

**What care do young people want
when they are acutely unwell?**

**Young people reflect on different
models of care**

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The Association for Young People's Health

AYPH is the UK's independent voice for youth health. We bridge the worlds of policy, practice and evidence to promote better understanding of young people's health needs. We support the development of youth friendly health services and believe these should be evidence-informed. We undertake projects that facilitate more effective communication between practitioners, raise the profile and understanding of young people's health needs, test out new ways of working, and ensure that young people's involvement is central to service development.

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**What care do young people want when they are acutely unwell?
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Executive summary

- Young people are sensitive to the **environment** when acutely unwell. Be it waiting rooms or consultation rooms, the condition of the buildings will affect young people's engagement
- Young people look for different ways of **managing pain** and value age appropriate solutions or distractions when visiting services
- Good **communication** from professionals, as well as choices in how they communicate, are essential for young people to have a meaningful experience
- Young people value support from different **networks**; family, friends, youth groups or religious communities when acutely unwell
- Young people need to **feel in control** of their treatment or consultation. Choosing whether they are seen on their own or by someone they know is important
- Young people recognize that doctors can treat them physically, however, when they are acutely injured or unwell they may need **additional support**, from counsellors or experienced peers to help them process a bad or traumatic experience
- Young people want **information about services**. Access to this information and local signposting is essential to make young people feel valued and able to seek help when they need it

1 Background

Being acutely unwell is extremely unpleasant. By definition, acute illness or injury occurs suddenly with a rapid onset. The term acute distinguishes illnesses and injuries from chronic problems that are persistent or long-lasting.

Acute does not necessarily mean serious. A dislocated wrist, a fever or vomiting is an acute issue but in a young person it is unlikely to lead to life-threatening illness. However in other cases the acute episode may be very serious or mark the start of something chronic. Either way, the episode is likely to be frightening and unexpected. Services for acute illness or injury are usually provided in hospitals (Emergency Departments, but also inpatient and outpatient medicine and surgery), or in drop-in NHS clinics and GP surgeries. Not all hospitals provide acute services.

Many hospital admissions for young people are emergencies so take place through presentation at Emergency Departments (ED). The Care Quality Commission (CQC) estimates that this stands at 47% of admissions for those aged 12-15. A study of 10,455 attendances by 8,303 young people aged 13-17 showed that reasons for attending EDs include injuries (72%), abdominal pain (16%), self-harm (11%), fits, faints and funny turns (10%), breathing difficulties (7%) and intoxication (6%). About a quarter of teenagers and young adults with cancer are diagnosed at Emergency Departments having presented as emergencies. (Key Data on Young People 2017)

The Healthy London Partnership's Children and Young People's programme has been working to consider different models of care for acutely unwell children and young people in order to improve their care in these circumstances. They created a compendium of new models of care aimed at commissioners and providers. Different services are described to help others understand what some areas are already doing.

Understanding young people's perspective on services is likely to be key to whether they work or not. The Association for Young People's Health (AYPH) was asked to work with a diverse range of young people in order to discover how they felt about the different models and what was important to them when they were acutely unwell.

AYPH and the Healthy London Partnership agreed that in order to work with young people on the compendium of new models of care, we needed first to identify the simplified principles behind the models in order to have a meaningful discussion about them. In this report we present the perspectives of young people on what they want from acute care, from a short series of workshops held in London in 2017/18.

2 The workshop process

Making acute care models accessible to young people: WHO, WHAT and WHERE

In order to understand the different models within the *compendium of new models of care for acutely unwell children and young people*, young people needed to understand: 1) what acute care is 2) what being acutely unwell is, and 3) what each service is and how it is designed to work.

AYPH and The Healthy London Partnership talked extensively about how to make the different models of care accessible in one workshop. It was agreed that one-off workshops would not provide the right setting for examining such a large document that described multiple health services, some of them quite specialised.

AYPH examined the document, identifying the key aspects of all the acute care services. Then these key aspects were distilled down into 'bitesize chunks' that summarised the services. These bitesize chunks would allow young people who did not have extensive healthcare literacy, experience or specific vocabulary to understand and contribute their thoughts and opinions.

The 'bitesize chunks' are set out below. All of these were discussed within the overall context of being acutely unwell. We talked about what it meant and gave examples at the beginning of the workshops:

1. **WHERE** would you like to access services and information?

- Should the service be closer to home, closer to school?
- Should the service be far away from home, far away from school?
- Would you prefer services in or out of a hospital setting?
- What type of FACE to FACE services would you prefer?

FACE TO FACE: School, Primary Care / GP, Urgent Treatment Centres (UTC), at home (community nurse), local clinics and surgeries, paediatricians in primary care, other bespoke services.

- What type of REMOTE services / communications would you prefer?

REMOTELY: technology; online messaging, telephone / video calls / facetime, telephone help lines, education programmes.

Is the 111 phone line helpful or have you heard of it?

2. **WHO** would you like to provide these services?

General questions surrounding who young people would want to see are:

1. Does it matter what type of staff member you see?
2. Someone you know / don't know or do you care?
3. What is most important to you about the professional you see?

Examples of professionals:

- Nurse
- Senior doctor / clinician
- Paediatrician
- GP

3. **WHAT** are the variables that are important to young people?

When young people are unwell is it important for them to

- Avoid being admitted to hospital if possible?
- If they are admitted to have as short a stay as possible in hospital?
- If they are not acutely unwell to have their health supported by their GP or another out of hospital service?

What else is important?

- What opening hours are best?
- Is the time in which you are seen important? (A&E seen within 4 hours)
- Would you prefer to go to a service like your GP where you are already registered or a service where you are not registered?

Identifying different groups of young people

AYPH and the Healthy London Partnership wanted these workshops to reflect a broad range of opinions from diverse groups of young people. Young people's experiences and definitions of acute care would vary, and they would be coming to the workshops with their own health concerns, personal or family medical history and their own pre-set beliefs about health services. We identified, a Youth Advice and counselling service in Croydon, a generic youth group in Fitzrovia and a special educational needs (SEN) school in Chessington South to work with:

- **Fitzrovia Youth In Action**
Supports local disadvantaged young people in developing projects which address issues they care about, such as community cohesion, healthy living, conflict, drugs and alcohol. They also work with local businesses to provide mentoring and work experience.
- **Croydon Drop in**
Supports young people and their families, offering free and confidential counselling, information, advice and advocacy services

- **St Philip's School**

A special educational needs school for young people aged 11-19 years. All students have Statements, or Education and Health Care Plans, for moderate learning difficulties. Many students have additional needs such as mild to moderate Autistic Spectrum Disorders, language impairment or emotional issues; a few have sensory or medical needs.

How the workshops worked

The workshops fundamentally worked the same for each group. Warm up exercises were changed depending on the groups energy, a 'focusing exercise' if the group were lively and an 'energy exercise' if the group were quiet or shy. Methods of feedback both in the warm up exercises and the main workshop varied slightly at St. Philip's School for reasons of accessibility. Feedback could be given in pictures or simply verbally, rather than written feedback. This was to allow engagement of young people who find writing challenging. The workshop structure included:

- **Introductions and hellos**

- Introduce facilitator/s (staff from AYPH and the Healthy London Partnership)
- Explain that the young people's opinions are confidential (ensuring everyone knows what confidential means) and that all their opinions are valid – there is literally no 'right' or 'wrong'
- Remind everyone that we want the young people to share their thoughts and opinions, not personal experience. We do not want people sharing anything too personal.

- **Warm up Game**

- Simple warm up game about health to introduce the theme and encourage discussion

- **Workshop activity**

Define Acute help and acutely unwell. Set the challenge: design the perfect acute care service reflecting on WHAT, WHERE and WHO

Group one: **WHAT**

What does the service look like? What would make young people feel more comfortable?

Group two: **WHERE**

Where would the service be? Could it be in school? Could you access it through a phone or online? What are the benefits to it being close to home?

Group three: **WHO**

Who would you want to see you? What qualities / skills would they need to have? Who would you want to have with you / would you want *not* to be there?

3 Themes from workshops

WHERE?

"Somewhere that's welcoming so you know that you can go to that place and you feel comfortable there"

Young people were very engaged with where an acute care service should be situated. Several of them had anecdotal stories of peers who had hurt themselves or were in distress and did not know where to get help. Or alternatively, many had looked for help at local services like pharmacists, or called the NHS 111 helpline, but been told to go to an ED.

When one group were asked specifically about calling 111 most of them had not heard of it. Others reported that they had not found it very helpful. One said that *"they just refer you to A&E"* and the other said that the person they spoke to was rude and they wouldn't use the service again.

The young people saw advantages and disadvantages to an acute healthcare service being situated near their communities, schools and homes. On one hand they considered being close to their support networks an advantage, however if they wanted to see a doctor privately an acute healthcare service further away would be of benefit. This would be particularly welcome if the problem was something with social stigma attached, like mental health or gender identity issues. Interestingly the Fitzrovia Youth in Action group – an all female group – said that their male peers would probably like a further away or more discreet service, as boys and men often don't ask for help.

Help in school was considered a good thing by all the young people. They realised that it might be embarrassing getting help in front of school friends but it could still be a safe way to access care *"some people are scared of their parents... people might feel safer at school"*

Being in or near school also allowed young people access to their regular support networks:

"I said this place would be near school... it could be near your community and friends. It would be near local transport, so it would be easy to get there. And the building should be obvious and not hidden, because it's easier for people to find it".

Use of technology may free up the location of acute services. There were different views on the use of technology. Some young people felt that apps would help young people access help, *"there's quite a lot of apps, there's quite a lot of apps out there that are accessible"*, while others said they'd prefer to talk face to face *"I'd prefer to talk to someone instead on the phone. I think it would be a lot easier."*

All agreed that the services needed to be near major public transport links. They wanted a service to be a bus or train ride away from school, and ideally in-between school and their home. Even in the cases where the young people felt that they'd want to visit a service that was not near their networks, they still wanted it easily accessible by public transport. In

addition, the Fitzrovia young people were very clear about services being open outside of regular hours, so they could visit after school or after school activities.

WHO?

"so that's what I was going to say, you don't really care about how many degrees a person has, it's about what they know and how they help"

Young people had a range of views on the kind of professionals they would like to be seen by in acute care. Overall, they wanted to feel as if they had control over who they saw for help. The type of healthcare professional did not matter as long as they were qualified to treat the young person. It was more important that young people had a say in the gender of the professional and that they had good communication skills. They also wanted a say in whether they were seen alone or with a friend or family member. They wanted to be asked whether they needed support or wanted to be seen alone.

Consistency in who they saw was very important to young people. As they commented, it can be stressful and difficult explaining to someone why you are in pain or talk about something that has happened to you. *"when you're seeing a doctor you don't want other doctors coming in so you need to explain yourself again"*. They went on to say that having more people involved in their treatment than is necessary makes them feel intimidated and uncomfortable, particularly when in pain, *"We also said we don't want unnecessary people around if you're in pain"*

The young people spoke about how it feels when waiting to be seen in a service that is understaffed or overly stretched and how that can have a negative effect on the young person, that might discourage them from seeking help again. *"there should be an appropriate amount of staff. (a lack of staff) means that a lot of people get ignored, or their problems get delayed which makes them feel like they're not as important or they feel devalued just because there isn't someone looking at them"*

All the young people agreed that healthcare professionals can get it wrong when talking to young people. Strong communication skills were an essential tool needed by professionals. Each group shared stories of feeling patronised or devalued by professional, *"some doctors, I always find, are patronising, and they're like 'Are you sure? What's actually the matter with you?' type of thing. It's like they don't care."* The young people wanted professionals to consider them as a whole person, not just defined by their illness or injury.

"...you know when you go in there and you're like 'I've broken my leg' but they just look at your leg, they don't look at you as a person. They go 'you've broken your leg now, I'm going to fix your leg, blah blah blah', well why don't you ask me how I am feeling as a person rather than just looking at that one injury. Look at me as a whole person. Like, say for example, you're a patient, you come in, 'oh yeah, you've broken your leg, I can see that, let me fix you and let you go on', ask me. This might have made me feel...it might have caused me to have anxiety or caused me to have some kind of mental health, and you're just trying to fix my leg, you're not looking into the whole picture of how I'm feeling as a person."

Young people felt that peer learning could help make them feel better both physically and mentally when they were in acute care. They felt doctors may not know what it feels like to be a young person with a serious injury, and while they may be able to help them physically, a peer to peer youth programme, led by young people who all had been through similar illnesses, could make them feel more at ease and treated as a person. The Fitzrovia youth group recognised that young people from smaller, less represented communities, particularly transgender communities, may need extra support from peers, rather than doctors who may not have an understanding of social issues affecting those communities.

WHAT?

"if you're finding it difficult to talk you should be able to write it on paper"

The young people raised a number of issues about the actual content of the time they spent in acute care. Some of these related to practical issues such as the content of medical records; others to experiential issues such as the environment. The young people from the Fitzrovia youth group understood why it is helpful for healthcare professionals to be able to access their medical record, however they wanted to be able to give consent over who gets to see these. They wanted control over what information professionals could access because they felt some professionals might judge them or not understand where they were coming from, *"You don't want every doctor knowing your business"*. Their conclusion was that professionals should only be allowed to see relevant information about them after asking permission, *"limited information on you, not all information.... On request"*

A lot of the young people were concerned about the environment of the waiting and consultation rooms. This is a common comment in relation to the whole range of medical situations of course, not just acute care. While waiting for care the young people were very vocal about how uncomfortable and intimidating a waiting area can be. *"when I go to A&E it just makes me scared"*. When asked for what would make them more comfortable they described an area that had relevant posters on the wall to their age group, along with a TV (Sky TV) and youth magazines. Some of the young people felt that distractions could help them manage when they are in pain. Games, radio, posters and information to other services all were suggestions of things that could help young people manage their discomfort.

Other young people just wanted an area that felt well looked after, *"I mean I don't really mind what goes on the wall or not, as long as it's decent, you know... there's no point going in there if there's a crumbled wall. If it looks pretty it'll make people go in there."*

The option to discuss sensitive issues in a private area was considered a good idea by all young people, one conversation went like this:

Young person A: *It needs to be like private so it's confidential.*

Young person B: *So it might be quite difficult to answer that question if you were in a big waiting room and there were loads of people round*

Young person C: *I feel a bit, you know, I'd want to go in a different room, not saying it in the waiting room, is a bit...you know, do you see what I mean?*

The young people acknowledged that some of their peers have trouble communicating, and that services should go out of their way to make it easier for young people by using simple tools and methods, such as "...*Good communication skills, so you can talk to them. There should be choices, like if you're finding it difficult to talk you should be able to write it on paper, or by using technology. Because some people will find it easier to write it on paper or using technology to talk.*"

4 Conclusions and reflections

Conclusions

Summary of WHERE

- Young people felt that acute services should be simple to get to if using public transport, whether they are close to local communities or not. Opening times need to be out of school hours to allow for drop-in sessions after school
- Services should take into consideration that while young people need to know where acute services are, it may be difficult for some young people to walk through the doors due to stigma, social pressures or because a young person's family may not support them seeking help - the young person may not want their family to know they are receiving medical care. Therefore the building needs to reflect a young person's need for anonymity
- Young people had different ideas on whether remote help (apps, phones, websites) would help or not with accessing acute care, they were all clear that services needed to be advertised in the local community, where the young people are, such as schools, communities, churches and hang out areas. It is very important to young people to know what services are out there and what they do. Services should realise that different young people will respond differently, not all young people will want a technological solution

Summary of WHO

- Young people do not look for specific qualifications in acute care staff, but they do need to feel like the person they are seeing can help them
- They would like to choose to have friends or family notified about their injury or illness or not
- Being able to ask for a specific gender and having one constant healthcare professional would help them feel safe
- Their perceptions of being spoken to in a non-patronizing way and treated like a human being, not just as an injury or illness to be fixed, are very important

- Support from peers who have been through similar experiences is very important to young people's recovery

Summary of WHAT

- Young people want to feel like they have control over the information professionals can access. In their view, professionals seeking consent to access medical records would make young people feel more in control of their healthcare
- Young people need the environment to be welcoming with their age group in mind. This could mean games, TV and radio for helping them manage any discomfort while they wait to be seen, or information about other services or relevant healthcare to young people. Younger teens may want toys, books or even fish tanks
- Young people can be intimidated by dirty or run down waiting areas
- Private areas to discuss sensitive or embarrassing issues are essential to young people

Services should be aware of young people who find it difficult communicating by using technology or creating ways to allow them to communicate

Reflections

All of the services listed in the Healthy London Partnership's document, *a Compendium of new models of care for acutely unwell children and young people*, reflect at least one area of good practice when we compare them to what the interviewed young people wanted.

A good example of this is the Walk-in Centre for Illness and Injury in Smithtown, Liverpool. The service is equipped to meet the most common needs as identified by a standardised algorithm, but due to the nature of a walk in service for 0 – 18 years old, recognises that staff require broader skills to meet the variety of issues that come up, for example, good communication. The service has weekly meetings with a paediatric consultant from the local DGH (District General Hospital).

Many of the services listed – *particularly standalone units, ones not associated with a GP practice* – have extend opening hours, from 10am to 10pm (with last patient triaged at 9pm). This reflects what many of the young people wanted; flexible drop in hours that fit around their school or work commitments.

While the young people had different feelings about using technology, such as phones, compared to face to face support, many services, including the GP Federation Hub model, and the Walk-in centres in Salford and Smithtown, all have the option of ongoing phone advice or nursing care at home. They also offer walk in follow up sessions via daily clinic attendance.

All of the services listed appear to have carefully considered accessibility to their service for young people, be it opening hours, remote follow up care or seeking consultations with experienced paediatricians. What we cannot know from the *Compendium* is the physical environment of the services, and attitudes of the staff. We have seen that along with accessibility, young people highly value clean and welcoming waiting rooms and consultation rooms, with distractions if they are in discomfort and further information. They want staff who are able to communicate well with them. What seems most crucial however, is that young people feel comfortable taking agency over their own treatment and healthcare. This can be achieved by ensuring young people understand decisions that are being made about their care and their rights, such as confidentiality. For example as well as explaining to young people why it is important to access medical records an Integrated Healthcare professional known to the young person could oversee this, explain referrals and coordinate with external parties like family, friends and other support networks.

All the young people that took part in the workshops knew A&E and what it is for. They knew what it looks like, where to find an A&E and who they would be seen by if they were to visit one. Ultimately this highlights the key to young people accessing any health service. It is essential that young people not just know where a service is, but properly understand what it is used for and what help they can expect from the service.

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