

#EssexYEAH!

YEAH!
report

**Young Essex Attitudes on
Health and Social Care
2014 - 2015**

Hannah Fletcher

Foreword

When Healthwatch Essex came to talk to us about the way young people feel about health and care, we were extremely happy to help. Not many people seem to care about the way we feel about what will happen in our future: we are not allowed to vote on anything major, and most things in our lives are decided by our parents, schools and so on.

Sharing our views and experiences, and hearing about those of others, was really valuable to us, and we really do hope it helped Healthwatch Essex, too. We found the sessions very helpful, as everybody was quite open about their experiences with health and care.

We think it's so very important for our voices to be heard, as we use the NHS and should have some level of say on the things

that affect our health and care. It's also really important because there are many things which are needed that not all adults will realise, so the more input we have, the better.

The YEAH! Report is important, as it is vital to get a full view of everyone's opinion, not just adults. After all, some young people have big problems in their lives such as mental health issues, STDs or being young carers.

We sincerely hope that this report will help raise awareness on the issues of young people, as we are usually seen as unimportant compared to anyone older than us, and our problems don't seem to matter as much.

We hope the YEAH! Report will be seen by people who can make changes, such as advertising services that will welcome young people and be able to help.

Bradley Pankhurst
Leah Nicholas
Kayleigh Youe
John Garner

(Participants of the
YEAH! Project, 2014)

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Introduction

In December 2013, as part of our Young People's Voice Network, Healthwatch Essex produced a film in which young people in Essex shared their experiences of, and thoughts about, health and care.

The video clearly showed that young people in Essex¹ have lived experience of health and care, and are aware of decisions affecting the services that they and their families use. Despite this, they felt that they were seldom listened to, and rarely had a chance to influence the way in which these services are run.

But Healthwatch Essex believes that solutions to many of the problems facing health and care lie in people's lived experience, and it is therefore crucial to listen to young people and understand their needs - but this report is not just an overview; we believe it offers some practical next steps. Public Health England (PHE), in collaboration with the Association for Young People's Health (AYPH), produced a document titled 'Improving Young People's Health and Wellbeing,' (2015) which states that adolescence is:

... a period of increased risks which, if left unchecked, can worsen in adulthood with life-long consequences.²

Public Health England claimed that, not only is this a time of learning, but an ideal time to promote positive health behaviour as most young people are in education. The report adds that "this is also a time when services are often seen to fail young people, particularly in the transition to adult services" (p.13).

In response to our film, Healthwatch Essex created the YEAH! Project: a unique study providing young people across Essex the platform to share their lived experiences of health and care.

Through working in partnership with Essex Boys and Girls Clubs, we were able to speak to 414 people from across Essex, aged 15-19, during the National Citizen Scheme (NCS). NCS has a proven record of ensuring participants represent the socio-demographic of Essex by comparing participant data to the National Pupil Database - this gave us a unique opportunity to engage with a representative snapshot of young people in Essex.

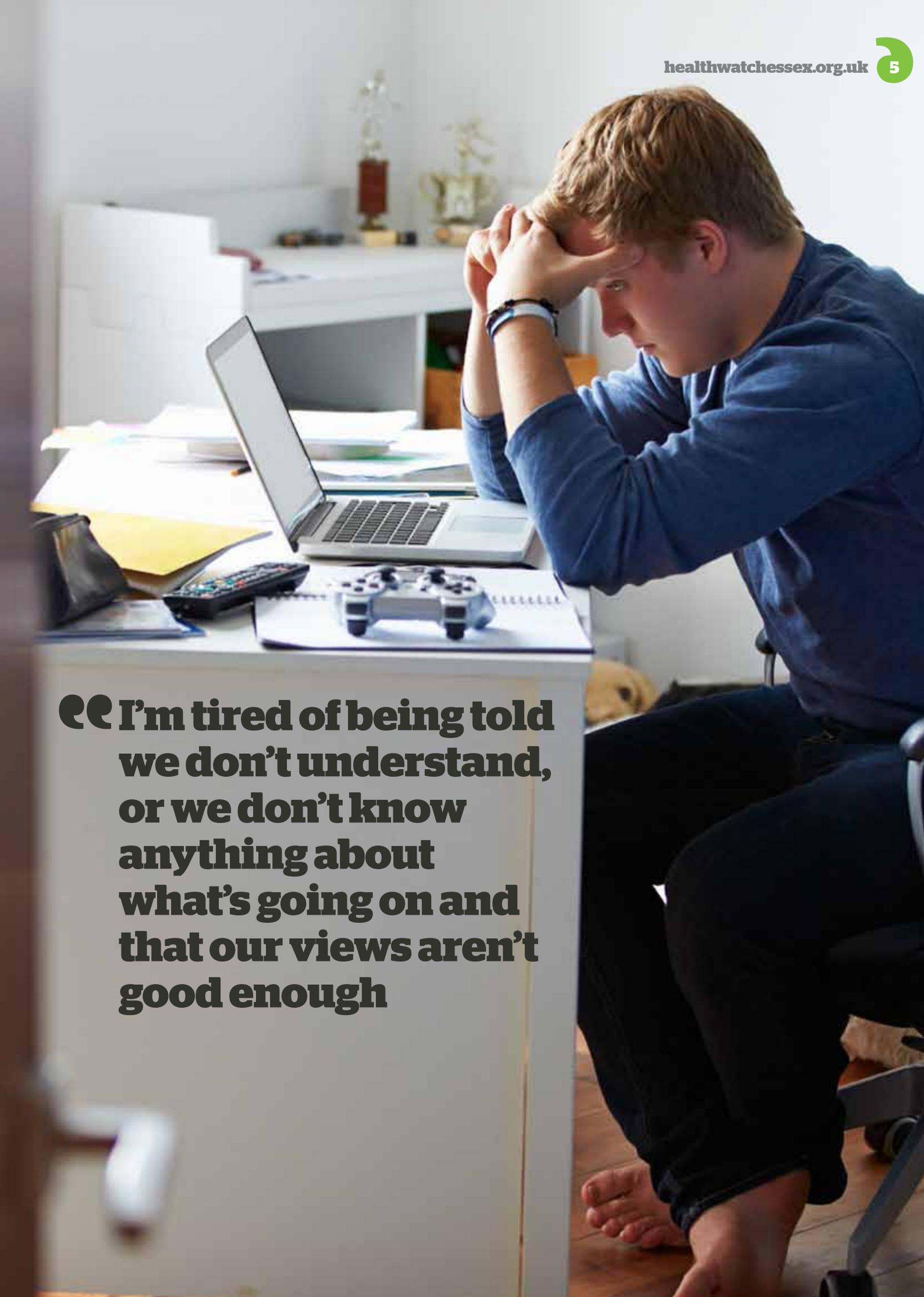
This report has been developed to convey our findings: both the lived experience of our participants, and the priorities and needs as identified by the young people themselves.

We believe that the YEAH! Report is a compelling portrait of the lived experience of young people in our county, and highlights the value of effectively engaging and consulting with this seldom-heard demographic.

¹While definitions of terms like "youth" and "young people" vary, the World Health Organisation argues that a young person is somewhere between childhood and adulthood - typically within the range of 10-19. (World Health Organisation: 2015. 'Adolescent Development:' http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/) though this definition is often used to describe mid-teens to the age of 25. The YEAH! Project engaged with people in the middle of this age range, 15-18, who the term "young people" covers throughout this report.

²Public Health England & AYPH (2014) 'Improving young people's health and wellbeing: A framework for public health.' London: Public Health England: p.4

³NatCen Social Research, Office for Public Management and New Philanthropy Capital (2013) 'Evaluation of National Citizen Service: Findings from the evaluations of the 2012 summer and autumn NCS programmes.' London: NatCen Social Research: p.20

A young man with short brown hair, wearing a blue long-sleeved shirt and dark trousers, is sitting at a white desk. He is leaning forward with his hands clasped over his forehead, looking down at a laptop. The desk is cluttered with papers, a calculator, and a game controller. In the background, there are trophies and a white cabinet. The lighting is soft and natural, suggesting an indoor setting.

“I’m tired of being told we don’t understand, or we don’t know anything about what’s going on and that our views aren’t good enough

**How we engaged
with young people**

Explain

Empower

Enjoy

We devised three principles that formed the key to our successful engagement with participants

We wanted to assure participants we were not just talking to them in order to “tick a box”. We told them about Healthwatch Essex and the value we place on lived

experience, as well as the impact our work had already had. When we explained our study, we began by telling them about the film we had produced, and explained that

the YEAH! Project hoped to collect their voices in order to influence positive change.

It was vital to the success of our engagement that the young people felt as comfortable as possible, and were empowered to raise the issues most important to them. The informality of unstructured focus groups allowed for the collection of rich, qualitative data that painted a compelling picture of young people’s experiences of health and care across Essex.

We spoke to the young people in the groups NCS had formed; engaging in a familiar setting amongst familiar peers meant they were relaxed and confident, and shared their stories with enthusiasm and ease.

We wanted all participants

to feel equal in the discussion, and demonstrate that their experiences were listened to and respected. We sat in circle formation on the grass so that we were able to see and engage everyone, showing we were listening when people spoke. This close observation also allowed us to collect the quantitative data used in this report.

Participants were first given scope to decide the course of our discussions. During the first week of our study we asked them to identify their health and care priorities, which shaped the questions we developed for use in the six weeks that followed. These questions were used as

guidelines to prompt discussion, but ultimately participants steered conversations, allowing detailed discussions on topics they felt passionately about as well as additional topics not included in our questions.

The young people also completed Healthwatch Essex’s confidential “How was it for you?” forms, allowing them to provide an individual statement to complement group discussions, and share experiences they may not have felt comfortable sharing with peers. These written responses captured accurate quotes from participants, and are used throughout the YEAH! Report to illustrate our findings.

We believe it is essential to show young people we have a genuine interest in their lives, value their time, and want them to feel able to contribute in future - we wanted participants to find our sessions as useful as we did.

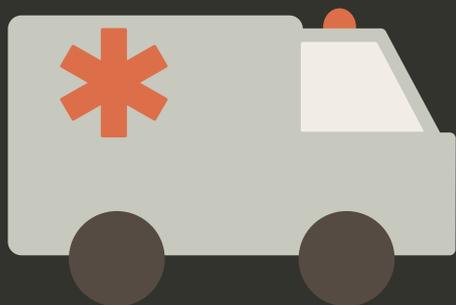
We asked about their NCS

experiences and the social action plans they were designing as part of the programme. They prepared lunch for us, which we ate alongside them, and they lead us on tours of their campsite. On GCSE results day we celebrated with the young people and learned

about their plans for the future.

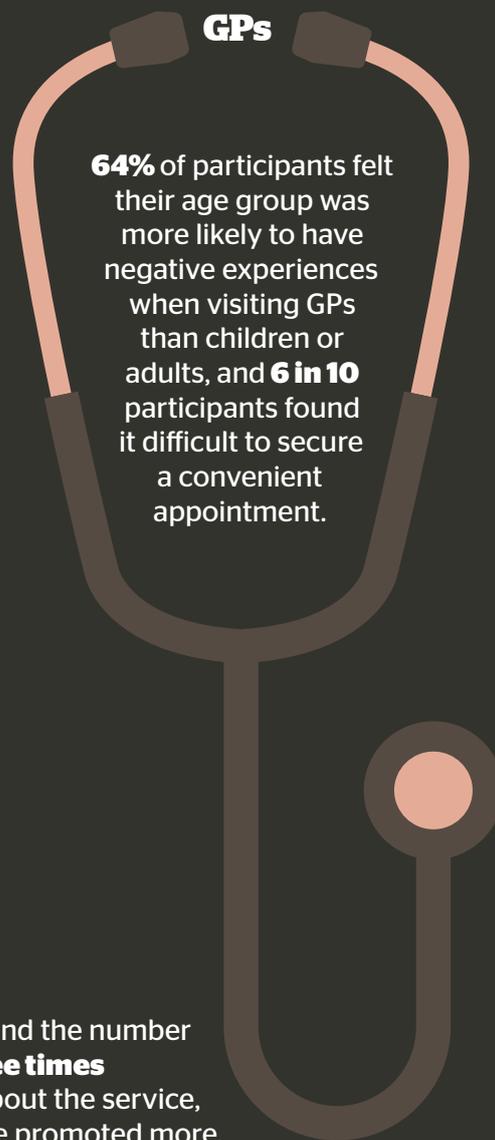
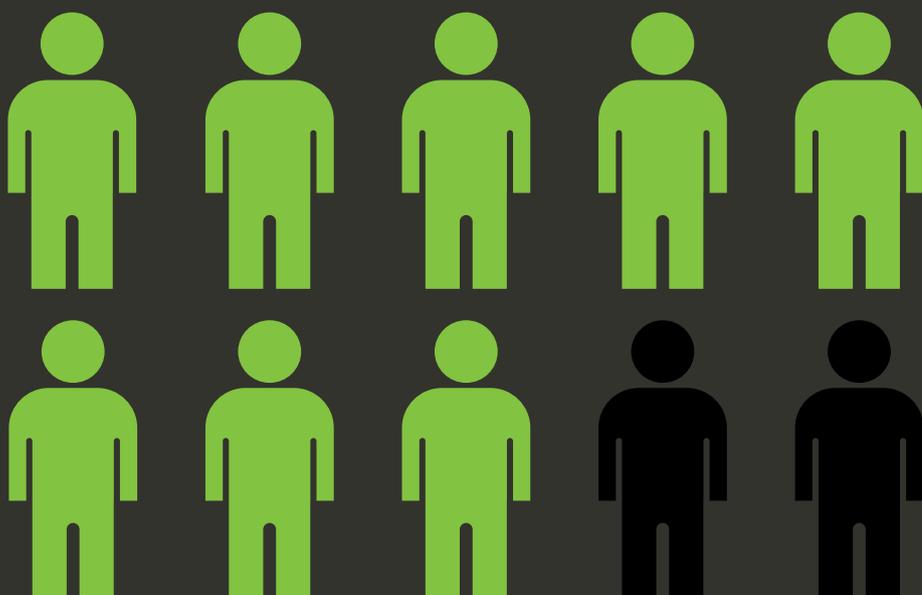
We were often thanked enthusiastically for listening to the young people, who felt they were rarely taken seriously, or given the chance to share their views and experiences.

Key findings



Emergency Services

Almost half of those who had called 999 praised ambulance arrival times, and participants placed great value on being assisted with shock and panic. **8 in 10** who had visited A&E reported negative experiences, with **83%** waiting **4-7 hours**.



Mental health

8 in 10 participants did not know how to access support for mental health issues, and had received no information on mental health in school or college. Yet we found that young people often have real experience of mental health issues, and that **9 in 10** wanted to learn about mental health alongside physical health.



111

7 in 10 participants had not heard of the 111 service, and the number of those who had experience of calling 999 was **three times higher** than those who had called 111. On learning about the service, and its potential benefits, participants wanted it to be promoted more.

Walk-In Centres

85% of participants had not heard of walk-in centres. The number of those who had used A&E was **five times** that of those who had used a walk-in centre. Participants were enthusiastic about using walk-in centres, and wanted them to be promoted more.

Information and Awareness

Almost all participants receive information on sexual health, drugs and alcohol, and smoking, yet the vast majority were unaware of services they could access around these topics.

Participants showed a real appetite for receiving awareness on learning disabilities and young carers.

Engaging with Young People

Above all, we found that young people have valuable experiences and opinions surrounding health and care, yet feel they are seldom heard. Engaging correctly with young people allows them to use their experiences to shape change.

Recommendations

The Yeah! Report highlights the need for improved awareness and better access to services for young people. We need to promote behaviour change to enable young people to better manage their own health and care.

We believe that these three outcomes can be met through a number of recommendations.

High Quality Engagement

The Yeah! Project allowed Healthwatch Essex to engage with 414 young people from across Essex. In sharing their lived experience, they have created a rich snapshot of how young people in Essex perceive, and use, health and social care services. This work shows the value that can be achieved through high quality engagement: in other words, engaging the right people, at the right time, using the right method.

We believe that this report lays down a marker that shows the potential of well executed and focussed engagement, as well as pointing a way forward to further lines of enquiry.

Our recommendation is that commissioners and providers do not shy away from engaging with young people, and involve them in decisions about the future of health and social care.

Develop a 'Young Person's Guide to Care'

Our findings indicated that young people are often unaware of the range of health and social care services they can access - particularly 111, walk-in centres and public health services. A lack of information prevents young people from managing their own health and care needs, and confidently seeking the support they require. It also means emergency services are used

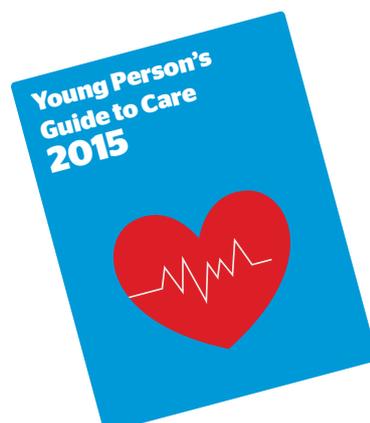
inappropriately by those who don't where else to go.

Our recommendation is that commissioners and providers work together to produce clear and accessible guides to health and social care services. Healthwatch Essex could help co-ordinate this under its own statutory responsibilities, as part of our Information Service.

We will continue to work with young people to create age-appropriate information on health and social care.

Raising Awareness

This report shows a lack of awareness amongst young people about the range of health and social care services available to young people. For example, our findings suggest a drastic lack of mental health awareness, which is worrying given that many young people are affected by issues such as self-harm and eating





disorders. Our young participants all suggested that the provision of health and social care information in education settings needs to be adapted to the interactive approach favoured by many young people. Improved access to information about health and social care could allow young people to make informed choices, and therefore prepare them for the responsibilities of adult life.

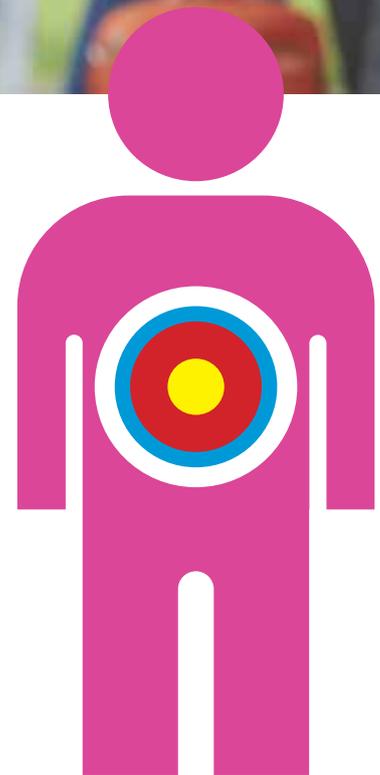
Our recommendation is that commissioners and providers of services should raise awareness of the services that are available to young people. Standards for youth-friendly services are already set out in the Department of Health's 'You're Welcome'⁴ document, which places an onus on health services to ensure that there are choices for young people. But unless young people are aware that these choices exist, they cannot make the best out of a service that may otherwise be 'youth-friendly.'

Person-Centred Services

A clear conclusion from the YEAH! Report is that young people want services that are accessible, equitable and age-appropriate - in other words, person-centred. Mainstream services offering a generic type of care are less effective than those that seek to engage and provide for specific targets.

Our recommendation is that commissioners and providers explore innovations across health and social care, such as young people's clinics and hospital wards, which will improve patient experience within existing services.

The YEAH! Report also shows that young people would like health and social care professionals who are friendly, empathetic and non-judgemental. Our recommendation is that commissioners and providers invest in training around active



listening, issues facing young people and good communication across all health and care services.

This could improve interactions with young patients and professionals, and give them the confidence to take control of their health and care.

⁴Department of Health (2011) 'Quality criteria for young people friendly health services'. London: Department of Health.

Visiting the Doctor



We asked participants about their experiences of visiting doctors. We wanted to know what made for a positive or negative experience, and what made them most comfortable when discussing their issues with a GP.

Five people reflected positively on their experiences with GPs, most commonly when they felt they had been treated with respect. Helpful and friendly surgery staff also contributed to positive experiences, as well as feeling accurate diagnoses were reached.

☞ The doctor knew how to solve the situation with my twisted ligaments, and made sure that I understood what was said. I felt very happy about it

Other aspects of good experiences included trusting their GP, good care from GPs and nurses, good quality information and feeling that receptionists were approachable and kind.

☞ I have had a really good experience with my GP. I find him really friendly, and all the staff are really approachable (such as the receptionists)

However, the majority of experiences reported were negative. This appears to be less of an issue for the adult population, as the GP Patient Survey found

Key findings

65% of participants felt their age group was more likely to have a negative experience, than children or adults, when visiting a GP



• **4 in 10** said doctors speak to their parent/guardian instead of to them



• **2 in 10** were unclear, or concerned, about patient confidentiality measures

• Participants wanted to feel listened to, have access to a regular GP, and be involved in discussions and decisions surrounding their care

that 83% respondents from Essex reported satisfaction with their GP surgery.⁵

For our participants, negative experiences often resulted from poor 'customer service,' with participants citing rudeness, interruptions when speaking, assumptions about sexual activity and awkwardness as disincentives to visit a GP.

Participants sometimes felt that GPs "don't care".

☞ They don't pay attention to you, no eye contact - like they don't even care. They treat you as if there is nothing wrong with you; they aren't very sensitive to you sometimes

This is important as the care a young person receives affects their future patterns of behaviour in how they engage with health and social care services.

Age

66 participants felt their age had no bearing on their treatment.

☞ My GP was very kind, and spoke to me like an adult (even when I was ten)

However, 256 participants perceived their age as having a negative impact on the care they received. Half of this number felt that young people were not seen as a priority, which led to them feeling rushed, patronised and not taken seriously. This sometimes resulted in participants feeling reluctant to visit a GP in future. Others told us they felt their doctor held power over them, and some reported feeling they had physically been treated more roughly because of their age.

continued on the next page

⁵ NHS England (2015) 'GP Patient Survey 2014' <http://gp-survey-production.s3.amazonaws.com/archive/2015/January/weighted/January%202015%20Practice%20Report%20weighted.xls>

☹☹ **I think younger people (teenagers) are normally regarded as not having serious problems**

☹☹ **GP surgeries should be more thorough with people 16 and over, and not try to hurry them out. I feel that younger people are seen as inferior to children and adults, and so less care is taken**

Many participants were old enough to make their own appointments, but negative experiences when attending alone had discouraged them from doing so in future. They felt that being young and unaccompanied had caused them to be judged by practice staff and other patients. Others feared that being rushed, patronised or not taken seriously was more likely when attending alone.

☹☹ **Doctors can be intimidating and make you feel like you're wasting their time**

41 participants said that using a service for young people would prevent them feeling judged by older patients, and by medical staff. Many were in favour of surgeries operating young people's clinics.

Feelings of not being taken seriously meant participants who had been misdiagnosed felt this was due to not having been taken seriously.

☹☹ **My doctor said I had hay fever, but the tablets didn't work. I got worse ... and couldn't stand up on my own. The doctor could have taken more time when checking what was wrong. I felt insecure about going to the doctors afterwards**

As proven consistently in other areas of the YEAH! Report, customer service is vital to young people's experiences of health and social care services. Feeling patronised or unimportant discourages younger patients from returning to their surgery, which creates an overuse of A&E, or disengagement with primary care.

Feeling Involved

Participants wanted to feel involved in discussions and decisions around their care, but 173 participants told us that GPs would talk to their parent/guardian instead during appointments.

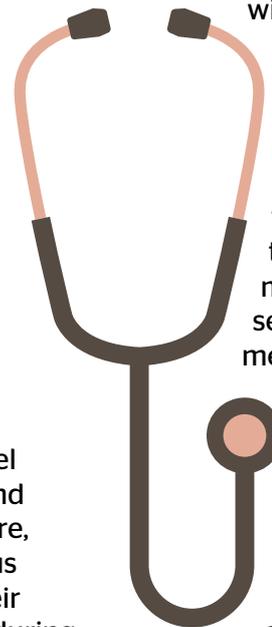
☹☹ **My doctor shut the door and talked to my mum and not me**

☹☹ **The doctor would ask my parents why I had chosen to book an appointment, and I would always be spoken over by both parties**

When GPs addressed young patients, as well as their parents/guardians, participants felt more in control of their care, and viewed this approach positively.

☹☹ **My doctor talks to me about why I'm there, while still involving my parents**

It is important that young people feel confident accessing primary care, and feel involved with discussions and decisions about how they are treated. Feelings of disregard can cause younger patients to avoid visiting their practice - an issue that contributes to misuse of emergency services, or untreated medical issues.



Patient Confidentiality

Participants wanted access to confidential support, but were unclear about confidentiality measures and age restrictions. 89 participants told us they felt uncomfortable visiting the GP alone, as they were unsure if information would be disclosed to their parents.

A further 13 wanted access to birth control, but were unaware of confidentiality measures and age restrictions that may prevent them from doing so.

☞ I called confidentially, but they called back my mum. The receptionist did not ask what number to call back on

38 people felt that a ‘young person’s clinic’ would feel more confidential, with a further 25 saying such a clinic would help them to establish trust, and be more open about their issues with professionals. 39 participants wanted to make and attend appointments by themselves, but were too young to do so.

To get the most out of services, young people need to be aware of patient confidentiality and age restrictions, and have a clear idea of what to expect when accessing services by themselves. Uncertainty about confidentiality can prevent young people from accessing primary care when they need to.

The ‘Improving Young People’s Health and Wellbeing framework’ suggests that “workforce training on confidentiality and communicating with young people ... knowing the lines between safeguarding and confidentiality” could improve services for young people who “felt there was a lack of provision for under-16s who were seeking help without their parents’ consent.”⁶

Having a Regular Doctor

☞ The person who sees me often changes

Participants often commented that they were not seen by the same GP each time, which they found problematic for a number of reasons. As well as feeling it prevented them building rapport, trust and confidence, they felt powerless when assigned a GP who they felt uncomfortable with/ did not feel would treat their issue. Female participants often stressed the wish to request to be seen by a female doctor.

Experiences were more likely to be positive when participants had regular GPs, although this mostly occurred in small, village surgeries.

☞ I like my doctor, he knows me and my history, and understands

The ‘Improving Young People’s Health’ framework also found that young people “did not know how to complain or ask to see a different doctor if they were unhappy” (p. 24).

Informing young people about the decisions they are entitled to make regarding their care will allow them to choose a regular GP. This could reduce a strain on emergency services, increase confidence in care and encourage young people to manage their own health and care.

Suggestions

The young people had many thoughts on how experiences with GPs could be improved, with 62 suggesting access to a GP that has

an understanding of young people and the issues they face.

☞ I think being able to choose your doctor is very important. What could be better is if GPs respect the patients, regardless of their age and the information they are seeking

Participants felt that access to a regular GP would increase confidence in their care, and cause them to feel more comfortable when discussing their issues.

Participants wanted GPs to involve themselves and their parents in discussions and decisions, and wanted to feel mutual respect between doctor and patient. Others wanted GPs to use age-appropriate language when discussing their care, as well as a medical database that meant their history could be accessed across services.

This echoes findings of the Improving Young People’s Health and Wellbeing framework, which states:

☞ Young people ... need services that understand what it is like to be young, services which can either give them help directly or to refer them to a service that can. Among all of this, young people want to have trusted sources of information and impartial advice.” (p. 6)

⁶ Public Health England & AYPH, ‘Improving young people’s health and wellbeing,’ p.10

GP Appointments

Securing Appointments

246 participants told us they faced difficulty when trying to make an appointment, and there seemed to be inequity across the county based on booking systems and surgery capacity.

☹☹ **Trying to get an appointment is a nightmare. You have to wait for 2-4 weeks just to get one, and then they are sometimes not on time.**

I always get an appointment within the first two days of making a phone call to the reception

For 175 participants, they had faced this difficulty with surgeries requiring them to call in the morning on the day they wished to be seen. We were often told that these appointments could run out in minutes. Participants faced a prolonged wait if they hoped to see a female GP, or if they could not book their own appointments and parents had left for work before their local practice opened.

☹☹ **It took quite a lot of time to get the appointment, as it was too busy almost every day for a few weeks**

Most participants said it usually took them a week to get an appointment, followed by those who said they could expect to wait for two weeks. Those who

were able to be seen on the same day mostly attended small village surgeries, or surgeries operating drop-in systems.

☹☹ **Even if you have not made an appointment and you walk in, they can still fit you in in good time**

The GP Patient Survey found that in Essex, 38% of respondents spoke to a GP or nurse on the same day, 12% the next day, 30% after a few days, and 16% after a week or more.⁷ This shows that our young participants faced an above-average wait for an appointment.

Key findings



- **6 in 10** participants had difficulty securing convenient appointments

- **71%** of this number reported problems with booking systems requiring them to call at surgery opening time

- A **third** had missed school, college or work to attend appointments

- Participants praised surgeries with flexible booking systems, or drop-in clinics

Opening Times

Many of the young people told us their surgery's opening hours conflicted with school, college or work commitments, contributing to the difficulties some had in making appointments.

☹☹ **There is an extremely long wait, as appointments always clash with work and school**

1 in 3 participants had missed school, college, or work to attend appointments. However, schools and employers can have strict attendance measures, with some participants having been reprimanded due to absence resulting from ongoing medical appointments.

☹☹ **I found that getting an appointment around school time can be difficult, and often results in missing large amounts of school, as I go to a school far away from where I live**

However, 2 in 3 participants were able to get an appointment without having to miss many of their educational or employment commitments, again suggesting inequity in appointment access across the county.

☹☹ **The wait wasn't very long and I was seen in the morning, so I didn't miss much school**

⁷ NHS England, 'GP Patient Survey 2014'

The GP Patient Survey found that 73% of participants in Essex were satisfied with their opening hours, but said that if surgeries were open Saturdays, or after 6:30pm, it would make it easier to speak to someone.⁸

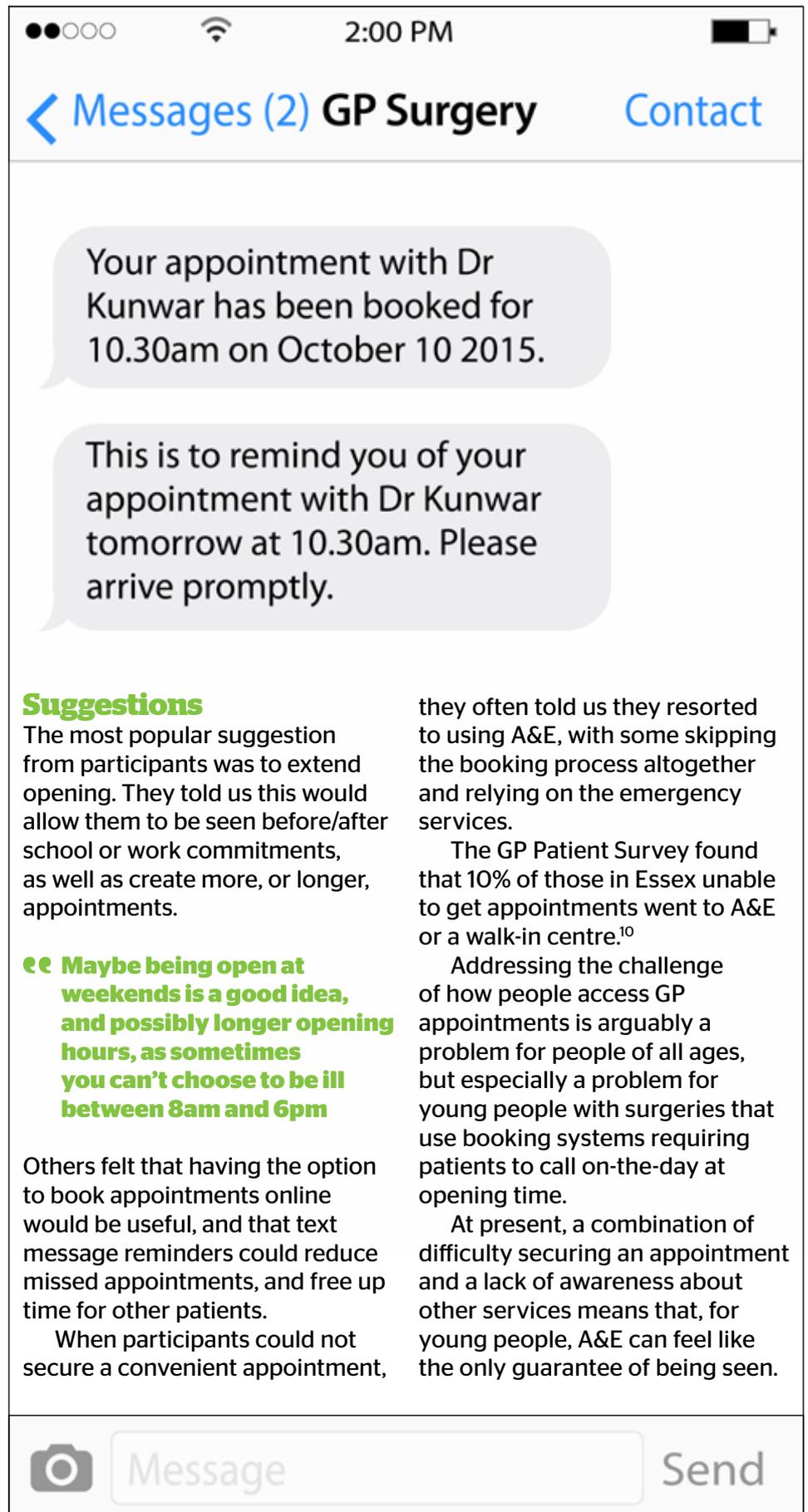
Appointment Timing

Some participants told us about waiting times they faced when arriving for their appointment. Those who told us they were unlikely to be seen on time put this down to impractical caps on appointment lengths, and a lack of staffing.

They felt that the set length of appointments was too short, causing a feeling of being “rushed” when they were seen. However, participants frequently acknowledged that this was not the fault of their GP, but rather the targets expected of them.

“Waiting times at my local GP are too long. They have unrealistically small time slots, and have to fit a certain number of appointments into one day. Therefore, they always run way behind schedule”

Similarly, participants of Healthwatch Essex’s 555 Report on mental health often claimed that it felt “impossible to discuss everything in a ten minute appointment.”⁹



Suggestions

The most popular suggestion from participants was to extend opening. They told us this would allow them to be seen before/after school or work commitments, as well as create more, or longer, appointments.

“Maybe being open at weekends is a good idea, and possibly longer opening hours, as sometimes you can’t choose to be ill between 8am and 6pm”

Others felt that having the option to book appointments online would be useful, and that text message reminders could reduce missed appointments, and free up time for other patients.

When participants could not secure a convenient appointment,

they often told us they resorted to using A&E, with some skipping the booking process altogether and relying on the emergency services.

The GP Patient Survey found that 10% of those in Essex unable to get appointments went to A&E or a walk-in centre.¹⁰

Addressing the challenge of how people access GP appointments is arguably a problem for people of all ages, but especially a problem for young people with surgeries that use booking systems requiring patients to call on-the-day at opening time.

At present, a combination of difficulty securing an appointment and a lack of awareness about other services means that, for young people, A&E can feel like the only guarantee of being seen.

⁸ NHS England, ‘GP Patient Survey 2014’

⁹ ecdp & Healthwatch Essex (2015). ‘555: Capturing the Lived Experience of Mental Health Service Users in Essex.’ Essex: Healthwatch Essex: p.24

¹⁰ NHS England, ‘GP Patient Survey 2014’

Hospital Stays

Ward Placement

When we asked young people about their experience of hospital stays, it was clear that this transitional 15-19 age range was a demographic that did not feel appropriately placed in either adult or children's hospital services. Participants frequently described adult wards as frightening, with patients on these wards often being much older. They had also experienced adults close to the end of their lives, in great pain, or suffering with dementia.

However, on children's wards, participants claimed they were treated like a much younger child and presented with entertainment activities unsuitable for their age range, resulting in hospital stays causing them to feel "displaced" on either ward.

☹☹ I was in a child's ward and treated like a baby

Participants frequently suggested a separate ward for this age group, and 9 in 10 were in favour of this idea. 71 people said this was because they would feel more comfortable placed in services among their peers. When asked what range this ward would cover, the average suggestion was 16-20.

Turning 16

Some suggested that after the age of 16, patients should be given the choice of which ward to stay on.

Others felt they had waited longer for surgery once they turned 16, some saying this was due to indecision about which ward they would be placed on.

Others who had begun medical proceedings when they were 15 found that when they turned 16 the nature of their treatment changed, and one participant described the confusion of being treated as an adult in hospital, but as a child during aftercare.

Overnight Stays

One of the biggest issues was that when staying on an adult ward, the young people's parents could not stay with them overnight.

☹☹ **As a 16 year old, I was on an older ward where I was kept for 3 days. My mum was not allowed to stay with me, which made me hysterical as she left. I think my recovery would have been better if my parents were allowed to stay and comfort me**

Participants felt strongly that while they were in their parents' care they should have the option to have their parents stay with them in hospital.



Key findings

- Participants in the 15-19 age range feel **"displaced"** in both adult and child wards



- **9 in 10** participants were in favour of a 'young people's ward' for 16-20 year olds



- Participants value having the option for parents to stay overnight
- Appropriate discharge and aftercare were important factors in participants' experiences

Discharge and Aftercare

Some participants felt that patients could sometimes be discharged too quickly. After donating a kidney to his father, one participant said he was discharged feeling very dizzy. His father collapsed, but he was too weak to help him up, and wished they had been given longer to recover. Other participants spoke about the aftercare they received following a stay in hospital. They valued feeling their care continued after discharge by being advised on how to take care of themselves, or receiving check-ups.

☞ **The staff treated me well, made me feel as comfortable as they could, and the follow-up treatment was good. After the care finished I felt happy**

☞ **I went to hospital for a broken ankle. I was treated like an adult, and given information on how to be careful with it, and how long it would take to heal**

Some people felt the aftercare they received after treatment had been absent or inadequate, with participants saying they would have liked further information on medication, the aftercare of injuries, and how to prevent future injuries.

Summary

In the current ward system, young

people risk being the oldest patient on the children's ward, or the youngest patient on the adult's ward, leading to feelings of discomfort and displacement. The Improving Young People's Health and Wellbeing framework states:

☞ **Transition points, such as between child and adults services around age 18 ... are critical times for supporting young people. We need to support the professionals who deliver child and adult services so that everyone has a shared understanding of the needs of young people. This means ensuring that local services have arrangements in place to manage transition to adult services safely and in cooperation with young people, using best practice.¹¹**

It is clear that being placed among older patients is inappropriate, as is placing 16 year olds among small children. Creating an adolescent ward, or section of an existing ward, would place patients appropriately among peers of their own age with age-appropriate decor and entertainment.

From our findings, it is also obvious that young people 16 and over still value the overnight support of parents, and it is worth remembering that this may be their first stay in hospital, and can be a difficult time.

¹¹Public Health England & AYPH, 'Improving young people's health and wellbeing,' p.9

Ongoing Care

During our discussions about GPs and hospitals, participants frequently reported issues with ongoing treatment around follow-up, results or check-ups.

☞ **They tend not to follow up on issues. My parents have to nag them to complete treatment, or follow up on an issue**

16 people felt there had been slow or absent follow-up to care they received, or asked to receive. Six of the young people were waiting for the results of scans or tests, and had been waiting for 2-8 weeks. Three participants had given up on ever receiving their results, and one person spoke of the anxiety that she and her family faced while awaiting results.

Two people complained that services were not streamlined enough, feeling that each referral simply lead to another referral.

Another two people told us they

had filled out a form when visiting their GP about mental health issues, but had never received follow-up from this. Another had been referred to a specialist hospital for mental health issues, but felt that the wait of 4-6 weeks was too long.

☞ **I went to the doctor because I'd been told I may have bipolar disorder caused by trauma. I was put on hormone control and filled in a form about how I had been feeling. The form was obviously aimed at children, but I filled it in anyway. I was asked to make another appointment about the tablets, but had no response to the form. I was not contacted again**

A risk to young people receiving slow/absent follow-up to mental health enquiries is that they may reach crisis point before intervention.

A participant with type 1 diabetes told us that he was supposed to have a check-up every three months, but has not had one for nine months.

Some participants believed that the delay of results and follow-up care could be cut by having all information available from one point of access, to prevent patients being referred from service to service.

A lack of follow-up appointments or results can cause anxieties for patients and their families, as well as making patients feel their issues are unimportant. Furthermore, being referred from service to service can seem as though the appropriate service to help them does not exist.

Patients may lack the confidence to chase follow-ups themselves, and it should be made clear when they are personally expected to make contact for further appointments or results, and how they can go about this.



Mental Health

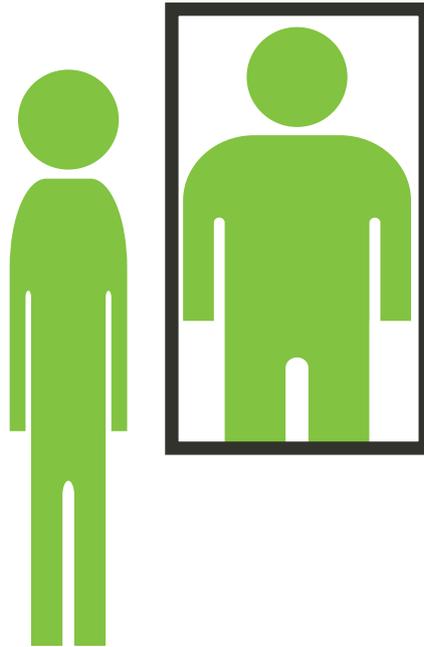
280 participants told us they had never received information on mental health. The young people were curious and concerned about mental health issues, and had sought information themselves through less reliable sources such as search engines, fictional TV programmes and discussions with friends.

“A lot of young people don’t know who to talk to about mental health, so my friends talk to me. I listen but I can’t do a lot, so often look for professionals they can talk to. It would be better if people were more aware of these professionals”

“I only know about depression and anxiety through the media, so it needs to be less intimidating to talk about mental health”

Those who had received information on mental health described it as short, or too basic. Some had covered specific aspects only, such as cyberbullying and eating disorders, which had been introduced inconsistently through topics such as PE, Science, ICT, Psychology and Drama.

Participants felt mental health should be a mandatory subject, such as sexual health and drugs and alcohol awareness. At present, they felt they received too much information on these subjects and would like to see some of this



time dedicated to learning about mental health.

“My school didn’t inform us about these sorts of topics (more on bullying or drugs). My whole situation could have been different if I was informed earlier on about this. It may have prevented or helped against the suicidal and depressed thoughts”

101 participants told us that people with mental health issues are frequently misunderstood, stigmatised or isolated, which they felt could be counteracted through education and awareness. Similarly, the adult participants in our 555 Report expressed a desire to see an increase in understanding and training to tackle misconceptions about mental health.¹² Furthermore, the Improving Young People’s Health and Wellbeing framework identified the need for “educating peer and staff groups to reduce stigma about mental health and promote positive emotional wellbeing”.¹³

“Mental health is not understood or funded enough. There are prejudices against certain people and conditions”

Key findings



- **8 in 10** participants had received no mental health information, and did not know how to access mental health support

- **9 in 10** participants felt it important to receive mental health awareness alongside physical health information

- **15%** of participants self-identified as having, or having had, a mental health problem

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¹² ecdp & Healthwatch Essex, ‘555,’ p.17

¹³ Public Health England & AYPH, ‘Improving young people’s health and wellbeing,’ p.7

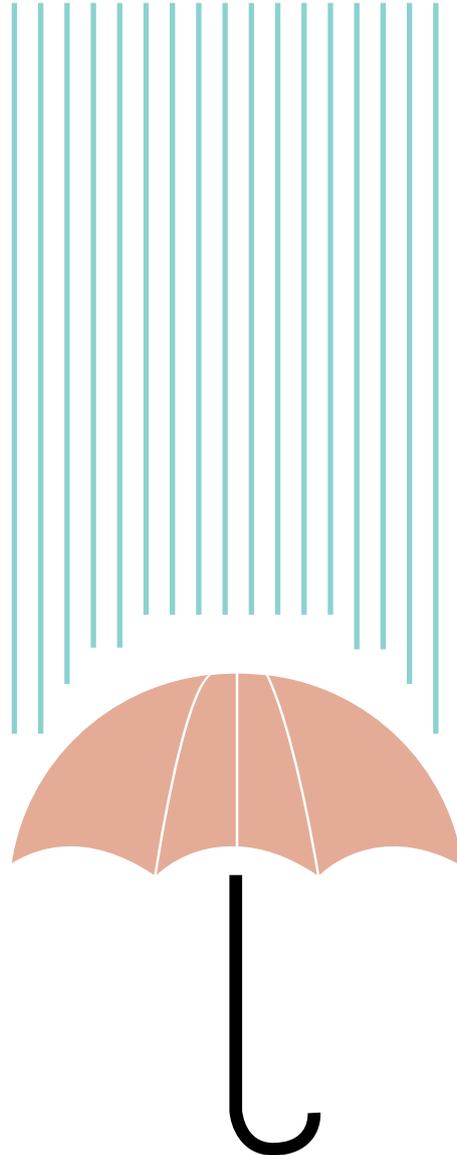
Others told us they felt it was important to develop an understanding of what people with mental health issues were experiencing, and to know what help was available.

☹☹ My best friend has an eating disorder, and was treated badly in school. We were never taught about eating disorders, and therefore she never spoke to anyone and was eventually admitted to hospital. My school dealt with her badly when she returned. If we had been taught about it, maybe it wouldn't have become such a problem for her if she knew who to talk to

Participants felt mental health issues were particularly prevalent in their age group, with self-harming behaviours sometimes developing as coping mechanisms. Participants of the YEAH! Report wanted to be comfortable discussing mental health openly, and wanted peers to realise how common mental illnesses are.

☹☹ There should be something to help self-harmers, as a lot of young people do it without getting help

☹☹ I think we should learn more about mental health at school, because I once had a panic attack and had no idea what it was, which made me panic even more



Participants were passionate about receiving mental health information, and it is clear that this would be beneficial in assisting them to access the relevant support, particularly in times of crisis.

One person said he felt that even in cases where mental health had been covered in schools, it was taught in very different ways, and there is a need to develop a uniformed approach.

Knowledge of Services

As the vast majority of participants had not received information about mental health, there was little awareness of mental health services. 49 people expressed frustration at not knowing how, or where, they could access services.

☹☹ I have experienced self-harm, depression and maybe other mental illnesses. I decided to get counselling, but I didn't know where to go. People told me about Childline, and I signed up, but it is all virtual. There was no actual help around me. It feels different getting help online than from an actual person

32 people knew they could speak to their GP about concerns surrounding their mental health, and 25 people were aware of counselling services in school.

Nine individuals knew of CAMHS, CMHTs or Rochford

Hospital, but only because they had personal experience of using those services.

€€ Mental health services need to be promoted, to make people aware that services exist and that people can get help

Healthwatch Essex's 555 Report also found that participants wanted more information and knowledge about services. People felt local Mind services and other voluntary, non-NHS services need greater promotion and funding available to them.¹⁴

Experiences

47 people shared their experiences of mental health issues. Among the issues reported were mood disorders, panic disorders, suicidal ideation, suicide attempts, eating disorders, gender dysphoria, and trauma following issues of bereavement, sexual assault and abuse.

Only four people had positive experiences to report, praising counselling services and supportive doctors.

€€ My doctor provided a lot of help, advice, and information and supported me when I started to get panic attacks, so I didn't feel like I was being an idiot

€€ I used a service for counselling sessions... it helped me a lot when I was in years 10 and 11. In my first year of college, I used the college counsellor and the service was great

€€ How quickly you recover correlates to how well you get on with your assigned counsellor. Luckily, I got along with mine, but I think therapists should be more specialist in mental health

The findings of the Improving Young People's Health and Wellbeing framework similarly state that young participants "valued the contribution of youth workers, and that of community counselling and therapeutic services."¹⁵

However, participants often felt that GPs did not understand mental health issues in young people, or treat them seriously.

€€ I went to the doctors about taking an overdose... he completely ignored the issue and told me to go somewhere else, because he did not want to deal with it

Again, these concerns were echoed on a national level in the findings of the Improving Young People's Health and Wellbeing framework, which states that participants "felt they had not



been taken seriously, especially concerning mental health issues at school or with health professionals" (p. 23).

We heard from young people who had been dismissed when trying to discuss mental health. Some had been told that age 16 was too young to access counselling, or that anxiety attacks were due to GCSE stress. These participants had often been asked to complete forms about their symptoms, to which no-follow up had been received.

€€ I found out about my dad's death, which was a suicide as a result of depression and bipolar disorder. I went into a state of depression myself, and my GP just told me his life story about how he was adopted, then told me I was not depressed. He was very condescending, because I was only 14 at the time, and he just abused my visit as an opportunity to confide in me, which I found unprofessional. It also made me feel worse in my situation, because I began to feel guilty for having my own feelings

As is a consistent theme throughout our findings, young people's uptake of services depends on how they feel a service will treat them.

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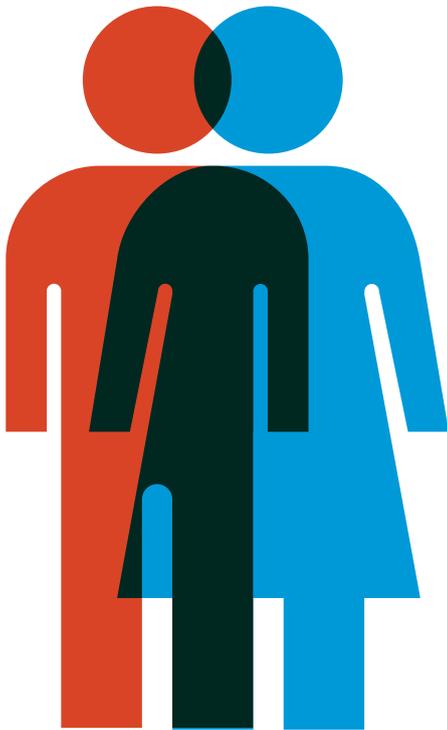
¹⁴ ecdp & Healthwatch Essex, '555,' p.22

¹⁵ Public Health England & AYPH, 'Improving young people's health and wellbeing,' p.23

Being dismissed by a GP, being made to wait a long time for help, or receiving no follow-up from appointments can cause young people to feel that their mental health issues are trivial, and can discourage them from seeking the support they need.

Our 555 Report also found that understanding, friendly and empathetic staff were really important to patients, and that professionals need to recognise and respond to people's testimony in terms of their mental health and support needs. At the very least this experience needs to be heard and not dismissed.¹⁶

Those who had received some intervention for mental health



issues often felt that more could be done. Five people who had been referred to a psychiatrist, counselling or CAMHS felt the waiting times for these services were too long.

☹☹ I went to my GP about depression and gender identity disorder. I was told to make a further appointment at a specialist hospital in 4-6 weeks. I feel the GP could have given me more information on my problem, and the waiting time should be shorter

This also echoes the 555 Report, in which the need for shorter waiting times from referral to accessing the service was highlighted.

☹☹ People felt it was really useful to have short referral times from GP to IAPT and receiving support from a psychiatrist quickly. People said this makes all the difference (p.24)

Two people had been prescribed antidepressants, but had stopped taking them because the side effect of feeling worse before feeling better had not been explained to them. Again, the adult participants of our 555 Report had similar experiences to the young people, and expressed a desire for more information about side effects of medication, suggesting

that professionals do not want the individual to be put off by the side effects and decide not to take the medication (p.14).

Others felt that counsellors could not relate to complex experiences, or had to stop counselling because sessions clashed with classes. Others felt stays in mental health hospitals could be improved by offering treatment to inpatients, and not grouping them with others who could coerce them into harming themselves.

☹☹ [It] was supposed to be a psychiatric facility; a place of healing. It was a prison. I received no treatment, no counselling and no group sessions in the two times I have been admitted. What is a hospital without treatment? I think the CAMHS service is seriously lacking in inpatient facilities. Locking people up and then putting them back into society is not going to help them, because there hasn't been a change. There needs to be more funding for these services to actually treat people, rather than institutionalise them

¹⁶ ecdp & Healthwatch Essex, '555,' p.15, p.19

☞ There should be more crisis beds in hospitals, so less people with mental health problems feel that there is nowhere to turn. They could also then be treated faster, which would save the NHS money

☞ I had counselling for a year or so, but didn't feel my counsellor was able to understand when I spoke to her about being a victim of rape and incest. I feel there should be counsellors that are specifically trained to help people who have been through that kind of stuff, because we have no one else to talk about it to, and getting over that experience has been a struggle

This was an issue again raised in our 555 Report, with some participants feeling that it would be valuable to have therapy if there were more professionals who were specialists in particular mental health conditions - not just generalists (p. 16). Furthermore, the Improving Young People's Health and Wellbeing framework suggests "providing an appropriate range of support for young people affected by violence, adverse childhood experiences and sexual exploitation."¹⁷

Suggestions

When we asked the young people how they would like to receive

mental health information, 20 people said it should be delivered realistically, and in a non-patronising manner. Another 18 people found it important that this information focused on their age group, where problems like self-harm and eating disorders can be prominent.

☞ Information on mental health and available services should be taught to adolescents if they feel they need advice or counselling

Many participants felt that stigma still surrounded mental health issues (evidenced by the fact that most who had experiences with mental health issues chose to tell us of them in writing, as opposed to as part of our group discussions). They believed an awareness of mental health issues would help negate this stigma, and could encourage more young people to seek help.

☞ I was scared about getting help (the tiny amount of help that was available), so no-one knows and my issues could still continue. It would be a lot better if everyone was aware. Everyone should be informed

ECC's Health and Wellbeing of Pupils Survey 2014 found that 10% of secondary school pupils have poor emotional well-being.¹⁸ Yet many YEAH! participants were

unaware of the services they could access for mental health advice, and in some instances it seems that GPs can often be unsure of these, too. 53 participants wanted more mental health services, and while reports of slow or inefficient services suggest this is an area where expansion is needed, it also seems to be the case that young people are not aware of services that already exist.

The Improving Young People's Health and Wellbeing framework states that three quarters of mental health problems start before age 24, and half start by age 14,¹⁹ but our findings show that young people experiencing mental health problems are at risk of falling through the net. Equipping young people with an understanding of mental health, and how to access services, improves the chances of successful intervention and builds resilience for adult life.

¹⁷ Public Health England & AYPH, 'Improving young people's health and wellbeing,' p.7

¹⁸ Baxter, V. (2015). 'Health and Wellbeing of Pupils 2014 Survey: Headline report on key findings and trends.' Essex: Essex County Council, Community Involvement & Engagement Team: p.12

¹⁹ Public Health England & AYPH, 'Improving young people's health and wellbeing,' p.12

Public Health

Experiences of Learning

Almost all the participants had received information about sexual health, drugs and alcohol, and smoking during the course of their education, although the majority did not feel comfortable or engaged in the way public health information is delivered. ECC's Health and Wellbeing of Pupils Survey 2014 found that just over half say that education about drugs, smoking and alcohol is useful, although fewer say this about lessons on sex and relationships.²⁰

Participants repeatedly explained feeling they were taught that sex, drugs and alcohol, and smoking were bad, but with little explanation as to why. It was raised several times that scare tactics were commonly used to discourage them from engaging in these activities, with "possibilities presented as certainties." Participants felt this created a feeling of distrust toward the information they received in school and college.

These subjects were often not taken seriously, and could be a source of boredom. This was because the information they received was often repetitive, or because non-interactive methods such as leaflets and videos were used, with sessions delivered "like a lecture". The Health and Wellbeing of Pupils Survey 2014 found that 71% of secondary pupils wanted more fun/interesting lessons in order to achieve their best in school (p. 5).

Feeling confident and comfortable is important to young people, many of whom felt they would be judged or reprimanded if they asked questions of a familiar teacher, and as a result often felt embarrassed or did not engage in sessions.

Some schools and colleges employ a more interactive approach, which participants responded to very well, and found to be of more benefit than the traditional sessions.

Participants praised learning methods that had allowed them to try on "beer goggles" or "marijuana glasses," which they claim answered their curiosity about what using certain drugs felt like, as well as dissuading them from taking these drugs.

25 people had been advised on drinking in moderation, and unit measurements, which made them feel they were being treated with respect, and without the unrealistic assumption that none of them would ever drink alcohol.

Key findings

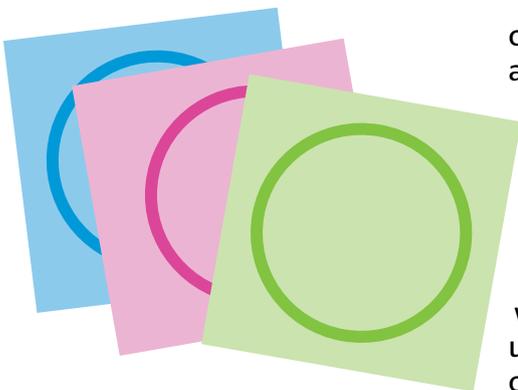
- Almost all participants had received information about sexual health, drugs and alcohol, and smoking
- However, few knew of where to go for information and support surrounding these issues
- Participants had disengaged with traditional methods of learning, and wanted the opportunity to ask questions without judgement, and make informed choices for themselves

Four people praised being taught about "legal highs," feeling this was an extremely relevant topic for their age group.

Participants favoured a balanced approach where they spoke to external speakers and had the opportunity to learn why people take drugs, how drugs make people feel, and the negative consequences of drug use.

Suggestions on Learning

Participants told us they were likely to be exposed to smoking, drugs, alcohol and sex (e.g. at house parties) and needed to be equipped to make informed choices. ECC's Health and Wellbeing of Pupils Survey 2014 found that 4% of secondary pupils smoke regularly (with 18% having



²⁰ Baxter, V., 'Health and Wellbeing of Pupils 2014 Survey,' p.5

tried it), 3% drink alcohol regularly (and 8% drink occasionally), 60% have been drunk before (with 11% having been drunk at least once in the past month) and 8.5% have taken drugs before.²¹ The 'Improving Young People's Health & Wellbeing' framework says:

☞ ...the proportion of children drinking alcohol remains well above the European average. We continue to rank among the countries with the highest levels of consumption among those who do drink, and British children are more likely to binge drink or get drunk compared to children in most other European countries²²

Participants frequently told us they couldn't remember the information they had learned, often because they felt it had been delivered when they were younger. They felt that now was a more relevant time in their lives to receive this information.

☞ My year nine sex education was really well done... however; I haven't had enough information since then

It is important to equip young people with the relevant knowledge at this stage in their lives, as the Improving Young People's Health and Wellbeing

framework explains: "Exploratory behaviours overlap - for example, early substance use is associated with risky sexual behaviour, antisocial behaviour and academic failure. The overlaps are stronger during adolescence than at earlier or later development stages" (p.8).

The majority of participants wanted to receive public health information from external speakers. 41 said that this was because qualified speakers would have more knowledge, and take a non-judgemental stance when answering questions - similarly, the framework suggests improving sexual health by "de-stigmatising asking for advice" (p.14). 23 people wanted an external speaker who was relatable, and closer to their age group or background than their teacher, with some female participants saying that older male sexual health trainers had caused them to feel uncomfortable.

29 people wanted the opportunity to ask a former drug user about the consequences of drugs, and four people praised lessons on smoking where their teacher spoke frankly about being a former smoker.

Participants felt strongly that comprehensive information on birth control should be covered,



as well as safe sex practices in same-sex relationships, and the Improving Young People's Health and Wellbeing framework reminds us that "teenage birth and abortion rates in the UK continue to be among the highest in Europe." The framework also says that this point of a young person's life is "a period of sexual exploration and exposure to health risks," noting "there were more than 139,000 diagnoses of chlamydia among 15-24 year olds in 2013" (p.11).

Participants wanted to know why people drank, smoke and took drugs - especially as a means to combat stress or low mood. They wanted to know what about these behaviours was addictive and what causes people to begin to use these substances.

106 people said that as well as learning that smoking was bad for them, they wanted to receive information on quitting, with participants pointing out that some people had already started smoking at the point when information was delivered. Others wanted to learn about the laws around smoking, basic scientific facts and detailed information on the impact of smoking on physical health.

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²¹ Baxter, V., 'Health and Wellbeing of Pupils 2014 Survey,' p.8

²² Public Health England & AYPH, 'Improving young people's health and wellbeing,' p.11

The Improving Young People's Health and Wellbeing framework says "almost two-thirds of adult smokers begin before they are 18 (p. 12), and therefore early intervention could be key in decreasing the number of regular smokers.

The impact of early intervention could be great, if delivered correctly. As the framework says:

☺☺ Promoting and strengthening young people's resilience and ability to cope are just as important as delivering services that deal with problems once they've arisen. This approach builds individual capacity that lasts into adulthood (p.21)



Above all, participants wanted to be taught about services they could access - for example, where they could find their nearest GUM clinic, or quit-smoking support group.

Knowledge of Services

While the vast majority had received awareness in these subjects, there was an obvious knowledge gap around the services available to them.

Only 49 people claimed to know what services they could access for sexual health (GUM clinic, SHA, on-site testing, GP), and only one person could name a drugs and alcohol service (Talk to Frank). Just 12 people were aware of smoking services they could access (NHS Smokefree, GP, SHA).

23 people requested a service where they could speak about sexual health on a one-to-one basis, which could be achieved by visiting their GP, their SHA, or a GUM clinic if they were made aware this was possible.

Essex County Council's Health and Wellbeing of Pupils Survey 2014 found that just over half of pupils say that, if they need it, they know where to go for advice and/or support on sexual health, smoking, alcohol and drugs. However, just over 10% of YEAH! participants were able to name such services. The Improving Young People's Health and Wellbeing framework found that "younger age groups (15-19) were most likely to say they

were stopped [from getting help] because they didn't know where to go."²³

Experience of Services

14 participants shared their experiences of using sexual health services. 12 did not like the C-card service, saying they felt uncomfortable and obvious when walking into a provider to ask for condoms. Six participants said that if free condoms could be delivered they felt there would be a higher uptake among young people.

A further five people told us in writing of sexual health services they had used: two had spoken to their GPs, two had visited a sexual health clinic, and one had visited their SHA. The comments we received highlighted how vital feeling comfortable is to young people accessing these services; good or bad experiences depend on how members of staff make young patients feel.

☺☺ I went to get checked, and they were really nice, and it was all confidential. They spoke to me in private about everything: STDs, protection and services

☺☺ My doctor was very assuming and intimidating when he asked about my sexual activity. This made me uncomfortable and embarrassed

²³ Public Health England & AYPH, 'Improving young people's health and wellbeing,' p.23

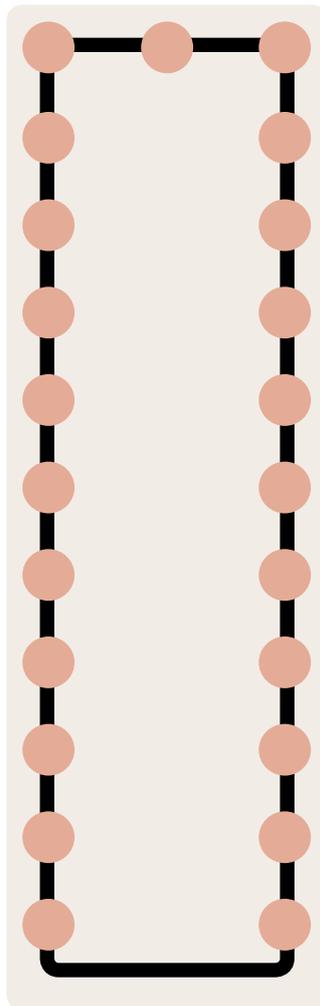
“ I find the staff really supportive and helpful at my local surgery. They provide women’s health and sexual health advice in a way which isn’t embarrassing, and they’re always willing to answer my queries

Summary

It is reassuring that almost all participants had received some form of sexual health, drugs and alcohol, and smoking awareness within the course of their education, although there seems to be two different delivery methods. Participants strongly favour interactive training over lecture-style sessions. They value information that they can apply to real-life situations, that equips them with enough knowledge to make informed choices for themselves.

Participants do not feel they benefit from, or are respected by, traditional lecture-style talks, feeling that being simply told not to engage in these behaviours is unrealistic. It is important to get this delivery method right, as the Improving Young People’s Health and Wellbeing framework states that “recognising that building good health behaviours at this life stage can prevent risky behaviour including unsafe sex and builds healthier adults” (p.9).

Some participants opened up about their experiences with drugs and alcohol. One person had attended A&E after drinking



excessively, and two females had been to hospital following drink spikings - both of whom had been sexually assaulted. Some young people told us they were likely to drink alcohol and wished to be

equipped with unit measurement and safety advice to allow them to make informed choices.

Furthermore, an awareness of services would enable young people to seek further information and practical advice or support. With The North Essex Partnership University NHS Foundation Trust (NEP) and South Essex Partnership University NHS Foundation Trust (SEPT) working together to set up a new drug and alcohol service, now would be a great opportunity to make young people aware of the support they can receive.

One person was reporting on behalf of a friend who had been sexually assaulted following a drink-spiking. She said that hospital staff judged them as if they were lying about the incident, and were dismissive, which she attributed to their age.

Essex County Council’s Health and Wellbeing of Pupils Survey 2014 found that drinking alcohol regularly, smoking regularly and taking drugs doubles or trebles the likelihood of pupils being a victim of crime.

90 participants felt it was a good idea to have young people’s services in all areas of health and social care (for example, young people’s hours at their surgery, sexual health clinic, and so on). They felt this would provide a more comfortable environment to seek help and information in, as well as feeling the issues their age group faced were believed and understood.

²⁴ North Essex Partnership University NHS Foundation Trust (2014). ‘Trusts join forces to tackle drug and alcohol misuse.’ North Essex Partnership website: <http://www.nep.nhs.uk/news/trusts-join-forces-tackle-drug-alcohol-misuse>

²⁵ Baxter, V., ‘Health and Wellbeing of Pupils 2014 Survey,’ p. 8

Learning Disabilities

In this report, the term “learning disabilities” reflects both learning *disabilities* and learning *difficulties*, as it became apparent during the YEAH! Project that young people use these terms in an interchangeable way to discuss their experiences.

75 participants felt it was important to know about this subject, so that people with an undiagnosed learning disability could understand the support they could access. Three participants with learning disabilities told us they had not been diagnosed during their school education, and felt their GCSE results had been negatively impacted by this.

“ I think schools should promote learning about learning difficulties, because at the moment they do not inform us about this a lot

A further 55 thought broader awareness of this subject would reduce the stigma that people with learning disabilities face. Some participants with learning disabilities told us that they are made fun of by classmates unaware of their needs.

15 of the young people had wanted to volunteer in services for young people with learning disabilities, but were told they did not have the experience or knowledge to do so. They felt that if young people received more information on these subjects they

Key findings



- **9 in 10** had not received information about learning disabilities, but felt it was important to be aware.
- Participants with learning disabilities valued scribes, readers and teaching support assistants
- Participants claimed that separating students with learning disabilities from their peers can lead to bullying and feelings of isolation and shame

would be able to use it to make a positive impact.

Experiences

Some of the young people opened up about learning disabilities that they, or someone they cared for, experienced. Having their needs met in education (for example, TSAs) was extremely valuable to them. They told us that they had found scribes and readers highly beneficial, particularly in exams, as well as extra time for those who find it difficult to write longer words.

“ I am autistic and dyspraxic. There are times when I wish there was a cure, but sadly there is not. However, my TSAs and family are amazing when it comes to supporting me

However, some told us they resented being separated from their classmates during exam or class time. These participants regretted not being able to feel they had had the same experience as everyone else, and feelings of shame as well as invasive questions from peers made this a negative experience. Essex County Council’s Health and Wellbeing of Pupils Survey 2014 found that pupils with learning disabilities are 11% more likely to be afraid to go to school because of bullying.²⁶

Others felt that they had been made to take a “social skills” class that had been offensive, or a spelling club that was too easy. They felt they should be assessed on their individual needs, and made to attend groups suitable for their individual learning requirements.

“ I’m dyslexic, and most of the time I feel patronised when people try to speak to me about my disability (for example, teachers). When taking the test at my school I felt like I was being treated as a 4 year-old

²⁶ Baxter, V., ‘Health and Wellbeing of Pupils 2014 Survey,’ p.13

ee At school, people are told they are dyslexic all the time. I got told I was dyslexic, and that I am capable still, but they never showed me how to feel capable. They didn't give me help, so I still feel special. Also, they didn't explain what type of dyslexia I had, just said that it was 'obvious.' That was a little insensitive

Participants showed a real appetite for information about learning disabilities, and wanted to learn about being of the best assistance to peers, common learning disabilities and how they affect people, and how to determine if they or someone they know has a learning disability.

With Essex County Council's Health and Wellbeing of Pupils Survey 2014 finding that 8% of secondary school pupils have special needs (p.12), it is evident that this awareness would be beneficial in reducing the stigma students with learning disabilities face, as well as encouraging those who may be struggling to seek support.

The young people were compassionate, and felt such awareness training would allow them to support peers with learning disabilities both in class and through volunteering.



Young Carers

159 participants had an understanding of what it meant to be a young carer. Participants wanted to learn about the roles of young carers, and the issues surrounding them. They specified a desire to learn the definition of a young carer, the experiences they face, and the services they can access for support.

The young people felt that the biggest benefit of receiving this information would be for young carers to be able to recognise when they fit this definition, and could therefore receive the help they were entitled to.

☞ **Get people to come into schools and tell us more about carers and illnesses**

☞ **I am a young carer and would like to know more about it and other people's experiences**

The Carers Trust has found that young carers miss, or cut short, multiple days of school, college, university or work each year because of their caring role. They also face higher rates of poor mental and physical health than the average young person. They rarely receive the assessments they are entitled to, with 22% of those surveyed receiving a formal assessment of their needs by the local authority.²⁷ 11 participants spoke openly about being young carers; one told us he speaks out about his young

carer identity because he wants to raise awareness of the support people may not know they can receive when caring for someone. A further two people were due to become young carers: one knew what support he would be entitled to, but the other did not know that he may qualify for a young carer's allowance.

The experiences of young carers within health and care were mixed. Young carers can find their role overwhelming at times, and value services that treat them, and those that they care for, well.

☞ **I care for my autistic brother who is 10, and there have been good services to make our lives easier**

☞ **My dad has a disability called Motor Neurone Disease, and he has been treated very well by very good doctors**

☞ **Overall, had a good experience... apart from the fact that I did not receive much help while carrying a wheelchair**

However, two young carers felt that health professionals treated the relatives they cared for unacceptably, causing them to feel judged. One person claimed that as a carer for two siblings, he was frequently dismissed by hospital staff when trying to find out how he should administer their

Key findings

- **57%** of participants had received an understanding of what it meant to be a young carer.
- Participants feel it is important to receive this information in the course of their education
- Young carers benefit from age-appropriate services which support them
- It can be difficult to speak about being a young carer to peers who cannot relate to those experiences

aftercare, or attempting to convey their needs to the staff treating them.

☞ **Being a carer and interpreter for my mother, I have to talk for my parents... but GPs seem to judge them for their inability to speak fluently and are very judgemental and patronising to talk to**

☞ **I have had terrible experiences with my GP and hospital... They have shown a lack of professionalism, especially since I am a young carer it makes it harder for my mum and I**

²⁷ Alexander, C. (2014). 'Time to be Heard: A Call for Recognition and Support for Young Adult Carers.' London: Carers Trust: p.2



Another young carer felt it was “impossible to speak about” with her peers, because she felt little is understood about the life of a young carer. ECC’s Health and Wellbeing of Pupils Survey 2014 found that 7% of secondary school pupils are young carers, and are 16% more likely to be afraid to go to school because of bullying.²⁸

When we asked participants what support young carers could access, most knew of young carer clubs. Some of the young carers we spoke to knew of these clubs, but their experiences were mixed. Two of the young carers said that they knew of these clubs, but said they were hard to find in nearby, so could not attend. One of the young

carers didn’t know that these clubs existed, and wanted to know where she could find her nearest club.

“ I found young carers club very boring as all there really was to do there was colouring. It was hard to talk to anyone there, even after a few weeks, and I felt better hanging around with people who didn’t have the same experiences as me... This was because they didn’t know my background, and I felt like I fitted in more that way, instead of feeling patronised. I quit young carers club after a month

Participants showed compassion for peers who were young carers, and a desire to learn about their experiences. A shared learning could allow carers to feel comfortable sharing their experiences with their peer groups, rather than having to rely on other young carers.

²⁸ Baxter, V., ‘Health and Wellbeing of Pupils 2014 Survey,’ p.15

Calling 999

Just under half of the number of participants who had called 999 felt that ambulances had arrived quickly, and 13 people were impressed with the knowledge and treatment provided by paramedics. Young people particularly praised paramedics and operators who were friendly, and who assisted them with feelings of shock and panic.

☎☎ The service was incredibly good. As it was my first time dealing with such an event in a public place, they kept me calm and it was dealt with efficiently

☎☎ I called 999 because my dad had passed out and was not waking up. The operator was very helpful, and there was an ambulance at my house by the time I was off the phone. I was very impressed with the services provided

While almost half of 999 callers reported positive experiences, this still stands in contrast to the 98.2% of those who rated the service to be satisfactory in the East of England Ambulance Patient Experience Survey, with 96.5% saying the wait for ambulances to arrive was acceptable.²⁹ Negative experiences were often based around customer service, with participants feeling unhappy when operators did not consider their panic or nervousness. This panic

became heightened for some participants asked questions they did not know the answer to, or instructed to check for signs of life on corpses.

The most frequent complaint was that ambulances had taken too long to arrive.

☎☎ I had to phone the ambulance for my mum because of her asthma. The service was okay, but it could have been quicker getting to my house

☎☎ The ambulance took a long time, and my injury got worse. It took two hours until they arrived, and I had lost a lot of blood

Participants who had negative experiences reported not feeling as though they were taken seriously, or having to convince the operator they needed assistance.

However, it is worth noting that only two YEAH! participants claimed that the medical issue they had called about had worsened during this wait, suggesting that some participants had unrealistic expectations about ambulance waiting times. Several participants told us that greater awareness was needed as to what constitutes a medical emergency, concerned that ambulances can be called when they are not needed.

It would be beneficial for young people to have an awareness of services such as 111 and the walk-in

centre for when situations do not require the emergency services. This could lead to fewer young people calling 999 in non-emergency circumstances, and could therefore reduce ambulance waiting times for those most in need.

One participant was deaf, and had been given a number to text in an emergency, but was unsure of what would happen if she needed to use this number while she was on her own. Another was concerned about how his cousin with muscular dystrophy had been treated.

☎☎ My cousin has muscular dystrophy; he had a fall and needed to go to hospital. When the ambulance arrived they were quite rude, and also told him he couldn't use his wheelchair. He can't walk or move without his wheelchair, so I didn't think that was very professional

Both positive and negative experiences once again show how valuable customer service is to young people seeking medical advice or assistance. For many participants, this was often the first time they had called 999, and was usually on behalf of a relative or friend - understandably contributing to feelings of distress. Therefore, it is important that operators and paramedics are empathetic to the feelings that young callers may be experiencing.

²⁹ Medler, T. (2015). 'Standard Patient Experience Report: Emergency Services Continuous Survey.' Cambridgeshire: East of England Ambulance Service: p.4

Calling 111

When asked, fewer than 1 in 3 participants had heard of the 111 service, and only 21 participants had ever called this number: a third of the number who had called 999.

Most of the participants who called 111 held favourable opinions of this service, claiming it was useful, operators were knowledgeable and friendly, and doctors had been dispatched quickly.

☎☎ **I think services like 111 should be recognised more, for when the doctors are shut, as they give good advice**

☎☎ **My dad rung 111 for a hernia and had emergency surgery within 24 hours. Everything is great now**

☎☎ **The 111 service was great and so quick**

Only three people reviewed the service negatively, believing it had been too slow, unhelpful, or was a “middle man” service that advised callers to use 999, A&E or their GP.

☎☎ **When my dad died, I had to call 111 to come round and confirm his death. It took them 4-5 hours to arrive. So the service was good, but it could have been quicker**

When the 111 service was explained to participants, the

entirety of those who had not heard of this service were enthusiastic about its benefits, particularly the 24 hour access.

☎☎ **I had to ring 999 when I witnessed someone being punched. I think if I had known about the minor service number, 111, that would have been a lot better**

All participants felt the 111 service needed better promotion to raise awareness. Those who had heard of the service had found out through their GP, through leaflets and through posters.

It was interesting that in one group, the five people who had heard of 111 were from the same area of Essex, which led to a discussion about whether services were promoted differently in different parts of the county. This group expressed that it was worth finding out what promotion techniques were the most successful in order to inform a county-wide promotional campaign. Several participants suggested that 111 should be advertised on television at times that young people are likely to be viewing.

Overall, our findings paint the picture of an effective service that has the potential to benefit many young people across the county. As well as 15% of participants having called 999, 39% had visited A&E. In both instances, a large number of reasons the

young people gave for doing this often did not warrant the use of emergency services. An increased awareness of 111 could contribute to a reduction of A&E and ambulance waiting times, as well as empowering young people to make responsible decisions about their health and care.

Key findings - 999

- **15%** of participants had called 999 with a medical issue
- **44%** of those who had called praised ambulance arrival times
- Participants placed great value in being assisted with shock and panic when calling 999

Key findings - 111

- **71%** of participants we asked were not aware of the 111 service
- The number of participants who had called 999 was **three times** higher than that of those who had called 111
- The majority of 111 callers reported positive experiences
- Participants were enthusiastic about the benefits of 111, and want the service to be well promoted

Accident & Emergency

Waiting Times

4 in 10 participants had used A&E. The most frequent complaint, reported by the vast majority of those who had used A&E, was that waiting times were too long.

The average waiting time participants reported was 4-7 hours, and only nine people felt they had received a “quick service” by being seen in an hour or under.

- ☞ **I was having heart palpitations and getting upset, so my parents decided to take me to A&E. We stayed in A&E from about 9pm until the early hours of the morning**
- ☞ **I've used A&E several times over the past few years, and I was seen relatively quickly**
- ☞ **I was once sent from the GP to A&E, and was meant to be seen straight away, but waited two hours**

A lot of participants understood the reasons for long waits, and said that they were happy to wait when someone else's emergency was greater than theirs.

- ☞ **Sometimes it is quick with different situations, such as near death, which is understandable**

13 people raised the point that some attended A&E when their problems were not severe enough

Key findings



- **4 in 10** participants had visited A&E



- **8 in 10** participants who visited A&E waited between **4-7 hours**



- **8 in 10** of those who had visited A&E reported negative experiences

- Participants are concerned about misdiagnosis, lack of staff and poor communication at A&E

to justify the use of this service.

It was evident that some young people visited A&E for problems that were not serious, as three people told us they use it for “minor issues,” and one said that whenever they visit A&E they have always recovered by the time they are seen.

While waiting times were a disappointment, participants often praised A&E staff who had taken care of them for being effective, kind and professional.

- ☞ **I had my drink spiked once. The nurses took really good care of me, and stayed with me until my mum got there. If it wasn't for the nurses, I probably would not be here**

- ☞ **I received excellent service by the nurses, but they were stretched thin and looked extremely tired. But despite this, they still put in extra effort**

Some participants told us that when they had been seen they felt rushed. This had led to concerns about misdiagnosis (which had resulted in permanent damage for two participants), and being incorrectly injected.

X-rays and Scans

Several participants who had used A&E raised concerns around x-rays and scans. They were particularly wary of having a condition missed, or misdiagnosed. There were also frustrations that after a long wait to be seen, they would face another wait for an x-ray.

One person was told that an x-ray of his ankle showed no damage, and he was expected to walk on it. As a result of this, his ankle is now permanently damaged. Another person had waited six hours for an x-ray of his finger, and was afterwards told there was no damage. He remained in a lot of pain until he was called back at a later date when a

re-examination of the x-ray revealed that his finger needed to be bolted. It has not healed properly, which he feels is down to the time between being told there was no damage and the eventual diagnosis.

One person's grandmother had been told she did not need an x-ray after a fall, yet was advised at a later date to have another x-ray which revealed she had fractured her knee. One person was told that an MRI revealed nothing was wrong, but was diagnosed with a snapped ligament 18 months later.

☞ **Going into A&E on a Saturday evening when I thought I'd broken my wrist... the waiting hours were said to be eight hours! Coming back on Sunday morning, the waiting time was a little over an hour. On being seen, the x-ray was read and a cast was put on. A few days later the wrist specialist took my cast off and sent me home. The nurses were wrong and had wasted my time**

☞ **When I went to A&E it took ages to be seen, and the next few times we were told contrasting things. It took a long time to find out what was wrong with my ankle, and to get an MRI. But once they knew, they gave me options about surgery and were very helpful about how to strengthen it**



Communication and Efficiency

Participants spoke frequently about feeling things at A&E were disorganised, and could be run more effectively with the right resources in place. 12 people told us they did not feel A&E effectively prioritised the order in which patients were seen, elaborating that they felt some people who had less severe problems experienced shorter waiting times.

☞ **A&E should be structured according to the injury, rather than "first come, first serve." When I was in A&E, I was pushed to the back of the queue. My liver had an infection and my face had swollen. I was in a lot of pain, but someone with a cut hand got seen first. I thought it was unfair**

Participants wanted to see better communication in A&E between staff and patients.

For many, no one had spoken to them throughout the duration of their wait, and they were left unsure of when they would be seen, or worried that they had been forgotten.

☞ **A&E waiting times are too long, and you are not kept updated on the progress of your waiting times**

continued on the next page

Some participants reported that staff had seemed “confused,” and that patients were referred from place to place, which often required them to fill out the same form numerous times. The young people felt that understaffing could sometimes be the cause of this.

People also reported having elongated waits due to their documents being misplaced, blood tests being lost, and having been forgotten.

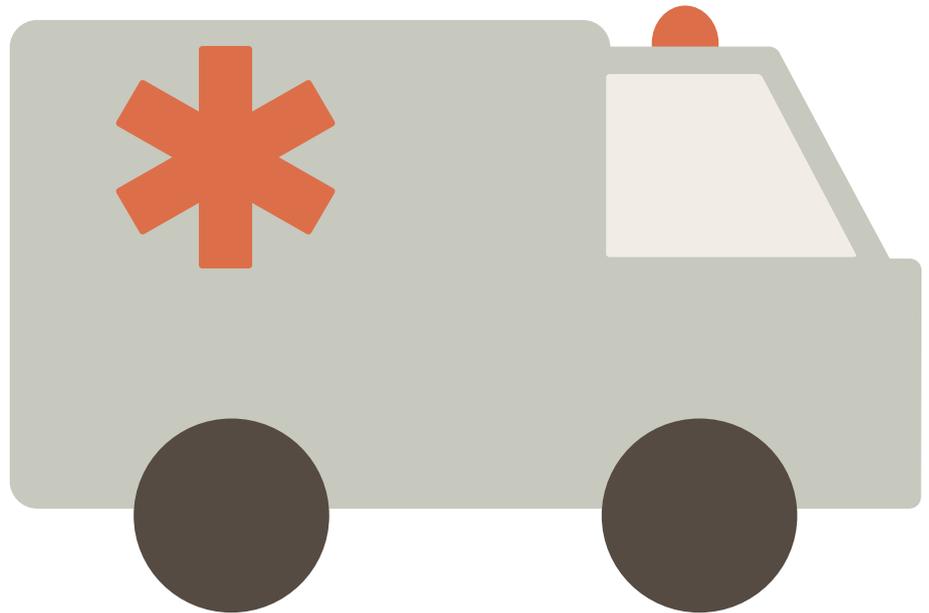
Suggestions

We asked young people to suggest ways in which they would improve these aspects of A&E. 91 participants told us they would like a member of staff to check on them during their wait, to update them on waiting times and to check if their condition had worsened.

☞ **I received false information on waiting times. There needs to be someone to come round and tell you when you are next**

☞ **There were too many people who were drunk. An improvement would be someone to comfort those who are waiting**

Others suggested a digital sign in the waiting room with an average estimation of waiting times, and some said they would like to be able to wait away from



traumatic incidents.

The participants' experiences of A&E paints the picture of an emergency service stretched thin, as reported also by The King's Fund in 'What's Going on in A&E?'³⁰

However, some of the medical situations that participants reported suggest that some young people use A&E when it is not the most appropriate service. One participant told his group that some of their issues could have been dealt with at a walk-in centre, although this was a lone voice among the hundreds of participants we spoke to.

This suggests young people need an understanding of which situations are, and are not, appropriate for attending A&E, as well as an awareness of alternative services such as 111 and walk-in centres. This could cut A&E waiting times for those most in need, and contribute to a reduction in the strain the services currently face.

The majority of experiences of A&E care reported by young participants were negative, in contrast to the British Social Attitudes survey 2014 which found 58% of the general public were satisfied with A&E.³¹ This suggests that managing the expectations of young people, alongside making improvements where possible, could reduce the number of those dissatisfied with emergency care.

Participants sometimes felt there should also be a young people's waiting room for A&E. The Princess Alexandra Hospital in Harlow recently opened a new Children's Emergency department, which was hoped would offer a larger and friendlier environment for patients under the age of 17.³²

Reviewing this recent service could provide guidance for further services targeted at young people, for example through monitoring the impact such a service has on patient experience.

³⁰ The King's Fund (2015). 'What's going on in A&E? The key questions answered,' The King's Fund website: <http://www.kingsfund.org.uk/projects/urgent-emergency-care/urgent-and-emergency-care-mythbusters>

³¹ The King's Fund (2015). 'Public satisfaction with the NHS in 2015,' The King's Fund website: <http://www.kingsfund.org.uk/projects/bsa-survey-2014>

³² Boon, A (2015). 'Health and Social Care Making Progress in 2015,' The Princess Alexandra Hospital NHS Trust website: http://www.pah.nhs.uk/news.php?news_id=352

Walk-In Centres

When we explained what a walk-in centre was, all who had not heard of this service agreed it seemed useful. The service was appealing to the young people for a number of reasons including reducing A&E waiting times, access to non-emergency advice outside of GP opening times, and a greater sense of confidentiality.

Much like the 111 service, all participants who were unaware of walk-in centres wished to see a greater promotion of these services, as well as receiving information on where their nearest centre could be found. Some suggested raising awareness via social media to attract the attention of young people.

31 participants had visited a walk-in centre (a figure five times smaller than the number of those who had visited A&E) and had done so for a number of reasons including: birth control, second

Key findings



- **8 in 10** participants were unaware of walk-in services

- Participants had used A&E **five times more** than walk-in centres

- **94%** of those who had used walk-in centres reported positive experiences

- Participants were enthusiastic about the benefits of walk-in centres, and wanted to see them well promoted

opinions, diagnosis and treatment. Of this number, only two were unhappy with waiting times or treatment.

☞ **I went to a walk-in centre and had to wait around four hours to be seen about ringworm on my face, and they prescribed me the wrong medicine for it**

☞ **I went to a walk-in centre. It was really good. The wait wasn't very long and they dealt with my injury quickly**

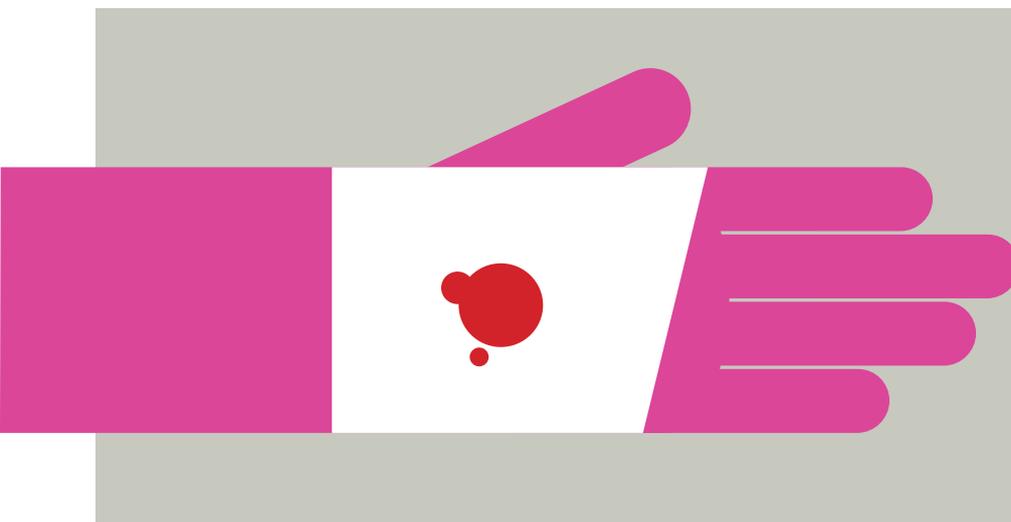
☞ **The walk-in centre helped me, and gave me medication to help get rid of my illness**

Others who knew of the service, but had not used it, said they didn't know where their nearest walk-in centre was located.

☞ **I think services like 111 and the walk-in clinic need to be better advertised, because often the doctors' surgery is fully-booked and the problem isn't severe enough to call 999**

It's apparent that young people recognise, and are enthusiastic about, the benefits of walk-in centres, with all participants thinking they should be better promoted.

They felt that a greater awareness would go some way to reduce A&E waiting times or ambulance response times, as well as being an option when they were unable to get a convenient doctor's appointment.



NHS Choices

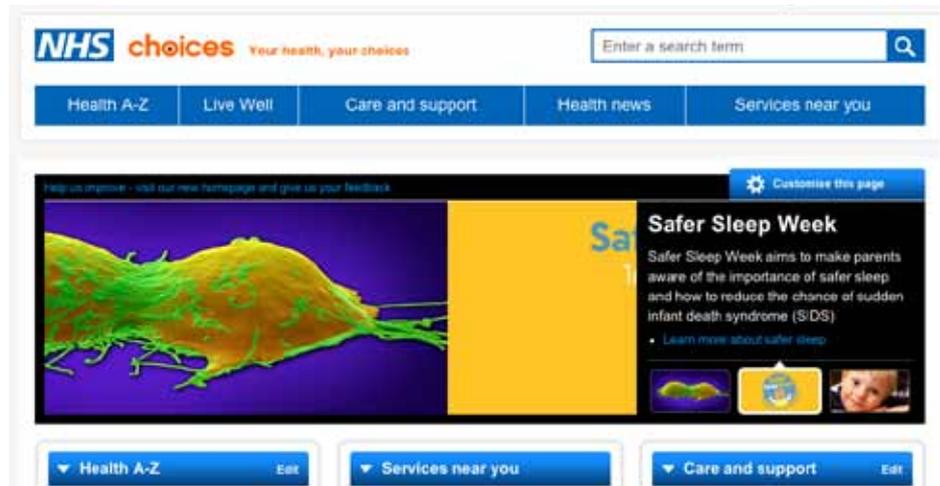
As with 111 and walk-in centres, the vast majority of participants had not heard of NHS Choices, but all wished for it to be better promoted. Most who knew of the NHS Choices website had found it when searching for health and care information online.

Participants frequently searched for their health and care information online (and the Improving Young People's Health and Wellbeing framework found "the favourite source of health issues was the internet"), and felt that the NHS Choices website sounded like the most reliable option. Participants also liked the fact that they would be able to use the site to search for services nearby.

The most common use of the website was to research medical symptoms, although participants had also used it to learn about takeaway food, body mass index (BMI) and vaccinations.

Feedback from those who had used the website was mostly positive. Seven people claimed that NHS Choices was good for looking up minor medical issues and advice on self-treatment, three people felt the design allowed relevant information to be accessed easily and one person said the website could be calming if you were panicked about your symptoms.

Five people who had used NHS Choices reported a negative experience. Four reported feeling panicked when a symptom-check



advised them to call 999. The other person felt he did not find as much instruction on managing his symptoms as he would have liked.

Young people gather much of their information online, so the fact that most participants were unaware of NHS Choices highlights the need to promote this service to them, particularly as they may otherwise seek medical information from less reliable online sources.

13 participants commented positively on the discretion of accessing services online.

This suggests that an increased awareness of NHS Choices could lead to young people receiving information on issues they would not share with parents, school health advisors and GPs.

Accessing NHS Choices could encourage young people to manage their own health through the opportunity to access a range of information with ease and discretion.

Another benefit could be a reduction in the booking of unnecessary GP appointments and A&E visits.

Key findings

87% of participants we asked were unaware of NHS Choices

Only **8%** had accessed NHS Choices

Those who had used the site mostly reported positive experiences

Participants wanted a greater promotion of NHS Choices

Concluding Thoughts and Next Steps

In many instances, the experiences that YEAH! participants shared with us echoed and validated conversations already taking place within the realms of health and social care. Issues such as a lack of awareness around mental health, or the 111 service, for example, are issues reported across all age ranges.

But the YEAH! Report shows the particular potential of high quality engagement with young people. Not only does it provide valuable insight into the experiences of young people, but it contributes to an understanding of how these experiences can shape change.

We urge those with the ability to make change to recognise the findings of this report, and feel enthused to change attitudes and cultures within health and social care. Young people are optimistic that their lived experiences can positively influence services they will use for the remainder of their lives.

As a result of the YEAH! Project, Healthwatch Essex has started to reflect these findings through further work with young people. We have conducted an audit of CAMHS user engagement, with the aim to share best practice across the county and ensure that user voice is at the centre of CAMHS promotion and development.

Based on our findings, we have started to develop an engagement model for young patients in hospitals, as well as exploring innovations around ward placements.

Healthwatch Essex continues to work with our partner, Essex Boys and Girls Clubs, on our 'Changing Attitudes' project where we engage with young people at their youth clubs across the county.

This ensures that the voice of young people is embedded in everything that we do. A number of YEAH! participants have continued working with us to help shape this report and our plan for YEAH! 2015.

List of abbreviations

A&E	Accident & Emergency department
AYPH	Association for Young People's Health
CAMHS	Child & Adolescent Mental Health Services
CMHT	Community Mental Health Team
ECC	Essex County Council
GP	General Practitioner
GUM	Genito-Urinary Medicine
HWE	Healthwatch Essex
IAPT	Improving Access to Psychological Therapies
ICT	Information Computer Technology
NCS	National Citizen Service
PE	Physical Education
PSHE	Personal, Social & Health Information
SHA	School Health Assistant
TSA	Teaching Support Assistant

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