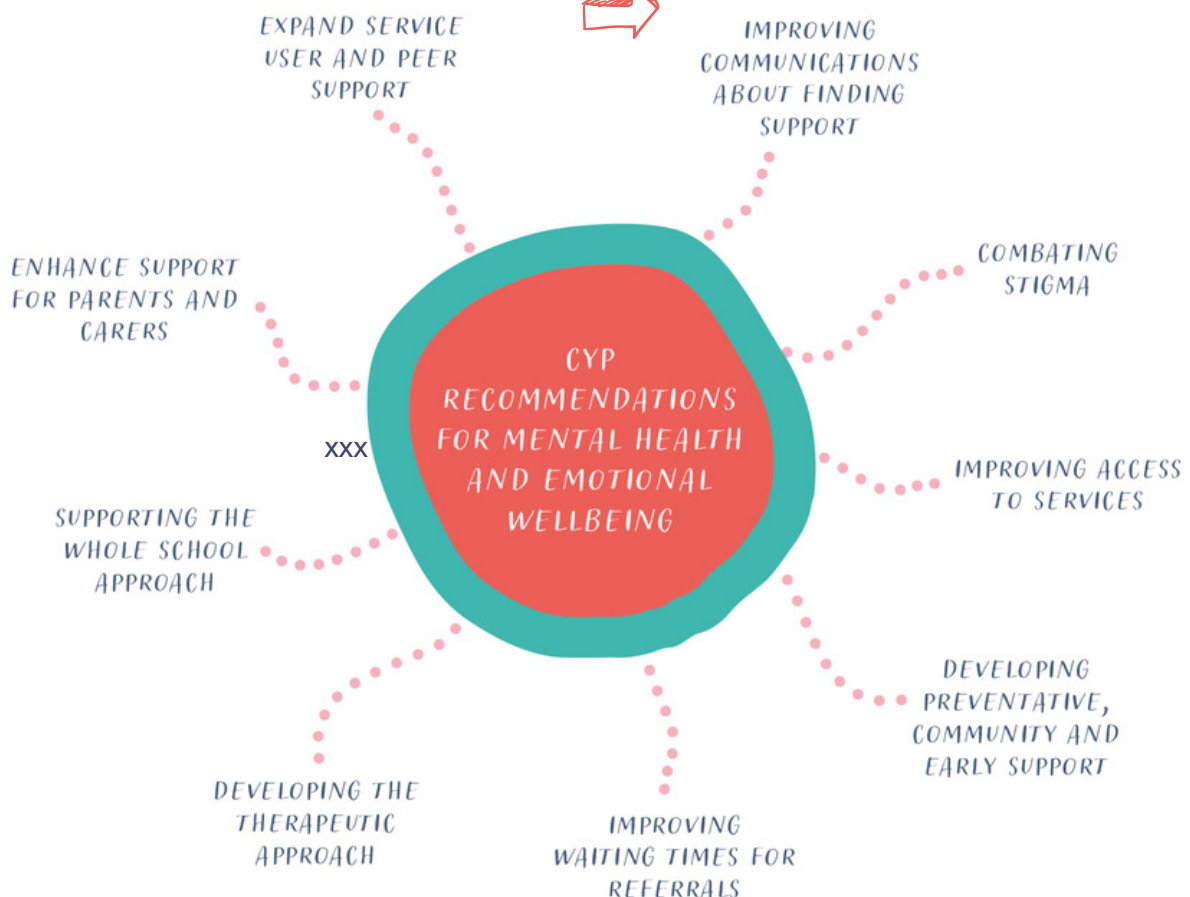
Youth voice groups from across East Sussex came together to:

Session 1

Map MHEW services they knew against the Thrive Framework, what the gaps and barriers were, and what they thought of these. Nine recommendations were developed to explore further.

Session 2

Discuss the recommendations. The young people requested that specialist staff, with a lead for the topic areas, join sessions to hear young people's experiences and explore ideas for improvements for each of the nine recommendations below...



These nine recommendations were built on to include Sussex-wide children and young people's priorities, that make up the eleven priorities as highlighted in the Foundations for our Future review

Developed by Amy Broadbent, NHS Youth Consultant, from the young people's insight gathered

Local youth voice collaboration

Key Insight

Social prescribing, positive activities

"Invest in what the offer is called, and how you will communicate it to all and don't just rely on doctors to deliver it."

Improving Communications about finding support

*"We don't know what's out there for us to get help!"
"Access to better information about referrals, disclosures and services."*

Supporting Whole School Approach

"We want regular and dynamic learning about MHEW issues, what they look like and how to stay well."

Click to view reports on how to improve stigma, communications, peer support, whole school approach, prevention and access

The impact

- insight has informed the development of the Children and Young People's MHEW Partnership Group and system wide-MHEW meetings
- provided an evidence-base to
 - establish four priority areas of focus for East Sussex:
 - Prevention, social prescribing - positive activities; early help; health in education; and Communications - Improving Information, Advice and Guidance (IAG)
 - fund two social prescribing projects
 - IAG included in the East Sussex Children and Young People's Plan to be developed through the sub-group
 - informing Mental Health Support Teams expansion

Local youth voice collaboration

We partnered with Wave Music Therapy, a team of Allied Health Professionals and Arts psychotherapists, with experience of working in settings supporting children and young people with additional needs to seek the views of younger people.

The need ?

A discrete engagement event brought together youth voice groups from some of our key local authority, voluntary and community sector and provider partners with the NHS Sussex Chair, to hear about changes to the health and care system and give their views, and talk about what they saw as the challenges and opportunities.

Young people told us that NHS Sussex should increase opportunities to involve lesser heard young people; including those with a special education need or disability (SEND), or with a social, emotional or behavioural (SEB) difficulty or disorder.



Focus of work

46 children and young people in primary and secondary, mainstream and SEND schools, and specialist settings, were engaged in two-hour workshops facilitated by their in-house rap and spoken word artist.

Using this creative engagement approach enabled the young people to share deeply personal feelings and experiences, too raw to speak, and culminated in a powerful audio recording to illustrate this.



Local youth voice collaboration

Key Insight

The report identified that the children and young people:

- want further opportunities to engage with the NHS and senior decision-makers, to understand NHS career opportunities
- further engagement using creative approaches
- to be included in conversations on health and care services from an early age.

*What I need is...
“people to
understand me.”*



Click [here](#) for the full report

The impact

The workshops have helped:

- 20 new young people to access Wave Music Therapy’s therapeutic support offer
- teachers better understand and support young people displaying complex behaviours
- inform Wave Music Therapy, the Working Together with People and Communities Strategy, the Physical Health Strategy and ongoing work across the Sussex Health and Care Partnership

Local youth voice collaboration

NHS Youth Consultant represented youth voice at the B&H Children and Young People's Mental Health and Emotional Wellbeing Partnership Group meetings feeding into the Foundations for our Future strategic meetings and led local consultation activity.

Focus of work ?

Working collaboratively with local authority youth voice groups to inform and influence system-level mental health and emotional wellbeing (MHEW) improvement.

15 young people from ten secondary schools and colleges from across Brighton and Hove were consulted to better understand

- what MHEW services young people knew
- what supports their MHEW
- what services are missing
- what young people would do if they had the budget
- how young people want services to look and feel

This insight informed ongoing Sussex Health and Care Partnership work, the Foundations for our Future priorities and contributed to the development of a local campaign plan for the B&H Youth Cabinet that will feed into ongoing going system-wide work.

Key insight

We need preventative and early help.

More knowledge about what is available outside of education settings.

Seeing a therapist with lived experience is key.

Safe and friendly space to go to.

Anonymous ways to get help.

Less clinical

Better information , advice and guidance that is accessible

Better hours outside of 9-5

More support for the whole family.

Don't shame us for our attendance.



Click [here](#) for the full report

YMCA

Young people influencing the Single Point of Access/Advice in Brighton and Hove

Insight gathered from YMCA's e-wellbeing group and included in the SPoA business case for funding

How would you like a physical space to work/online service?

Online services should not replace existing face-to-face, the latter is more effective for many facing MH issues...
...A balance between both based on service user need, not convenience for the service.

Central Transport links
I would like the services and spaces be closer to their local area. So that there are not limitations or barriers, for them to access it and easier to get to.

Online services should give young people information on all the options before they make a decision. Online would be good to reach a wide range of people across Sussex

Physical - A comfy environment, easy to reach with public transport

Should the service be for 18-25 year olds? Why?

18-25 - people aged 22 are still in uni

The more young people supported with their mental health the better. We have a lot of arbitrary rules on age parameters which don't often make sense. The larger the catchment for people, the better.

Online - easy to navigate, accessible

When should a service be available?

Should be available out of school hours - eg evenings and weekends

could there be levels of availability- depending on need? some low level resources could be self referred

Balance of online and in person. Provide a set time than a series of hours of waiting .

Do you think CYP should be involved in monitoring and evaluation - if so how? Secret shoppers, service user feedback etc?

Yes young people should definitely be involved accessible quick feedback should be available to all

Extending funding and support for reducing waiting times is more important. But I think that reflecting on service improvements is also important...

...Targeted funding and staffing towards addressing existing shortages is more effective than having more staff to evaluate the gaps.

What would you like the acknowledgement of referrals to look like or what would you like to take away?

Referrals should be person-centred and have service user need at heart. All actions should address the long waiting times for people struggling with their mental health...

Series of relevant and suitable care packages.
...for a timely and effective service that empowers the user and support for the interrim period.

follow up people who visit in person with emails/calls
If contacted digitally, get digital referral- could do a tickbox to see if people would prefer to get feedback via email/phone

I would like an email or something from the post , to remind me. Given a breakdown and structure on what each of the referrals could look like.

NHS Youth Consultants involved in delivering the above YMCA session to co-produce what a B&H SPoA model could look like and four Task and Finish Group sessions comment on progress, and influence the development of the model and business case.



What if someone overhears my session?

Click [here](#) to read what YMCAs young people had to say about their health and wellbeing during the Covid-19 restrictions

The need

Privacy and Confidentiality

The shift from in-person to online and blended therapy sessions post Covid-19 restrictions, highlighted young people's concerns linked to privacy and confidentiality.

Focus of work

A video was co-produced with young people and therapists to explain confidentiality and shares tips for feeling safe during online therapy sessions.

Impact

The film has been shared across the health and care system, including YMCA's database of children and young people and families and social media.

The film has been viewed XX times and is shared in outreach work with schools through the e-Wellbeing Ambassadors.

Click [here](#) to view the privacy film

Tips for keeping your session private



The need

Supporting the workforce priority

Young people have identified that a diverse workforce, and support from staff with lived experiences like their own is important. They want young people encouraged into entry level health and wellbeing roles as a preventative measure for the NHS, in addition to support in transitioning into these roles.

Focus of work

To raise awareness of young people's experiences when they transition into the world of work, and encourage employers to provide more support during the transition.

Film includes young people's experiences, what good would look like, and mental health and emotional wellbeing tips for young people needing support.

This work is ongoing and is due to complete June 2023.

Ambitions for the film



The film aims to support young people's transition to the workplace, and inform the NHS Workforce priority by hearing about what the barriers are and what attracts young people to public and voluntary sector roles.

The need

Routine Outcome Monitoring (ROM)

Used by mental health clinicians and service users to track progress of treatment and interventions

There are varied and complex ways services record treatment outcomes at present, with no universal way to use data across Sussex to make better clinical, commissioning, and technical decisions.

The system aims to improve data collection, use and flow with partners.

Focus of work - Phase One

Young people from YMCA influenced the ROM prototype development to:

1. Understand different ROM systems across Tier 3 CAMHS
2. Highlight the most useful and preferred ROMs
3. Explore the best ways to share ROM data back to users
4. Inform prototype development across four key points of engagement:
 - before a first session
 - consent and sharing data
 - at the first session
 - within the sessions
5. Identify gaps and opportunities to improve data collection, use and flow

It's not always clear to children and young people why they are being asked to complete therapy surveys and how they are used

Children and young people would like to be able to see how the therapy surveys that they complete are being used to help inform the clinician and they would like to see the data from across their journey themselves

Children and young people would like to be able to complete survey's where they feel most comfortable. Ideally, this would be done before the session so the counsellor has enough time to understand the results.

Children and young people would like to understand how therapy survey data is used so that they feel confident about providing it and are able to change their consent settings so that they feel in control of their data

What we heard from young people

Young people should own their own data and interact with the prototype in a way that is most useful for them

Next Steps

Phase two looking at where to house a system is complete and proposals are being shared for next steps.

Contact **Jo Robertson** for full Report

Priority 1-54

Eating Difficulties

The need

The number of young people with “eating disorders” increased in England over the pandemic, with associated pressure on clinical services that provide care and support – whether as outpatients or inpatients. Nationally, the waiting list for treatment trebled, and those that are being seen are having to wait longer for care.



How is it being addressed?

Work is ongoing to increase capacity across the system in existing services and to develop new models of care, including a re-design of the all-ages Eating Disorder pathway led by NHS Sussex and partners.



Key Challenge

The brief included a review of existing information and support nationally and across Sussex. This research identified similar commissioned work and led to a new working group to explore how the two projects could support and compliment each other.



Focus of this work

The original aim of the project was to co-produce an early intervention resource to support young people with an eating disorder, their families and friends, and non-clinical practitioners. In addition, it was used as an exemplar for co-production activity for NHE/I. [Click here to see film](#)



What we did

- activity to identify local and national evidence-based practice - *Cornwall Managing Eating Problems*
- recruited a Youth Forum to co-design a programme of engaging activities - meeting monthly
- delivered 9 consultations in schools/colleges including, one parent-carer consultation that produced top tips for other parents and carers
- co-produced an impact framework ‘youth-led charter’



Click [here](#) to view the full report

Priority 154

Eating Difficulties

Key recommendations

- Terminology in the early stages of an Eating Disorder (ED) must be less stigmatising - eating difficulties, eating challenges, eating priorities are useful
- Resource a dedicated children and young people focused social media content developer to communicate directly with children and young people in a responsive way online
- More proactive staff regularly checking in, and opening up space to talk openly with children and young people
- Expand trained peer mentors
- Support sports sectors to better understand ED and encourage them to have open preventative discussions
- Include young people's recovery journey's and body positivity in any resource development
- Encourage a more joined-up approach to the intersectionality between an ED and neurodiversity

Impact: *Benefit to the health and care system*

- The scoping exercise prevented a duplication of work and saved resources
- the project steering group strengthened partnerships across the Integrated Care System
- Consultation findings continue to inform the all age Eating Disorder pathway redesign
- Open discussion in schools/colleges helped them to identify previously unknown issues and enabled them to better understand their pupil needs
- Produced a youth-led charter to inform a resource design



Next steps

- Produce a 'You said, we are doing' report for the Youth Forum
- Continue to attend the ED steering group meetings and draw on the report findings
- Invite the Priority 154 youth forum members to be involved in the ED re-design
- Use the report as an introduction for any children and young people as and parent/carer involvement
- Utilise the report as a baseline to measure impact



PRIORITY
1-54

Reflections

- As highlighted in this collection of participation activity, there has been great examples of children and young people's participation across the mental health and emotional wellbeing workstreams, delivered through the Foundations for our Future programme and Mental Health collaborative.
- There is a vast amount of high quality children and young people's participation work organised locally across Sussex that has been brought together by the programme and the collaborative to influence system-level strategic decision-making.
- Partnership working and co-design with children and young people and parents and carers is key to deliver meaningful and impactful participation. This helps to
 - build relationships required to integrate and improve health and care services
 - incorporate 'system' expertise by staff sharing knowledge and best practice
 - highlight gaps and opportunities, and strengthens the evidence base required to fulfil the needs of services and service users
 - reduce duplication and make better use of resources
 - build a culture of participation where service users are involved from the outset
- In order to continue to maximise opportunities to hear from children and young people and families, to inform planning and commissioning decisions it requires ongoing co-ordination. This will help to ensure the requirements, as set out in the national duties to involve our people and communities and commitment stated in the three system-wide local children and young people strategies, are met.

Recommendations

NHS Sussex Participation - Report 2023

Co-design a framework for children and young people's involvement in the strategic decision-making structures

Extend our pool of CYP “Consultants” – i.e. CYP Strategic Leaders to include CYP with physical and mental health lived experience; align with the existing Community Ambassador programme to ensure support, thorough processes and procedures, and access to wider training and support.

Expand the Children and Young People Consultant Group with a Terms of Reference and define a clear link to the Children’s Board accounting for all three strategies - Physical Health Strategy, Learning Difficulties and Autism Strategy and Mental Health and Emotional Wellbeing Strategy.

Network consolidation:

Build and nurture relationships with community and voluntary sector organisations and education providers. Draw together existing networks at place, and develop a Sussex-wide network structure for children and young people's participation.

Review family participation structures and networks, and develop a Sussex-wide proposal for family participation.

Insight review:

Draw together existing insight from children and young people and families and ensure inclusion on the system Insight Bank. Develop summary insight to action reports for the Children’s Board and others as required.

Develop an “Equalities Lens” outline for CYP work:

Review how to increase opportunities to reach and hear from children and young people with protected characteristics or part of an inclusion groups drawing on the Children and Young People's Core20+5 Framework.

Recommendations

NHS Sussex Participation - Report 2023

Co-produce a children and young peoples system-wide Participation Strategy

Building on the 'Working with People and Communities Strategy' to outline our organisations aspirations for children and young people's involvement highlighting steps to achieve these, including how these will be monitored and evaluated.

Develop a theory of change or logic model with commissioners

In order to meet 'Foundations for Our Future Recommendation 19' - children and young people to prioritise financial resources for themselves and their community - scope out how to embed children and young people's involvement in commissioning

Involve system partners in scoping and agreeing common principles for Service User Feedback

Organise Task and Finish Group together to share best practice, gaps, understand quality and impact, key principles, common core questions, promote equality monitoring according to equality protected characteristic/Core Plus 5 groups

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