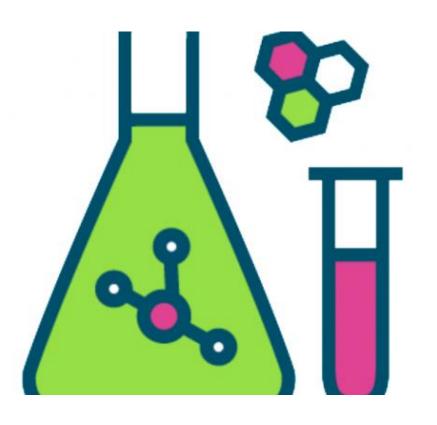


Strengthening youth voice and participation within:

COVID-19 Vaccination Services for Children and Young People in East Sussex

Young People's Experiences, Ideas and Recommendations for Professionals



Brought to you by Young Healthwatch East Sussex

September 2021 -January 2022



Contents

1. Exe	ecutive Summary	. 4
1.1 F	Project Aims	. 4
1.2 ٨	Nethodology	. 4
1.3 F	Recommendations	. 5
2.Intr	oduction	. 7
2.1 Y	outh Voice and Vaccinations	. 7
2.1	1.1 Context and Consultations	. 7
2.1	1.2 Project Overview and Aims	. 7
2.1	1.3 Enquiry Topics	. 8
2.1	1.4 Volunteer Involvement and Participation	. 8
2.1	1.5 Prior HWES activity on COVID-19 vaccinations	. 8
3. Me	thodology	10
3.1 F	Pan-Sussex Vaccination Survey	10
3.2 (Community Outreach Exercises	10
3.3 (Coproduction with Young People	10
4. Fin	ndings	12
4.1 V	/accination Survey Findings	12
4.1	1.1 Getting Vaccinated	12
4.1	1.2 Impacts of Vaccines and COVID-19	17
4.2 (Community Outreach Findings	20
4.3 (Coproduction Findings	22
4.3	3.1 Issues and Barriers for children and young people	22
4.3	3.2 Key Debates within COVID-19 Mass-Vaccinations	23
	3.2 Potential strategies to increase COVID-19 vaccination uptake among ildren and young people	. 25
	commendations	
5.1	Recommendations for Vaccinators	
5.2	Recommendations for the Youth and Education Sector in East Sussex	
5.3	Recommendations for Communications and Engagement Professionals	
5.4	Recommendations for Vaccination Service-Providers	



6. Appendices		34
	6.1 About Healthwatch East Sussex (HWES)	
	6.2 About Young Healthwatch East Sussex (YHW)	34
	6.3 About East Sussex Community Voice (ESCV)	34
	6.4 Survey Promotion	35
	6.5 Community Outreach Template	36
	6.6 Examples of coproduction discussions	36
	6.7 Social media promotion	37



Contact Us



Healthwatch East Sussex

Freepost RTTT-BYBX-KCEY

Greencoat House

32 St Leonards Road

Eastbourne

Website:

www.healthwatcheastsussex.co.uk

Telephone: 0333 101 4007

Email:

enquiries@healthwatcheastsussex.co.uk

Twitter: @HealthwatchES



1. Executive Summary

This Healthwatch East Sussex report summarises independent deliberative engagement¹ with children and young people, that took place between September 2021 and January 2022, on the theme of young people's Coronavirus (COVID-19) vaccinations.

Our original age remit for this project was for young people aged 16-18, but since initation, eligibility has broadened to younger ages. Young Healthwatch East Sussex are confident that recommendations and guidance can still be applied to all ages under 18, but please note that the majority of our exercises took place with 16-18 year olds.

1.1 Project Aims

In response to changes in NHS eligibility in late 2021 meaning that young people aged 16-18 became eligible to be immunised against COVID-19, the project was created, informed by consultations with Young Healthwatch volunteers and what they are experiencing and observing as our 'eyes and ears' in youth communities.

The project aims were as follows:

- 1. To establish a core group of young volunteers with a keen interest in COVID-19, Health and Wellbeing and the interplay between physical & mental health;
- 2. To conduct engagement activities which will gather insight around youth vaccination efforts and local opinions on these;
- To coproduce guidance for decision-makers with children and young people, to promote a youth-friendly approach to the delivery and marketing of COVID-19 vaccinations in East Sussex;
- 4. To collate insight and recommendations from youth engagement to share with practitioners to inform the work of health and care partners across East Sussex.

1.2 Methodology

Young Healthwatch deployed three different strands of community engagement with young people on the topic of COVID-19 vaccinations, all coproduced and co-designed by our core group of young volunteers.

- 1. A pan-Sussex survey was launched with colleagues at Healthwatch West Sussex and Healthwatch Brighton and Hove, to investigate local patient experience and the wider impacts of the vaccination programme and COVID-19 on young people.
- 2. Community outreach activities in two vaccination venues in East Sussex, to have indepth discussions with local young people to gage an understanding of local issues, barriers, attitudes, exposure to information, and anxieties, regarding the vaccine.

¹ *"Deliberative engagement is a distinctive approach to involving people in decision-making, giving participants time to consider and discuss an issue in depth before they come to a considered view" – www.involve.org.uk



3. Coproduction of insight and recommendations with a core group of Young Healthwatch volunteers, to gather ideas and local knowledge about issues, barriers, debates and strategies to increase local vaccination uptake among youth communities.

1.3 Recommendations

From the findings of these three engagement strands, Young Healthwatch recommend the following for East Sussex professionals who operate both directly and indirectly within the COVID-19 vaccination system:

Vaccinators should be aware of varying-to-high levels of anxiety (with particular focus on needles and the clinical environment) and be aware of strategies to actively reduce anxiety and distress for young patients. Vaccinators should also ensure that young people have a chance to discuss side-effects, aftercare, and their next vaccination with staff.

The East Sussex Youth and Education sector should provide education and learning on young patient rights, so that young patients feel more confident in going to a healthcare setting and having an appointment, both within and outside of the context of vaccines. Youth and Education staff members should empower young people to feel confident in making their own choices about their healthcare, and this should be accompanied by support, information and appropriate signposting where possible. Likewise, professionals should support young people to identify and appropriately respond to, scam or false communications about COVID-19 vaccinations and wider health.

Communications and Engagement Professionals should recognise and utilise (in communications and marketing) the reliance that East Sussex young people have on their families and households for information on vaccinations. Traffic should be encouraged towards the NHS website functions, and further communications should be released regarding patient transport alternatives for young people who need support in travelling to and from a vaccination appointment. Young people valued science and objectivity in understanding vaccinations, and communications and engagement should promote research and objective facts regarding the vaccine, to aid myth-busting. Young Healthwatch's communications workstream will monitor and support these recommendations, where appropriate.

Vaccination Services should recognise that the presence of a parent or guardian can be a positive one for some young people, and so facilities should allow this where possible, particularly where guardians can be support networks for anxious young patients. Young People should be made aware that sensitive questions (e.g. pregnancy-related) might be asked, so that they can make an informed decision about who they attend with. Young People consistently highlighted anti-social appointments (evenings, weekends) as a significant incentive, and these hours of operations should continue where possible.

The Sussex Integrated Care System (ICS) should recognise the importance of educational settings but ensure that additional provisions are maintained and furthered so that young people outside of education can still be vaccinated conveniently. Location can be a barrier, and young people should be consulted on future decisions relating to the shuttering or opening of new facilities in East Sussex. Vaccination ambassadors and community-based volunteers play a significant role in the vaccination system and this should be recognised in the funding, staffing and long-term maintenance of different volunteer programmes in East Sussex.



HWES and Young Healthwatch will share the learning with statutory and voluntary sector partners, across other Local Healthwatch services and with Healthwatch England. Young Healthwatch will continue to monitor the implementation of recommendations and provide ad hoc support to our health and care partners to support the embedding of youth voice and young people's guidance into the programme.



2.Introduction

This report summarises independent deliberative engagement undertaken by Young Healthwatch East Sussex with children and young people, that took place between September 2021 and January 2022, on the theme of young people's Coronavirus (COVID-19) vaccinations.

The original remit was for young people aged 16-18, but since project initiation, vaccination eligibility has broadened to younger ages. Young Healthwatch East Sussex are confident that recommendations and guidance within the report can be extrapolated across all ages under 18, but focuses on those aged between 16-18, particularly among our survey and outreach exercises.

2.1 Youth Voice and Vaccinations

2.1.1 Context and Consultations

Young Healthwatch East Sussex undertook a series of scoping and mapping discussions with newly recruited young volunteers in the summer of 2021.

Young People highlighted that COVID-19 vaccinations were considered a *hot topic* among their peers and classmates. Likewise, in consultation with Healthwatch East Sussex's pool of adult volunteers through fortnightly vaccination drop-in discussions, children and young people's vaccinations were highlighted as an important topic within East Sussex health and care which requires further patient participation and youth outreach.

2.1.2 Project Overview and Aims

The Youth Voice in COVID-19 Vaccination Services project was established at the start of September 2021, in response to early consultations (2.4.1) and changes in the law meaning that more young people were eligible to be vaccinated.

The project coupled deliberative engagement methods to actively involve young people in creating recommendations for policymakers, with HWES research approaches to investigate local needs and perspectives.

The project aims were as follows:

- 1. To establish a core group of young volunteers with a keen interest in COVID-19, Health and Wellbeing and the interplay between physical & mental health;
- 2. To conduct engagement activities which will gather insight around youth vaccination efforts and local opinions on these;
- To coproduce guidance for decision-makers with children and young people, to promote a youth-friendly approach to the delivery and marketing of COVID-19 vaccinations in East Sussex;
- 4. To collate insight and recommendations from youth engagement to share with practitioners to inform the work of health and care partners across East Sussex.

The insight gleaned is intended to:

• Inform the work of vaccinators, volunteers, and vaccination champions



- Identify strengths and limitations within the vaccination system in East Sussex and suggest strategies to enhance the system's engagement with children and young people
- Inform future policy and service delivery decisions, and support the decision-making of strategic bodies, including the East Sussex Placed Based Vaccination Programme Cell, Communications and Engagement Steering Group for Health and Care in East Sussex, Health and Wellbeing Board and support the work of Public Health and CCG colleagues who coordinate the COVID-19 immunisation across the county
- Contribute to broader HWES and YHW objectives of championing the voices of children and youth to create public-centred services

2.1.3 Enquiry Topics

Engagement activity within the project was focused upon the following enquiry topics, coproduced with young volunteers and HWES staff:

The Vaccination Service

- How has the overall quality of care been for young people when they've received their jabs, including staff, facilities and aftercare?
- How effective has current communications and marketing been, and what could be done to make vaccination promotional materials more accessible and appropriate for youth audiences?

Wider Impacts and Uptake

- What are young people's motivations for getting vaccinated against COVID-19?
- What barriers, anxieties and worries could prevent an eligible young person from being vaccinated against COVID-19?
- What strategies could be suitable to increase vaccination uptake in youth communities?
- How has the pandemic impacted children and young people's health, and to what extent is being vaccinated rectifying negative impacts?

2.1.4 Volunteer Involvement and Participation

Five young volunteers supported the development of this project, including preparing for and facilitating engagement mechanisms.

Young volunteers co-designed the community survey and were involved in developing the questions for the community outreach exercises. One young volunteer supported the delivery of outreach exercises, while the remaining volunteers supported the promotion of the community survey. All volunteers received 'Getting Ready to visit the Care Environment' training to support their professional development and ensure strong knowledge of safeguarding, confidentiality and equal opportunities.

Throughout this period, young volunteers also attended co-production meetings, hosted by HWES staff, where they could share their own ideas and opinions as a *core group*.

2.1.5 Prior HWES activity on COVID-19 vaccinations

HWES have engaged with the wider public on COVID-19 vaccinations prior, through a community survey to gather public and patient experiences and map out trends and patterns in uptake.



HWES adult volunteers also attend a fortnightly drop-in where they can share learning in their area, discuss current uptake and meet with professionals to understand more about how volunteers and community action can enact change within the vaccination system to improve public health and boost immunity. Please see our prior activity here: https://healthwatcheastsussex.co.uk/covid-19-vaccination-survey/



3. Methodology

Young Healthwatch East Sussex used the following methods to engage with children and young people, enabling the investigation of topics highlighted by YHW volunteers (section 2.4) and the subsequent generation of recommendations (section 5).

3.1 Pan-Sussex Vaccination Survey

YHW volunteers co-wrote a survey with HWES staff to investigate young people's experiences with the East Sussex vaccination service, as well as the wider motivations for being vaccinated and the impacts of this.

The survey was designed to act as a feedback hub for young patients across the three geographical areas to gage a broader understanding of:

- Young People's exposure to information, awareness and education on COVID jabs
- Young People's experiences with vaccination staff, facilities and overall quality of care
- The wider impacts of COVID-19 vaccinations and the COVID-19 pandemic on young people's health and wellbeing

At the time of project initiation, COVID-19 vaccinations were not offered to young people under the age of sixteen. Therefore, YHW volunteers decided to focus this survey on 16 and 17 year olds, with further methodologies (3.2, 3.3) reflecting a wider age remit.

The survey was adopted by Healthwatch in Sussex (HWiS), which joins-up the three Local Healthwatch services working across Brighton & Hove, East Sussex and West Sussex. The survey was promoted across all three geographies by a variety of youth, community, education and health professionals.

The survey was launched on 21st November 2021 and ran until 31st of January 2022.

3.2 Community Outreach Exercises

HWES Staff and a Young Healthwatch East Sussex volunteer visited two vaccination centres. We visited Sovereign Harbour Medical Centre in October 2021, and The Hastings Centre (The Ridge) in November 2021. We visited each venue for four hours, and both visits occurred on a Saturday.

Our line of inquiry, co-designed by Young Healthwatch volunteers, led to semi-structured discussions with young patients across both venues, finding out more about motivation, access, anxieties, and wider uptake.

3.3 Coproduction with Young People

Alongside YHW volunteers' involvement in designing and promoting the survey and preparing for, and facilitating community outreach, HWES staff facilitated four coproduction workshops with a core group of YHW volunteers who were interested in COVID-19 vaccinations, public health, and young people's issues. *All young people involved were aged between 15-18*.



HWES staff used creative activities & ICT and facilitated engaging discussions to capture YHW volunteer's own experiences and perspectives as community champions and our 'eyes and ears' among youth communities in East Sussex.

Co-production activities were themed on potential issues and debates which could prevent a young person from being vaccinated, evaluating the promotion of vaccinations to children and young people, and the usefulness of prospective strategies to increase uptake among children and youth in East Sussex.



4. Findings

Young Healthwatch East Sussex found the following from our community survey and outreach exercises.

4.1 Vaccination Survey Findings

HWiS received 28 full feedback reviews through the survey, across the three geographies. Young People's feedback is summarised below:

4.1.1 Getting Vaccinated

85% knew lots or a little about the vaccination service.



Alternatively, 15% knew little or nothing about the vaccination service.

Where did you find trusted info about the COVID-19 vaccination service? Select all that apply.

Family and Parents (68%)

NHS Website (57%)

College (36%)
Other Websites (26%)
School (10%)
Youth Centre (5%)
Community Centre (5%)



And 5% couldn't find any trusted information on COVID-19 vaccines.

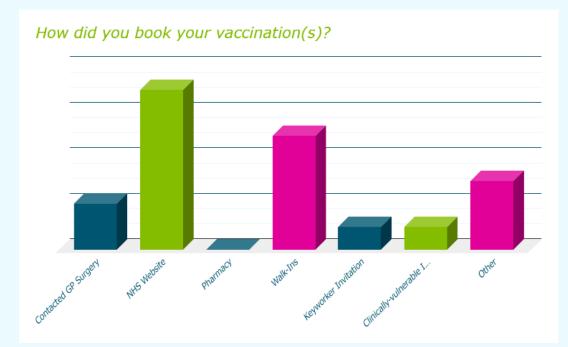


84% knew what vaccination(s) their age group is entitled to.



10% were unsure, and 5% did not know what they were entitled to.

How did you book your vaccination?



Highest responses:

NHS Website (36%) Walk-In Clinics (26%)

'Other' responses:

Using different methods for each vaccination. Not receiving a vaccination.



73% found it very easy or easy to book.

The remaining 15% found it difficult or very difficult to book.



12% had no opinion on this matter.

33% were

55% were

Vaccinated at the same venue for both first and second COVID-19 jabs.

Vaccinated at different venues for the first and second COVID-19 jabs.

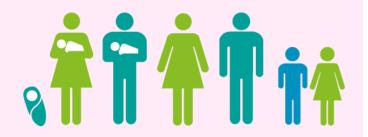
And 11% answered 'other' as they could not remember or were not vaccinated.

Participant quote:

"I tried four drop-ins but was turned away each time. I was turning 12 weeks in the following week (while on holiday) but no one would vaccinate me"

76% went to get their vaccination with a parent, carer or guardian, either for travel, consent or support reasons, or a combination.

23% went to get their vaccination on their own.





My parent/carer came to my appointment with me, and that made me feel: Select all that apply.

<u>Calmer:</u> **42**% <u>Safer:</u> **36**% Relaxed: **26**%

Embarrassed: 5% Awkward: 10%

No Difference: 15%

N/A: 15%



Other Response: "Parent came with me to the clinic for comfort, but attended the appointment alone"

How long did you have to wait before you were seen by a member of staff?

4.1% were seen immediately

8.5% were seen in less than one minute

45.8% were seen in under five minutes

16.6% were seen in under ten minutes

25% were not seen until after ten minutes





How clear was the layout of site at your COVID-19 vaccination appointment?



30.4% said that the layout was <u>extremely clear</u> 47.8% said that the layout was <u>very clear</u>

"It had stickers on the floor of where to go and we got told where to go next"

"The people were very helpful" "There were posters telling me the direction"

"You were directed by staff so it was easy to navigate"

"I was told where to go immediately and there were clear instructions given"



13.2% said that the layout was <u>not so clear</u> 8.6% said that the layout was <u>not at all clear</u>

"Lots of doors and entrances" made getting my vaccination difficult, Uckfield

How comfortable did you feel during your vaccination appointment?

29.1% felt very comfortable 58.3% felt comfortable

4.1% felt uncomfortable, and 4.1% felt very uncomfortable. Explanations for this focused on nervous feelings regarding being in a clinical space, and concerns about needles.



The remaining responses were unsure or did not answer.

Anxiety levels, worry and distress during appointments:

16.6% felt fairly anxious, and 45.8% felt a little bit anxious.

33.3% did not feel anxious, and the remaining responses were unsure or did not respond.

Cleanliness and organisation of facilities during appointments:

70.8% found the facilities very tidy and clean, 20.8% found them fairly tidy and clean.

No responses found the facilities untidy or unclean.

4.3% were unsure, and the remaining responders left the question unanswered.



How were the staff during your appointment? Select all that apply.

KIND (19 responses) CALM (15 responses) SUPPORTIVE (14 responses) APPROACHABLE (14 responses) PATIENT (11 responses)

Unprofessional (2 responses) and Rushed (2 responses)

Provision of appropriate aftercare advice (such as information on side effects)

33.3% were given lots of aftercare advice 45.8% were given some aftercare advice

12.5% felt that they were not given appropriate aftercare advice

4.2% were unsure, and 4.2% did not respond.

4.1.2 Impacts of Vaccines and COVID-19

What are young people's main motivations for getting vaccinated?

37.5% said to protect vulnerable people close to them (friends, family)



37.5% said to protect their immune system and prevent themselves from being ill

12% said to prevent the spread of COVID-19
9% said other social factors, such as holiday
4% said to encourage others to be vaccinated

Impacts of the COVID-19 pandemic:

1. Physical Health

- + 4.3% said the pandemic has had a positive influence on their physical health
- 34.7% said the pandemic has had a negative influence

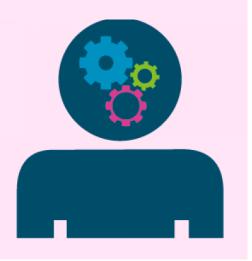
And 61% said that there has been no impact.



2. Mental Health

- + 13% said there has been a positive impact on their mental health
- 52% said there has been a negative impact on their mental health

And 35% said that there has been no impact.





Please tell us about any negative impacts that the COVID-19 pandemic has had on your health, both mental and physical?

"Mental Breakdowns" "Anxiety about social interactions"

"Weight gain, less exercise" "More tiredness and fatigue"

"More social anxiety as lockdowns were lifted"

"I didn't exercise nearly as much"

"Made me feel disconnected from reality as I was already suffering mentally before the pandemic"

"Lack of social interaction" "More anxiety and less exercise"

Please tell us about any positive impacts that the COVID-19 pandemic has had on your health, both mental and physical?

"More time to prepare healthier meals occasionally"

"Fewer socially anxious situations during lockdown periods"

"It has made me appreciate those around me more (family and friends)"

"Gave me time to reflect and become more mindful"

"More time to work on personal hobbies"

"Made new friends online"

During the pandemic, did you know where to go if you needed help or support?

Yes: 17.3%

To an extent: 21.7%

No: 30.5%

Unsure: 30.5%





Did you feel supported by your school, college, or workplace during the COVID-19 pandemic?

Yes - 13.6%, to an extent - 41% No - 36.4% Unsure - 9%

To what extent has being vaccinated allowed you to return to 'normal' activities and everyday life?

- "It would've been the same anyway"
- "No effect"
- "It hasn't there's still a pandemic"
- "Not at all"
- + "Very more confidence to go out to venues"
- + "To some extent" "A bit"
- + "I feel more safe and accepted by society"
- + The vaccination has made me feel more safe and comfortable to return to activities"
- + "I got them on the weekend so it didn't affect my normal activities"
- + "Almost back to normal"

4.2 Community Outreach Findings

Young Healthwatch East Sussex spoke to 17 young patients in-depth, across our two visits to vaccination venues, and found the following about motivation, access, anxieties and wider uptake.

1. Age

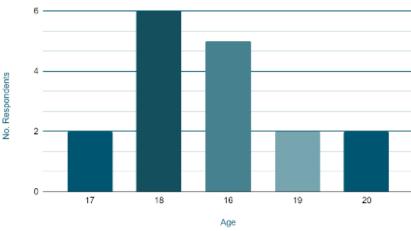
We spoke to 17 young patients across the two activities. The youngest age bracket we spoke to was 16, and the highest youth age bracket was 20.

2. Motivation

Respondents were asked to describe why they decided to receive their COVID-19 jab. Responses were similar in their nature, to the survey.

 Four respondents referenced avoiding the virus and keeping themselves safe in their answer.





• Three respondents referred to a **vulnerable parent** in their answer, namely mothers.



- Two respondents referred to being able to go on holiday as a motivator.
- One respondent referred to preparing for surgery in their answer.
- One respondent referred to having a previous negative experience of suffering from COVID-19.
- One respondent suggested that their motivation was **because everyone else** around them was getting vaccinated.

3. Access and Convenience

Respondents were asked to reflect upon, and describe, how easy and convenient they found access to the vaccination clinic in question.

Ease of Access:

Thirteen respondents spoke of the ease of access to the clinics.

Issues with Access:

One respondent referenced the closure of the Mothercare clinic in Eastbourne as a barrier to access. Another shared that they had to arrange and pay for a taxi to get the vaccine. Two respondents at Eastbourne noted traffic congestion around the clinic.

4. Anxieties. Worries and Concerns

Respondents were asked to share any anxieties, worries or concerns that they felt before they received their vaccination.

- Six respondents shared nerves and concerns about needles and being needlephobic, with one respondent sharing prior negative experiences with other vaccinations by needles.
- One respondent shared nerves and concerns about being in the clinical environment and the negative associations that they have with medical spaces.
- One respondent was concerned about the impacts of the vaccination from information that they had read about online.
- One respondent was nervous about side effects, and mitigated this by getting vaccinated at the weekend.
- The remaining responders did not share with us any information on potential anxiety levels towards their appointment.

5. Wider uptake

Respondents were asked to share wider feedback on uptake among their community.

- 13 responders shared that most of their friends and peers are getting vaccinated, if they have not been already.
- Three responders shared that there are low levels of uptake among their friends and peers.



 One responder shared that they believe that uptake is lower among apprenticeships and industry-based occupations than within post-16 education in a school environment.

4.3 Coproduction Findings

4.3.1 Issues and Barriers for children and young people

Young People identified a variety of issues with the current vaccination service and with wider societal knowledge and understanding of COVID-19 vaccines, which could pose as barriers to young people, including:

Access to vaccination sites

Young People identified that **Location** is a significant issue and potential barrier for young people to access their vaccination appointments. Closures of different walk-in centres in East Sussex, including the shuttering of the Mothercare site in Eastbourne, has made access harder for young people to receive their vaccine.

Young People recognised the importance of **Patient Transport Support Systems** which will support young people to travel to their vaccination, making them less reliant on parents/carers and helping them to get their vaccine at a more flexible time that suits them.

Spread of misinformation

Young People were concerned about the **truth** within information that can be unofficially circulated on **social media platforms** about COVID-19, vaccinations, and the wider pandemic. One young person dubbed this the *deadly spread of misinformation* and compared it with the Autistic Spectrum Condition MMR Vaccine controversy.

Young People argued that the spread of misinformation can create a lack of clarity around the risks and dangers of vaccinations. Young People suggested that Communications and Engagement professionals should take a **Scientific Approach** to encouraging vaccine uptake among young people. They suggested that focus within Communications should be on providing scientific evidence and research, which is translated into accessible information for young people, so that they can have the objective facts surrounding vaccinations. They suggested that this would help young people make an **informed choice**.

O Parental consent

Young People understood the important role of **parent/carer consent** in medical procedures and treatments, including vaccinations. However, they were concerned and suggested that adults can also be '*irresponsible*' and may not make an informed choice which will help protect their child from COVID-19. Young People suggested that the principles of **Gillick Competency** should be respected and championed within the vaccination procedure, where possible, to allow young people to have a say in their health and care.



Young People also suggested the idea of **robust and validated information** being circulated to children and their families via schools & colleges, to enable parents and carers to receive accessible, reliable, scientific information which will help them to make the right choice for their child.

NHS Communications

Young People spoke without prompt about Booster Text Messages and Communications. While this is important, Young People noted that Booster reminders often start being sent as soon as you receive your second dose, and this is ineffective timing as they still have to wait three months before receiving their booster jab. Young People also noted that constant messaging can be frustrating for them, though sometimes reminders can be helpful for a young person who has forgotten.

One young person suggested that, along with marketing messages, **incentives** should be offered to encourage uptake, such as entering a competition to win a gift voucher. While young people said this is unlikely to be able to happen at a larger scale, they said that this may be an appropriate method for smaller communities, such as towns/villages and social groups/marginalised communities who may have lower uptake, to encourage uptake within that community.

Young People also noted an increase in scam messages, often by text, which can confuse young people. This may also lead to some distrust for the system.

4.3.2 Key Debates within COVID-19 Mass-Vaccinations

Young Volunteers were provided with overviews of a selection of key debates that government decision-makers, local health and care partners, other young people and media professionals are highlighting, and shared their opinions below:

1. Parental Consent Vs Young Person Consent

Young People noted that parental consent can be a major factor in whether a young person gets vaccinated. Even if the parent/carer does not actively try to stop their child from getting vaccinated, if they are against vaccinations, Young People may be worried that they will be treated differently by the parent/carer if they get vaccinated, or that they will be 'letting them down'. This may deter them from getting vaccinated.

Young People also suggested that lots of young people do and should have the ability to consent to getting vaccinated, particularly when this is accompanied by:

- 1) Education about the vaccination process and dangers of viral pandemics.
- 2) And awareness and communications materials to share scientific evidence and FAQs to allow an informed, scientifically rooted decision.



2. Health Disclosures Vs Feeling Comfortable

Young People were concerned about the questions which are required to be asked before a vaccination is administered, namely: "Are you pregnant or breastfeeding?"

Young People understood the clinical and medical significance of this question and why it needs to be asked. However, they were concerned that this could **out** young people as being sexually active to parents/carers/relatives who might be at their appointment with them, as well as to friends or locals who might be within earshot in a mass-clinic. This could cause distress or worry for them.

One young person noted that this could also create trouble for them at home, such as punishments or bullying within the family. Moreover, this could lead to discussions around sexuality and gender expression, which young people noted can be tricky to have, and should be had when the young person is ready. This could also lead to a disclosure around sexual assault or abuse, and the young person might not be ready to share this issue with their family yet.

Young People suggested to counter this, that vaccine communications and materials should make patients aware that they will be asked this question, so that they can make an appropriate choice about who to bring with them for their appointment, so that they can still answer the question honestly and ensure that the professional administering their vaccine has all the facts before giving the young patient their dose.

3. Vaccinating in Schools Vs Vaccination Venues

Young People had a lively discussion about vaccinating in schools, and concluded that it is worthwhile, including the prospect of vaccinating in **primary schools**, to ensure that protection and immunity is established from a young age. However, they noted that we cannot be too reliant on schools and colleges, and that some young people:

- Do not attend school/college (or were absent during the vaccination period)
- Are more comfortable receiving their vaccine with their parent/carer/support network, who will not be present in an educational setting
- Would rather receive their vaccination in a more relaxed environment (some young people find schools stressful, particularly in assembly halls, which they may associate with exams)

Therefore, triangulating venue options is thus the most appropriate way to cover a wide remit of young people.

Young People also suggested that settings should follow-up if parental consent is suddenly withdrawn or just not given, to aid organisational learning and help professionals at a local authority and NHS commissioning level to understand what factors can prevent a dose being successfully administered to a school pupil.



4. Vaccination of Children Vs Waiting until they're older

Young People suggested that **primary school children should be receiving a COVID-19 vaccination** to ensure that they are best protected from a young age. However, this should be accompanied by:

- 1. Adaptions to the delivery, such as the use of no-needle-vaccines (e.g Flu jabs).
- 2. Appropriate parent/carer liaison.
- 3. Delivery of vaccination within primary schools, with further opportunities in community healthcare settings (with adaptations to mass-clinics to ensure they are friendly and relaxing environments).
- 4. Ensuring young people are aware of what vaccinating means encouraging schools to this as an opportunity to educate and embed vaccination (such as the processes and impacts) into teaching and learning (likely within the Science curriculum).
- 5. Providing appropriate Communications and targeted community engagement to ensure that children, staff, governors, and parents/carers feel confident in decision-making on vaccines. A cost-benefit analysis (CBA) was suggested by one young person as an appropriate tool for both organisational(school) and individual decision-making.

Young People are aware that this is still an ongoing decision and debate within the department of Health and Social Care, but wished to share their opinions on the matter.

4.3.2 Potential strategies to increase COVID-19 vaccination uptake among children and young people

Young People shared their views on a variety of strategies to increase uptake and gave valuable insight into whether these would be appropriate, feasible and well-received by young people in East Sussex who are pending vaccinations.

They commented on both strategies that are implemented and those which have been discussed or contemplated to be used in the future if low uptake persists.

Strategies that were deemed likely to be well-received by young people:

Myth-Busting and Frequently Asked Questions (FAQs)

Both Healthwatch East Sussex Young People and Staff have highlighted a need for communications and marketing materials which include myth-busters and FAQs. This links into earlier recommendations about promoting the scientific basis for receiving a COVID-19 vaccine dose.

This was ranked likely to be well-received by young people because it would clearly explain what is involved, and will debunk any unfounded accusations, myths, and irrational concerns regarding vaccinations. Policies and guidance regarding Vaccines and COVID-19 precautions are often changing, and so producing and releasing these documents regularly would help to ensure that young people have easy, clear, up-to-date information that tackles their concerns and explains more about the process. One volunteer noted that little information may have worked for the first cohort who knew they were vulnerable, but we now need to be 'much more intensive with our marketing to young people' so that they have all the information they need to decide.



Strategies that recognise the role of friendship groups

Young People noted that peer groups receiving their vaccinations together might encourage uptake, to enable them as a group to attend social events which require or is best practice to be vaccinated, like concerts, gigs, and pubs. Young People suggested that professionals should not underestimate the power of friendship groups and social groupings, with young people going to get their vaccinations together and supporting each other through the process.

More Weekend Vaccinations

Young People wanted decision-makers to note that students are often tired at the end of the day (or during the school day, for school-based vaccinations), and so weekend vaccination centres are often a good solution. Parents/carers are also more available, and this alleviates worries around transport and 'going in alone'. Young People can also go with friends and make it a *social* event.

More Accessible and Easy-Read Information

As highlighted in the Communications section of this report, young people again noted the importance of communications that is friendly in its nature. Marketing materials should be youth-proofed and 'cringey' graphics and 'cheesy' messages should be avoided; young people often just want the facts, such as the date and time of local venues, and what the law says (such as duration between 1st and 2nd jabs). Young People also noted the importance of Tiktok and Memes which allow for comedic value while still transmitting important messages about vaccinations; these are still significant news sources for a lot of young people and are therefore channels that we cannot and should not underestimate.

Young Ambassadors and Champions

Young People stressed the importance of community ambassadors and volunteers who, are the same age as a young person or slightly older, who can act as role models to encourage uptake. It was suggested that young people would respond well to this, with young volunteers resonating with students in a way that older representatives might not.

Support with Patient Transport

As highlighted elsewhere in this report, patient transport remains a significant factor in a young person's decision-making processes for getting vaccinated. The Young People we spoke to suggested that receiving support and guidance with patient transport can help turn a 'maybe' into a 'yes', and also allows for more patient choice, enabling young people who might not be comfortable answering medical questions in front of parents or guardians, to have another option. However, more communications and marketing is required to increase young people's knowledge and exposure to alternative transport opportunities for their vaccination appointments.



Targeted Youth Work

Young People noted that on-the-ground youth support workers are a key stakeholder in the distribution of COVID-19 vaccinations as they are able to disseminate information and communications materials to young people in a supportive and inclusive environment.

More Positive Media Coverage

Young People reflected on their personal exposure to media (particularly news media and social medias) and noted that, within the context of COVID-19 Vaccinations:

- Media coverage often showed limitations of vaccination provisions, such as difficulties receiving an appointment and long queues outside of centres
- Media coverage often focused on showing areas that have low uptake, without necessarily always showing how uptake could be increased

Young People urged media coverage to focus more on answering FAQs and showing scientific evidence of vaccinations, to encourage uptake among youth communities. Furthermore, they suggested that interviews or stories involving young leaders who are speaking up about positive vaccination experiences and why it is important to get vaccinated, would also help to increase uptake among young people currently undecided.

This strategy brings together other key focuses identified by the young people we spoke to, but is fundamentally underpinned by an understanding that young people are media-saturated and that system leaders need to be using media and communications functions to interact with youth in a positive way if we wish to encourage uptake.

Young People's Reflections on School-based Strategies:

As summarised elsewhere in this report, young people ultimately recommended that, while school-based vaccination services and promotion is important, NHS leaders risk being overly reliant on the education system and need to think about reaching young people who *slip through the net*. This recommendation is further supported by young people's thoughts on school-based strategies to increase uptake:

Vaccination Delivery within Educational Settings

Young People suggested that vaccination services within educational settings could be successful in increasing COVID-19 vaccine uptake, however they were concerned that this is not, and should not be, a universal approach; there are young people who this will not reach. We need to be reaching young people not in education. One young person was particularly concerned that Pupil Referral Units (PRUs) and other establishments separate to mainstream education might be overlooked or forgotten about within both the promoting and providing of vaccinations.



Vaccination Promotion within Educational Settings

Young People did suggest that promoting vaccinations through educational settings might be well-received by youth in East Sussex. They noted that this could take different forms, including:

- 1) <u>Understanding of Vaccinations</u>: Embedding knowledge about the vaccination procedure, the meaning of immunity and the role of the Immune System, within teaching and learning.
- 2) <u>Promoting Uptake</u>: Visitors and guest speakers to encourage uptake (this could also be in the form of videos).
- 3) <u>Provision of Information</u>: A space to provide young people and their guardians with clear, unbiased, scientifically rooted information about vaccines, as well as the distribution of up-to-date COVID-19 guidance and information about upcoming vaccination clinics and opportunities.

Schools are undeniably an important distribution network, though decision-makers still need to be cautious to ensure that young people outside of *traditional* education have access to the same materials and learning on the topic of COVID-19 vaccines.

Strategies that Young People found questionable or unlikely to be successful with young communities:

Mandatory Vaccinations

Young People were hesitant to support the idea of mandatory vaccinations. They believed that this may have the opposite effect on young people - young people want to feel empowered and in control of their own health and care. We want young people to get vaccinated, but we want them to feel autonomy and have all the information and support networks needed to make the right choice for them. Forced vaccinations can prevent children and young people from developing this important ability to assess the benefits and costs of treatments and healthcare, which is a skill that they will require throughout their life and journey through British healthcare.

Vaccination Passports

Young People suggested that passports would be an effective strategy at certain points of the year, such as when festivals occur, and when holidays are more likely (such as school holidays and celebrations throughout the calendar). This is supported by Enter & View engagement findings which showed that getting vaccinated for holiday was a key motivator for people. One young person also praised the use of digital passports, noting that young people might be liable to losing a hard copy of a passport.

However, young people noted that other youth in their circles have struggled with understanding how to use passports and when you need them for. This shows a communications and engagement need, and therefore that passports might be a more appropriate method of increasing uptake if guidance is given on how and when to use them.



Letting People view the effects of COVID-19 for themselves

While this is not a Public Health-adopted approach and is more of a concept that is sometimes discussed by some people (potentially in the mass media), Young People showed immediate concern and viewed this perspective as incredibly dangerous to the health and wellbeing of youth communities.

This forgets the impact on anxiety and Mental Health & wider wellbeing that having COVID-19 can have. Also, while most argue that young people will have weaker symptoms and suffer less, this is not always the case, and symptoms can still be painful and distressing (not all children and young people are asymptomatic). Furthermore, while a young person themselves may not suffer, they may spread it to others who might suffer, all the while increasing the circulation of coronavirus within their community and social circles.



5. Recommendations

Using our findings from the three distinct exercises, Young Healthwatch East Sussex recommend the following, in relation to children and young people's vaccinations:

(We recognise that some recommendations are in the process of being implemented. Where this is the case, these recommendations are about maintenance and sustainability of the recommendation and monitoring for a successful implementation).

5.1 Recommendations for Vaccinators

All methodologies used showed that levels of anxiety related to the clinical environment and medical instruments can be a barrier or additional worry for young patients.

- 1. Training for new vaccinators should continuously incorporate how to respond to, support and comfort, anxious young patients. Vaccinators should be conscious to respond in a calm, measured and respectful way. Vaccinators should avoid patronising language which could further distress the patient. Likewise, vaccinators should be reminded to discuss side-effects, aftercare, and offer a chance for patients to ask questions before the vaccine is administered.
- 2. Vaccinators should be aware of high numbers of needle-phobic cases among children and young people and be supported by volunteer coordinators and practice managers to feel confident in engaging with a young person who is needle-phobic. A baseline level of knowledge of the behavioural basis behind phobias should be provided to vaccinators so that they are aware of why phobias can occur and what might be helpful to say and what may be less helpful.
- 3. Vaccinators (and wider staff members involved) should be aware of high levels of mental health complications among local children and young people, exacerbated by the pandemic. Strategies should be designed with young people and Mental Health First-Aiders to tackle this and provide a safe and supportive environment for young patients.

5.2 Recommendations for the Youth and Education Sector in East Sussex

- 4. Young People may be unaware of their rights as a patient, and at what age these rights change at. Youth and Education professionals should embed awareness on young people's rights as a patient into youth curriculums, such as Lifelearning, or youth groups/clubs that are themed around personal and social development.
- 5. Young People should be trusted to make their own decisions about their health and care. Youth and Education professionals should empower children and young people with knowledge about health, care and what services are available, and help to connect children and youth up to services that can help them navigate the health and care system in East Sussex, such as the HWES Information and Signposting hotline.
- 6. Youth Workers, Teachers and Community Volunteers are a significant stakeholder in a child's life, and this importance should be reflected in NHS decision-making and policy-shaping.



7. Regarding scam texts and other ICT issues relating to vaccines & wider health, professionals who work with young people should actively engage young people in discussions around online safety and how to detect a fake message, and how to respond appropriately.

5.3 Recommendations for Communications and Engagement Professionals

- 8. Families and Households remain a key provider of information for children and young people aged 16-18, and vaccination services and associated communications & engagement should take this into account when designing materials and carrying out targeted promotions.
- 9. Communications and Engagement with children and young people in this age bracket should encourage traffic towards the NHS Website, as this appears to be a dominant mechanism for young people when they're seeking a vaccination appointment. However, some found the NHS booking system difficult to navigate, which could be rectified by ICT adaptations or the provision of appropriate supporting resources to help a young person book online (see 5.2).
- 10. Young People's motivations are varied but tend to be selfless and community-focused/family-oriented, which is important for communications professionals to understand when creating materials aimed at encouraging uptake.
- 11. Young People suggested that patient transport alternatives need to be promoted further and clarifications need to be made to young people regarding cost and eligibility for transport support.
- 12. Young People suggested that Communications and Engagement professionals should take a Scientific Approach (data-driven, factual sources of information) to encouraging vaccine uptake among young people, which is likely to resonate best and have the biggest impact upon their understanding of vaccines. Communications with young patients should be well-considered due to the potential for it's nature to be counterproductive and the impact that would have. Coproduction and co-design with young people (such as a focus group or young volunteers) would aid this.
- 13. FAQs should be provided where possible to help make children and young people make an informed choice, supporting them to digest information on the vaccine and the process of receiving it.
- 14. Alternative methods, such as videos or social media, should be explored to create an engaging and unique way of communicating information that may be more youth-friendly.
- 15. Communications and resources should comply with existing standards and strategies across the UK to support neurodiverse individuals, outlined in the NHS Accessibility Standards.
- 16. Young Healthwatch East Sussex will monitor communications and engagement activity and support local professionals to develop their marketing with children and young people through a workshop in youth-friendly communications. Young Healthwatch's Communications and Campaigns group will monitor vaccination communications and provide support to the local authority and ICS, acting as a 'sounding board' to support codesign and effective promotion where possible.



5.4 Recommendations for Vaccination Service-Providers

- 17. The presence of parents/carers/guardians is reported to be a positive presence for some young people still. Facilities should allow for the presence of the caregiver, where possible, and be mindful of guardians as support networks for anxious young patients.
- 18. Some young people (25%) were not seen until after 10 minutes. Providers should be honest about possible waiting times and offer timings that are more flexible to young people, to avoid build-up of queues.
- 19. Young People should be made aware that questions of a sensitive nature might be asked during their appointments so that they can prepare for this.
- 20. Vaccination services should continue to offer clinics and appointments outside of office hours and provide more antisocial appointments where possible (such as 6-10PM).

5.5 Recommendations for the Integrated Care System (ICS)

- 21. Young People are concerned about side-effects and this is something that system-leaders need to be aware of, as side effects could affect a young person's ability to work or be in education for short periods of time to recover.
- 22. Location can be a barrier for young people who can't drive or rely on public transport, particularly in rural areas. Young People should be consulted on future decisions relating to the shuttering or opening of new vaccination facilities in East Sussex. Likewise, Young People suggested that patient transport alternatives need to be promoted further and clarifications need to be made to young people regarding cost and eligibility for transport support.
- 23. Vaccination services should not be over-reliant on schools and colleges to reach children and young people who might 'slip through the net'.
- 24. Decision-makers need to recognise that there is power in friendship groups and the role of peers in influencing choice.
- 25. Vaccination Ambassadors, champions and volunteers play a strong role in supporting a young patient to make their decision and have a safe and supportive appointment, and this should be reflected in commissioning and consequently in budgets, staffing and future opportunities/programmes.
- 26. The ICS should be aware that some young people are struggling with understanding and using their vaccination passports. This should be considered in future approaches to COVID immunisation and appropriate support/communications should be in place to help young people navigate COVID-19 vaccination passports.

5.6 Recommendations for HWES and Young Healthwatch East Sussex

27. HWES to take the learning from this project to inform how we carry out future reviews of other Children and Young People's Health services in East Sussex. HWES to share the learning from this review with statutory and voluntary sector partners across Sussex, other



local Healthwatch and with Healthwatch England. HWES and ESCV to use strategic networks and connections to share recommendations with policy-makers and system leaders.

- 28. HWES to continue to engage with children and young people and develop the Young Healthwatch provisions further to keep the conversation going with young patients. Further research and deliberative engagement to take place into younger age brackets to gain a broader understanding of COVID-19 immunisation for children and young people.
- 29. Young Healthwatch East Sussex to continue to monitor the implementation of communications and engagement guidance to ensure youth-friendly approaches are used within the COVID immunisation programme.
- 30. Young Healthwatch East Sussex to create an engaging, youth-friendly resource to accompany recommendations in this report, to extend recommendations across different audiences and to share learning with other young people.

Acknowledgements

We would like to thank our Young Healthwatch volunteers for their passion, excitement, and knowledge throughout this project.

We also acknowledge and thank our staff, board members and adult volunteers for their support and guidance throughout these activities.

We extend thanks to our Healthwatch colleagues in Brighton & Hove and West Sussex for supporting aspects of our deliberative exercises.

Follow our work

Please get in touch with Young Healthwatch East Sussex to hear more about our projects and the young people who work with us.

Your staff contact for this report is:

Edward Peasgood

Participation Worker

Healthwatch East Sussex

Email the team: enquiries@healthwatcheastsussex.co.uk

Check out our website:

https://healthwatcheastsussex.co.uk/young-healthwatch/

Give us a call (we can call back): 01323 403 590

Our office address is: Barbican Suite, Greencoat House, 32 St Leonards Road, Eastbourne, BN21 3UT



6. Appendices

6.1 About Healthwatch East Sussex (HWES)

Healthwatch East Sussex is the independent watchdog for Health and Social Care patients in East Sussex. HWES shine a spotlight on patient experience and work with system leaders and decision-makers to initiate change using service-user feedback, furthering our aim for public-centred services in East Sussex.

6.2 About Young Healthwatch East Sussex (YHW)

Young Healthwatch East Sussex is a new youth voice group, set up in July 2021, to explore and highlight health and care issues that face children and young people across our county. YHW's approach combine traditional youth work practices with creativity, technology, and youth leadership, to create an exciting and engaging program for local young people to act as community ambassadors and support our projects and campaigns on children and young people's health topics.

Young Healthwatch East Sussex - Service Aims:

- To capture young people's experiences of the Health & Social Care sector in East Sussex.
- To engage young people to better understand the services that are available to them locally.
- To work with young people to ensure their voice is heard by those planning, commissioning, and delivering Health & Care services locally and nationally.
- To engage with young people across East Sussex and capture their experiences of Health and Social Care.
- To promote the involvement of young people in the monitoring, commissioning, and provisioning of health and social care services.

6.3 About East Sussex Community Voice (ESCV)

East Sussex Community Voice is a community-interest company set up to champion the voices of local people.

East Sussex Community Voice delivers Healthwatch East Sussex, It Takes a Village to Raise A Child (VRAC), and a number of youth voice and participation initiatives aimed at amplifying young people's voices. Our approach to youth voice and participation is explored more here: https://www.escv.org.uk/services/youth-voice-and-participation-services

ESCV's commitment to youth voice and participation has supported the development of Young Healthwatch East Sussex, with learning and recommendations shared across projects.



6.4 Survey Promotion



Experiences of Vaccinations across Sussex

Aged 16-17 and vaccinated against COVID-19?



Complete our COVID-19 Vaccination Experiences survey so that we can let local health care providers know what worked well for you and what needed to be improved.

Your Local Healthwatch wants to hear about:

- Your motivation for getting vaccinated
- The information you received and found about getting the vaccines



 The wider impacts of the COVID-19 pandemic on your education, mental health, and physical health

Survey Deadline; 31st January 2022

You can complete the survey via this link, or a paper copy can be downloaded via our website.

https://www.surveymonkey.co.uk/r/COVID19Vax1617

Contact us:

Healthwatch East Sussex: enquiries@healthwatcheastsussex.co.uk

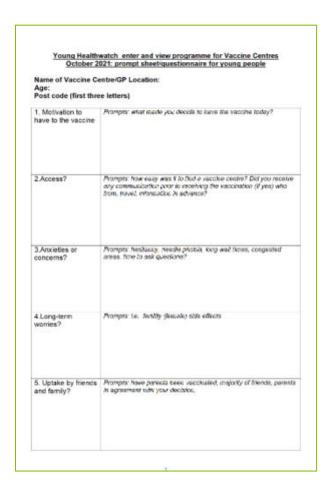
Healthwatch West Sussex:helpdeck@healthwatchwectsussex.co.uk

Healthwatch Brighton & Hove: office@healthwatchbrightonandhove.co.uk

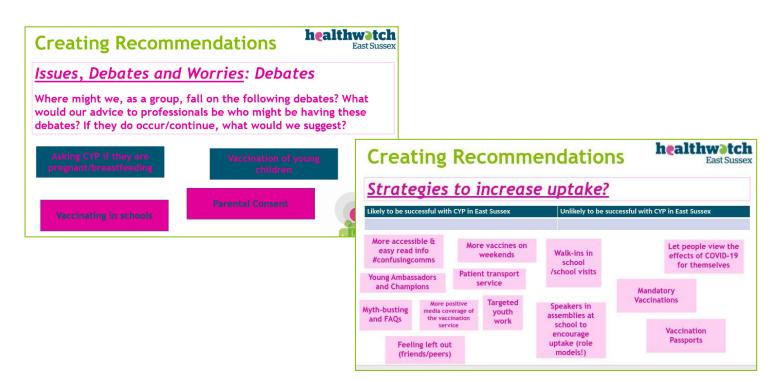
Survey created by volunteers from Young Healthwatch East Sussex



6.5 Community Outreach Template



6.6 Examples of coproduction discussions





6.7 Social media promotion





Young Healthwatch East Sussex

Run by young people, for young people

Shining a spotlight on young people's experiences of health and care in East Sussex

