

# HEALTH AND CARE RESEARCH

## LISTENING PROJECT

NHS

Mid and South Essex



We are collaborative



We are compassionate



We are innovative



We are living well

Working together for better lives

Mid and South Essex NHS commissioned ECVYS to run a listening project with youth groups and organisations in the Mid and South areas of Essex, with the aim of getting a better understanding of young people's participation in, and understanding of health and care research.

The Mid and South Essex NHS wanted to establish what subjects young people feel are important to them, what the barriers are for young people to take part in research and what would promote more young people's engagement.

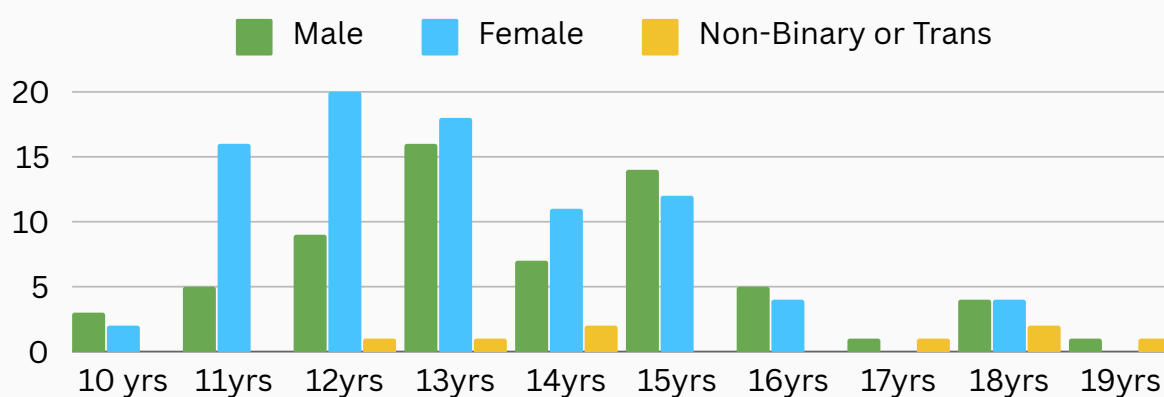
Five of the groups that participated in our listening project were groups for young people with protected characteristics, and the other five groups were open access youth groups.

Through this listening project, Mid and South Essex NHS intend to get more young people involved in future research so that they can provide a better service, more opportunities and enhance the lives of young people.

### QUESTIONS FOR YOUNG PEOPLE...

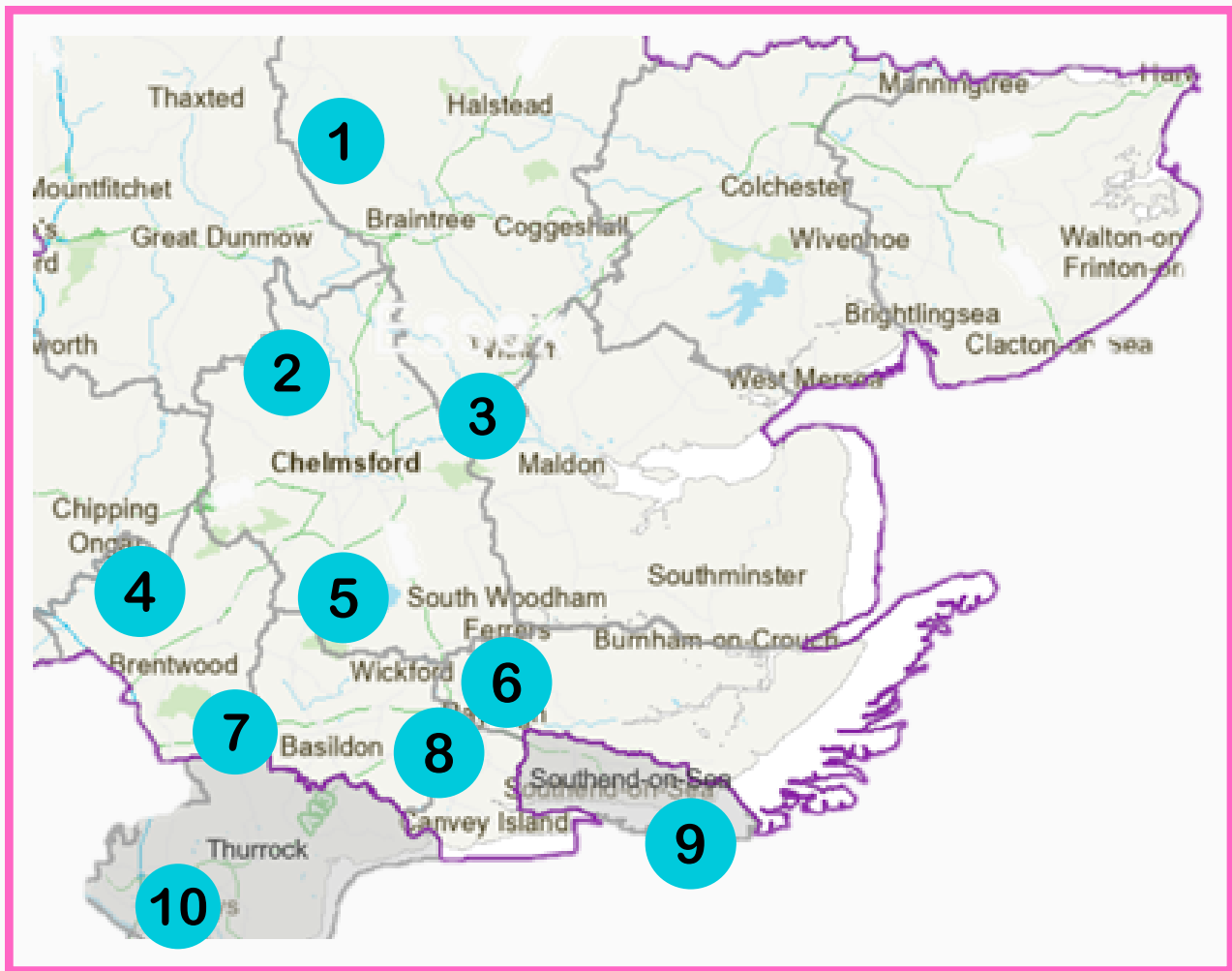
- 1) Have young people been given the opportunity to take part in health and care research?
- 2) Would young people like to take part?
- 3) Why/why not?
- 4) What do young people think are the most important health and care issues for them that they think should be researched further?
- 5) Do young people think their views would be respected and valued if they took part in the research?
- 6) Why/why not?
- 7) What are the barriers for young people to take part in health and care research?
- 8) What would motivate young people to take part?
- 9) What is the best way to let young people know about opportunities to take part in health and care research?

### 160 YOUNG PEOPLE AGED BETWEEN 10 – 25 YEARS OLD TOOK PART



50

# LOCATION OF THE PARTICIPATING GROUPS



1



SEN youth group  
in Braintree

2



LGBTQ+ youth group  
in Chelmsford

3



Uniformed girls group  
in Heybridge

4



Church youth group  
in Brentwood

5



Ethnic minority youth group  
in Wickford

6



Detached youth work in  
Rochford

7



Ethnic minority youth group  
in Basildon

8



Youth boxing Club  
in Canvey Island

9



Open access youth group  
in Southend

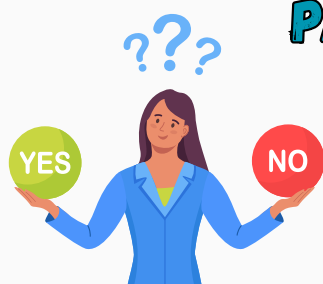
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Open access youth club  
in Thurrock



# HAVE YOUNG PEOPLE BEEN GIVEN THE OPPORTUNITY TO TAKE PART IN HEALTH AND CARE RESEARCH?



One group of young people said they take part in an annual wellbeing survey at school.

## PART IN HEALTH AND CARE RESEARCH?

### 72% SAID "NO"

Although this statistic shows that 28% of young people said they have taken part in Health and Care Research, we feel that this is actually a much lower percentage. Youth leaders fed back to us that many of the young people did not understand what was meant by 'Health and Care research'. Because of this misunderstanding, many young people answered "yes" thinking they have taken part because they have completed first aid training or a health and social care course.

# WOULD YOUNG PEOPLE LIKE TO TAKE PART IN HEALTH AND CARE RESEARCH ?

### 74% SAID "YES"



*Comment from young person:*

*"I feel we are at a good age to give a good perspective on this subject"*

2% of young people said "Maybe"

## WHY TAKE PART?

These percentages are based on the number of comments given, as not all the 160 young people that took part in this listening project left feedback for this question.

- 37%** It could help me, or people I know, in the future
- 17%** It would be interesting and I might learn something
- 14%** If I get paid for it, why not?
- 13%** If it means more health and care support for LGBTQ+ community
- 7%** It sounds like fun
- 7%** I've got nothing better to do
- 1%** I'm happy to do something positive
- 1%** It will raise awareness
- 1%** I like doing quizzes/surveys
- 1%** If it gets me out of school
- 1%** It might help with exams

*Comments from young people:*

*"If there's a chance it will save people's lives, then I will"*

*"It might be educational and I'll learn about illnesses"*

*"I would like to give back to the community"*

## WHY WOULDN'T THEY TAKE PART?

- 14%** It's boring
- 13%** I don't understand what it means
- 12%** I don't like hospitals or doctors
- 11%** I wouldn't take part in physical research, but would do a survey
- 9%** I don't feel educated enough on the topic
- 9%** I can't be bothered
- 8%** I don't see the need to be involved
- 7%** I don't really understand why I would be asked
- 7%** I don't know enough about what it would involve
- 5%** I'm concerned about privacy
- 2.5%** It won't help anyone
- 2.5%** I don't have time

*Comments from young people:*

*"It's not my problem"*

*"Not sure if the information I can give would be of much benefit"*

*"I wouldn't take part in research if I'm not interested in it"*

WHAT ARE THE MOST IMPORTANT HEALTH AND CARE  
ISSUES FOR YOUNG PEOPLE THAT SHOULD BE RESEARCHED  
FURTHER?



Mental health was the most frequent response, with some young people mentioning that there should be better counsellors and support for students in school. Young people talked about the **“overwhelming pressure and expectations”** at school, and some young people commented **“School don’t care about mental health, just our grades and education”**.

Young people that said “Exercise” discussed **“the positive effects”** and said that **“young people are not getting enough exercise and more should join sports clubs”**

There were some insightful discussions around sleep deprivation; how this can be down to screen time, which can then have a negative impact on their lives by causing tiredness and being less productive in education and life in general.

ECVYS were asked to ensure 50% of the groups involved were with people with protected characteristics, so the data collected may be emphasized by the needs of those groups.

Young person’s comment:

**“Please research why teenagers are addicted to social media”**

# DO YOUNG PEOPLE THINK THEIR VIEWS WOULD BE RESPECTED AND VALUED IF THEY TOOK PART IN RESEARCH?

**YES!**  
**47%**



**11%**

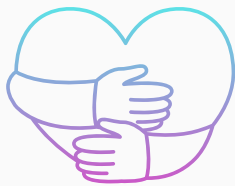
\*SOME YOUNG PEOPLE SAID "WE WOULDN'T TAKE PART IF IT WASN'T ANONYMOUS"

**NO!**  
**42%**

## WHY?

These percentages are based on the number of comments given, as not all the 160 young people that took part in this listening project gave feedback for this question.

- 33%** Because they are asking questions, we hope they care and will listen and make positive changes
- 13%** Professionals should take everyone seriously
- 9%** It's a big deal I guess
- 9%** If they are nice people, then they will listen
- 9%** Because cancer is a big problem
- 9%** Because there are a lot of us
- 8%** We have more experience about issues facing young people
- 6%** Because some people want to help
- 4%** They should care about young people's views because they are the future



### Comments from young people:

**"I think the NHS would want to know what young people think"**

**"Research is important"**

**"Stress is an illness"**

**"Yes my views would be respected if my opinions or answers were popular ones!"**

## WHY NOT?

- 40%** Young people get looked down upon and are not respected or taken seriously
- 17%** Lack of communication, follow up, and feedback for taking part.
- 7%** Concerns about confidentiality around disclosing sexuality, gender and sexual relationships
- 7%** People don't care or listen
- 5%** Prejudices such as women with menstrual issues or chronic pain
- 4%** Men and women being treated differently even with the same condition
- 4%** Lack of realistic solutions
- 3.4%** Have not been asked, so don't think they really care about young people
- 3%** I don't understand
- 3%** Because I will mess around
- 2.2%** No action would probably come from it
- 2.2%** Fear of being unheard or misunderstood
- 2.2%** Lack of trust

### A Comment from a young person:

**"The NHS do not listen to women, so why would they listen to me" ~ said by a young person with personal experience of the NHS through GOSH**

There were a lot more responses from young people about why they think their views would **not** be respected and valued if they took part in health and care research. Many of the comments expressed feelings that they think adults don't listen to them because they are young;

**"Adults think they know best" "Researchers might expect children to lie or exaggerate"**

The young people also relayed concerns around communication in feeding back to young people about the impact or change that may have happened as a result of their participation in research.

# WHAT ARE THE BARRIERS THAT STOP YOUNG PEOPLE TAKING PART IN HEALTH AND CARE RESEARCH?



The top two answers clearly show that young people feel that the lack of incentives and opportunity to take part are the biggest barriers to getting involved in health and care research.

Many young people stated that ***“We might be more involved if given the chance or opportunity”***

Worries around their privacy was the third highest concern, with various comments like ***“I feel afraid to speak out” “I would be anxious my answers wouldn’t be anonymous”***.

***Comments from young people:***

***“It depends what the subject is”***

***“I’m worried about not being believed”***

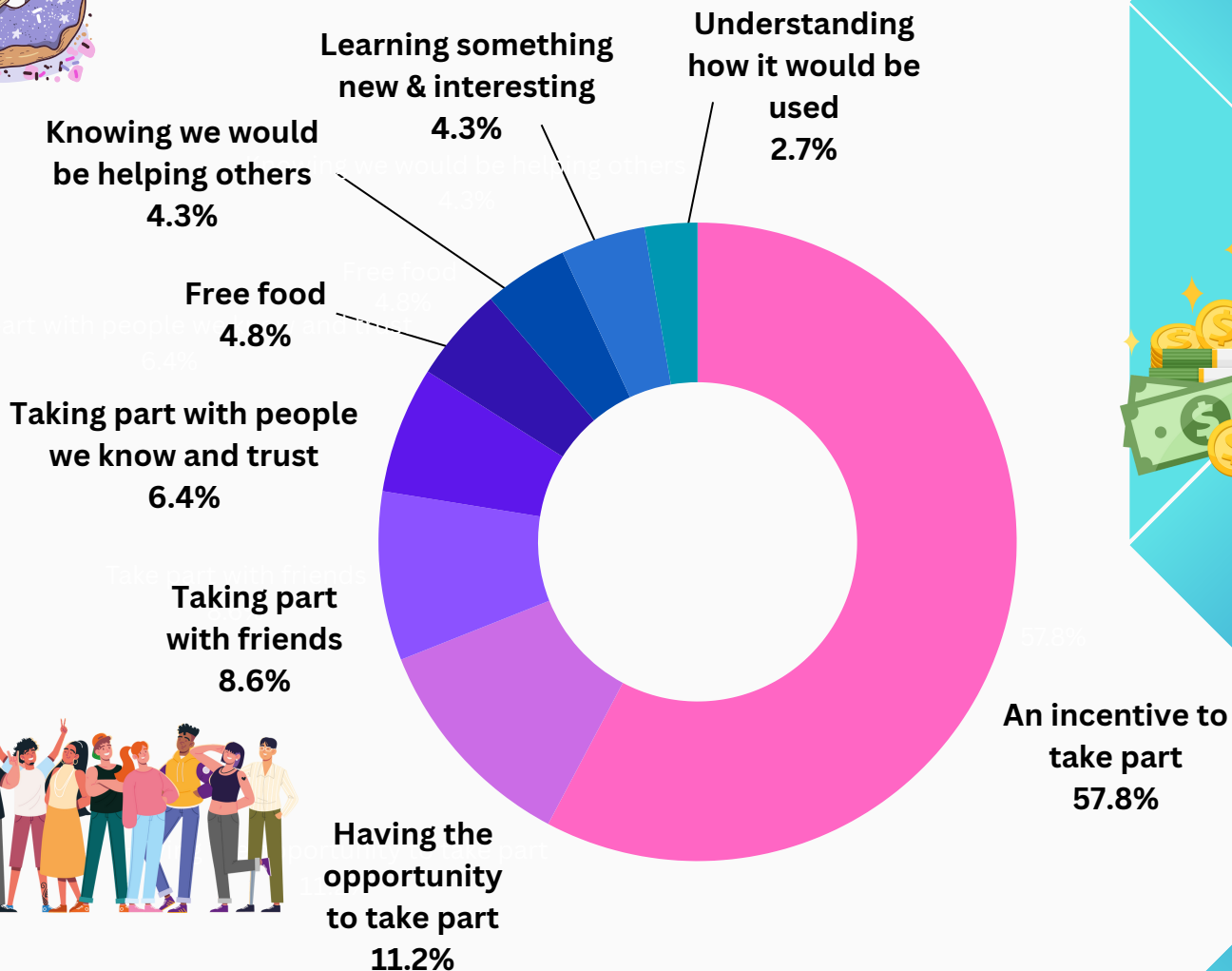
***“It depends when they do it, I don’t want it in holidays or weekends”***

***“Adults don’t think our views are worth listening to”***

***“I had a bad experience with my GP” ~ said by some young people***



# WHAT WOULD MOTIVATE YOUNG PEOPLE TO TAKE PART IN RESEARCH?



**OUT OF THE 108 YOUNG PEOPLE THAT SAID “INCENTIVES” WOULD BE THE BEST MOTIVATION TO TAKE PART IN HEALTH AND CARE RESEARCH, 84% SPECIFICALLY MENTIONED “MONEY”**

Offering young people incentives to encourage them to participate in research is a clear winner for this question as **“incentives” was stated by almost 60% of the young people; and was over five times more popular than the next response!**

There is a consistent consensus from young people across all the participating groups, that they struggled to understand what was meant by ‘health and care research’, and that their not understanding what this entails is automatically a barrier that stops them getting involved.



# WHAT IS THE BEST WAY TO LET YOUNG PEOPLE KNOW ABOUT OPPORTUNITIES TO TAKE PART IN HEALTH AND CARE RESEARCH?



**“Social Media” was the most popular way that young people would like to be used to let them know about opportunities to take part in health and care research.** Social Media was said more than double the amount of times than the next response “School”.

**Comment from young person:**

***“Tell us on Roblox”***

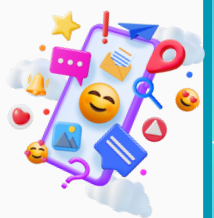
**Young people said that although “School” would be a good place to let them know about research opportunities, there were mixed views about whether school should be the location that the research is run from.**

A couple of young people said they would be more likely to take part on a school day because it would be mandatory, but some others said that it would feel too much like a lesson and they would be less likely to get involved properly.

**“Youth groups” was a very close third place answer, and had only three less votes than “at School”.**

The young people that mentioned **“posters”** said that the best place to put them up would be in School toilets, or at the Doctors and Dentist.

The young people that said they would like to be told about opportunities **“by post”** said that they like getting letters addressed directly to them.



## SUMMARY OF FINDINGS

This was an interesting topic for young people to participate in and has highlighted a resounding theme that **Young people do want to take part in research, and be listened to:**



***“Please research how to make young people be heard”***

***“Please actively listen to youth groups”***



**However, the young people who took part really struggled with the concept of “health and care research”, what it was, what it involves and why they would be asked to participate in it.**

Youth leaders fed back to ECVYS that, because young people do not have much interaction or need to use NHS services directly, they could **not** comprehend why they were being asked about taking part in health research. This lack of knowledge and understanding meant that some young people thought that taking part would be boring, or that they may have already taken part because they had completed educational courses such as Health and Social Care and First Aid.

**This confusion had an impact on some of the feedback for this listening project, and we would recommend that a basic awareness of health and care research for young people is invested in.**

**This would also need to promote the importance of their views, and the difference that they can make if they take part.**



***“We would like more information on the topic”***



***“We want services to be transparent and open about what happens with our feedback”***

**Overall, this listening project shows that the majority of young people have NOT taken part in health and care research, but that almost three quarters of the young people WOULD LIKE the opportunity to take part.**

**37%** of the young people said they would like to take part so they can help other people and **17%** said they would participate just to learn something new.

**Many of the young people who said that they would NOT want to take part, said it was due to a lack of understanding, privacy fears and because they didn’t like hospitals or G.P’s.**

**Mental Health** is the most important topic that young people feels needs more research, followed closely by **vaping**.

There was an almost even split among young people about whether they feel their views would be respected in research, with 47% saying yes and 42% saying no.

**40% of the young people who said “no” said that they feel that young people are looked down upon and not taken seriously.**

Young people said the lack of opportunities and concerns around confidentiality are barriers for getting involved in research, but the young people overwhelmingly felt that **there is a lack of incentive to get involved, with 60% of young people saying that incentives would motivate them to participate in health and care research.**

The best way to let young people know about opportunities to get involved in research is through **Social media**, as it was mentioned more than twice as many times as the next top answer of “school”.

It is really important that young people can go on to see the outcomes of their participation in research, and know the difference that they have made:

***“Once feedback is given, we need to see action”***

**Thank you so much to the Mid and South Essex NHS for funding this listening project, and to all the groups that took part. We do hope that these findings will be really useful in engaging more young people in health and care research- Nicole Redgwell, ECVYS Youth Researcher**