

What do young people want from Primary Care Networks?

Key themes and messages from young people

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Executive Summary

- When Primary Care Networks take proactive steps to engage young people in the places they are, they have a better understanding of services and feel more welcome
- Peer to peer support in Primary Care Settings is highly valued by young people
- Young people look to Primary Care Networks to help them communicate their health needs with their parents, carers and support networks
- Technology can help young people feel empowered and included in their care plans
- Young people are interested in Primary Care Networks and would welcome engagement in them beyond being a patient

This report was presented and agreed by the Children and Young People's Board of the Healthy London Partnership in January 2020 where the messages highlighted were universally welcomed. There was recognition of the significant opportunity which Primary Care Networks create for care, support and prevention work with children and young people. Health leaders stressed the importance of a focus on how Primary Care Networks present themselves to children and young people and the need to find effective ways to share learning from this work through regional networks.

1. Background and aims

The Healthy London Partnership (HLP) is a partnership of London's NHS, London Councils, Public Health England, Mayor of London, plus other organisations and individuals working together to improve health and healthcare in London. Clinicians and commissioners from the children and young people's transformation programme within Healthy London Partnership wanted to understand how Primary Care Networks can work effectively for children and young people and how young people's voices can be included in the planning and development of their work. Healthy London Partnership commissioned the Association for Young People's Health (AYPH) to hear from young people about their views. The aim was to engage a diverse group of young people to understand what they would like Primary Care Networks to look like, how they could best meet young people's health and wellbeing needs and what would help young people to access support.

2. Defining Primary Care Networks in a young person appropriate way

“Primary Care Networks build on the current, local primary care services and enable a greater provision of joined up, proactive and integrated health and social care.” <https://www.england.nhs.uk/primary-care/primary-care-networks/>

Primary Care Networks (PCNs) are local networks designed to enable the full range of primary care services to work together in the interest of patients, joining up different parts of the system, whilst ensuring consistent high quality care is provided to everyone. It is the ambition of NHS England and NHS Improvement for all primary care services (such as GP surgeries) to be part of a PCN.

When we are seeking young people's views on parts of the health system it is really important to agree youth friendly ways of describing the focus of our conversations. The simple definition of PCNs that we agreed upon to inform our conversations with young people was as follows:

- A network that means a young person can access a range of different health services in different locations within the borough and still get the same outcome in care and quality.
- A network being a range of services working together to support the health needs of the community it serves.

3. Why seek young people's views?

Despite national and regional focus on the development of Primary Care Networks there has been little focus on models in relation to the specific needs of children or young people. Nearly a third of the UK population is aged 0-25 and a fifth is aged 10-24. In total there are 11.6 million young people in the UK aged 10-24¹. Young people access their GP regularly for a wide range of health issues. Over half of Year 10 pupils (age 14-15) report visiting the GP within the last three months².

In 2018 33% of Tower Hamlets population was age 0-24 years. It is predicted that 16-24 year olds in the borough will see a 20% growth in 10 years - the second fastest growing age group after adults aged over

¹ Key Data on Young People 2019, Association for Young People's Health

² Balding and Regis (2018), Young People into 2018

65.³ The number of households in the borough is projected to increase from 132,100 in 2018 to 160,000 in 2028. Households with multiple children and with only young people, for example flat shares, are projected to see the biggest increase.

Getting services right for young people is thus critically important. For this work we focused on young people aged over 10.

4. How we engaged with young people

In order to improve young people's health outcomes, it is key that the way in which we deliver primary care fits their needs. We aimed to gather the views of a diverse group of young people to discuss:

- What would young people like Primary Care Networks to look like?
- How could Primary Care Networks best meet young people's health and wellbeing needs?
- What would help young people to access support from Primary Care Networks?

Given the importance of local need in how Primary Care Networks are designed and delivered we took a place-based approach to this piece of engagement work. AYPH worked in partnership with the Clinical Lead for Children and Young people from Tower Hamlets CCG, enabling us to ensure that the engagement would be embedded in the specific local context and relevant to local decision makers.

From our existing links with the borough we were aware of several young people's groups in Tower Hamlets and clear potential for engagement with three or four of them on the development of primary care services. When we commenced our work, we also identified pre-existing work undertaken in Tower Hamlets where young people had reflected on health and primary care.⁴ We adapted our methodology to ensure that we were not duplicating but adding to the important work already undertaken.

5. Areas of particular interest to stakeholders

It was important to agree a broad outline of the scope of the work we would undertake with young people. As well as agreeing the broad definition of Primary Care Networks described above, AYPH also worked with Healthy London Partnership, Tower Hamlets CCG and other local stakeholders to agree the scope for the engagement work and areas of interest to stakeholders. Whilst the engagement would allow all young people to focus on their particular concerns and interest, AYPH also agreed to include the stakeholder-identified issues in the sessions in order to build on existing work and uncover new insights.

Stakeholder areas of interest included:

- **Mental Health** - including low mood and poor mental health before point of crisis
- **Asthma** – Focusing specifically on asthma management with the hope of learning for management of other long-term health conditions

³https://www.towerhamlets.gov.uk/Documents/Borough_statistics/Population/Population_Projections_for_Tower_Hamlets.pdf

⁴<https://www.healthwatchtowerhamlets.co.uk/our-work/documents/>

- **Digital access to services** - to include apps, online access to GPs and webchats
- **Information sharing across networks** - What do young people understand about their rights, how would they like their personal information to be handled and when would they like consent and confidentiality to be explained to them?
- **The younger age range of young people** - Where possible seek the opinions of younger people, in the age range 10–15 years.

AYPH created a plan for engagement sessions which included an exploration of these particular areas of interest via simple case studies. While stakeholders had clear areas of interest, it was also important to ensure that the young people had the support and freedom to voice their opinions, ideas and thoughts about all aspects of Primary Care Networks.

6. Who we spoke to

AYPH had an initial meeting with the CCG, Clinical Lead for Children & Young People and the Transformation Manager for Maternity, Children and Young People at Tower Hamlets CCG. We identified local partners within the borough to create a stakeholder group and potential groups of young people who could be involved in the participation work. Following this initial meeting we met with a broader range of stakeholders before the engagement work started and also after the engagement work had taken place. This included CCG engagement, clinical leads and Healthy London Partnership staff.

From our conversations with stakeholders in April 2019 we identified the groups of young people to approach to be part of this consultation. The aim was to build on previous engagement work undertaken in the borough – not to duplicate, and to engage as broad a range of young people as possible. Four youth groups in Tower Hamlets were able to take part in the participation work over the summer and autumn, before the end of the project, in November 2019. A fifth expressed an interest but was not able to get young people together within the timeframe of the work.

We ran engagement workshops with the following groups:

- **Step Forward, Step Out Group**, Bethnal Green Road. An LGBTQ+ group creating a friendly and safe space for LGBTQ young people to explore, learn, discuss and socialise.
- **Spotlight** Youth Centre in Langdon Park. A free creative youth service designed to inspire, shaped by young people, for young people. Open to all young people in the borough and beyond.
- **St Bartholomew's and the Royal London Hospital's Health Youth Forum** called the Youth Empowerment Squad (YES) at the Royal London Hospital. A forum made up of young people who have extensive experience and knowledge of the healthcare system.

- **Healthwatch Tower Hamlets**, Group of young people working to influence and improve NHS and social care services within the borough.

Once the results of the participation sessions with the first three groups were written up they were presented to the Healthwatch youth group at Mile End Hospital. This youth group had already done significant work in the borough, thinking about health and primary care. This final workshop was therefore designed in a different way. It focused on asking young people to reflect on the themes from the initial three sessions, identify any gaps informed by their previous work in the borough, and focus on how they would want the suggestions to be implemented.

In total 45 young people who were either from the borough or accessed healthcare within the borough were consulted. These young people were aged between 10 and 24 years old.

All young people involved in the project were contacted by a local youth organisation and were supported by youth workers from this local organisation. This model of engaging with young people ensures that young people are effectively supported throughout and can seek support after the session should they need to from a trusted worker.

The engagement took place within the context of the local organisations safeguarding policies with AYPH staff working within AYPH's safeguarding policy and procedures. At the start of each conversation with young people the participation worker informed young people that this was a confidential space and that no identifiable information would be taken away from the session. Young people were also informed that they were welcome to contact AYPH via their youth worker should they want to change anything they had said. Notes were taken from the session and the final report of the project was agreed with each youth organisation.

6 Delivering workshops

The workshops designed by members of the AYPH participation team had to be delivered flexibly, as each youth group ran differently. One service was a drop in that lasted for a whole evening, one held more formal times and allocated us a specific slot on their agenda, while the other programmed a one-off, two-hour workshop with their cohort of young people.

Central elements of the workshop were as follows:

- Clearly explaining what Primary Care Networks are,
- Setting out the project objectives,
- Creating a safe space where participants could listen to each other's ideas and develop their own opinions, as well as keeping the experience safe, informative and enjoyable.

Workshops started with fun ice breaker activities, as not all the young people knew each other, and it was the first time they had met the AYPH participation facilitator. These activities introduced the theme of health in a general sense.

Once the initial activities had finished, a set of ground rules were created by the group and confidentiality was explained to create a safe environment.

The young people then came up with priorities that they felt were important. These covered a range of areas from confidentiality, communications and digital interaction, to outreach and engagement.

Once the priorities were created, the participants tested them against several health scenarios young people may find themselves in. The scenarios were designed to cover the areas of interest that had been agreed on at the stakeholder meeting.

The box below presents the priorities that the young people came up with and used in order to create the key findings and themes.

Priorities for workshop discussion as determined by youth participants

- **Peer support and youth work skills:** Additional support was needed to help manage the social impact of certain health conditions, particularly long-term conditions or conditions that can have stigma attached (such as sexual health or mental health)
- **Option to choose who they see:** knowing that they can choose the gender or ethnicity of the healthcare professional would make them feel more comfortable and engaged with their care
- **Primary Care Networks to be proactive:** Services to actively advertise and educate young people in places where young people are: schools; colleges; social or religious community groups
- **Support in communicating with family:** young people wanted primary care networks to help them explain their health needs with their family, particularly around mental health or sexual health.
- **Consent and confidentiality:** Services should not take for granted that young people understand what this means in the context of their health and in relation to information sharing
- **Young people should be kept informed about their treatment:** Young people valued being kept up to date with treatments, waiting lists and referrals
- **Choice:** Knowing what services are out there and what they do helps young people feel in control of their health
- **Access:** young people felt that they should be able to access services around their schedules, some of which could be very busy. This included drop-in clinics or peer support groups
- **Online and app-based support:** Accessing support, information and practical guidance online and through technology was useful for young people to feel empowered, less alone and able to seek health support

- **Professionals understanding young people:** Healthcare staff should believe young people, respect their opinions and work to understand their point of view.

7 Key findings & themes

We have set out below the feedback from young people grouped into five themes where Primary Care Networks could take action to improve their offer to this age group:

- **Primary Care Networks need to take proactive steps to ensure young people understand what services are available and are made to feel welcome**

Young people told us that they want to understand what different services primary care could provide. This could potentially be particularly empowering when managing a long-term health condition. However, opportunities for engagement are often missed. Many young people had stories about not knowing where to go when they were presented with a particular health concern. As one commented,

“I had no idea I could go to my GP when I was struggling with my mental health”

They also had stories about health services visiting their school, college or university with information about different services (most commonly sexual health services) and finding this really useful:

“My college asked the local sexual health service to come in to talk about sex education. My friend and I got to take away flyers with information about sex and local services and no one made a big deal of it.”

Black and minority ethnic young people and LGBTQ+ young people told us that they did not automatically feel welcome or understood in healthcare services. They reported that doctors did not necessarily understand LGBTQ+ young people’s particular needs or the importance of different religious cultures and primary care services did not always look welcoming to young people from these backgrounds. Many of the young people we spoke to had stories of GPs being insensitive to a young person’s identity and this having a negative impact on their health condition:

“I went to the doctor’s for one thing, but all they wanted to talk about was that I was Trans... that literally had nothing to do with why I was there”

“As a Muslim I really wanted to see a female doctor, but I didn’t know I could ask for one, so I saw a male doctor and just lied about why I was there”.

The younger groups of young people we spoke to (10 – 13 year olds) were very keen on healthcare professionals doing outreach work to educate and discuss different health issues.

- **Primary Care Networks could encourage peer to peer support for young people**

Young people told us healthcare professionals were good at helping them with diagnoses and access to prescriptions. However, they felt that these may not be the best people to help them manage their condition in day to day life. All the different groups of young people we spoke to felt that meeting other

young people with similar conditions, or from similar backgrounds could help them manage their condition and feel less stigmatised and isolated. This was particularly mentioned by young people who were managing long term conditions, such as asthma or any condition that required adherence to medication or regular clinic appointments. Encouraging and supporting peer to peer networks requires certain frameworks and ongoing monitoring and management, but is a potentially valuable way to broaden the offer to this age group.

- **Primary Care Networks could support improved intergenerational communication and understanding**

Young people from minority backgrounds saw a distinction between westernised concepts of mental health that they had grown up with and identified with, and their families' concept of mental health. This difference means they find it difficult to explain issues with mental health,

"It can be hard to explain anxiety to a parent who only speaks Bengali, even with an interpreter, they may not have the appropriate language to explain that".

Similarly, young LGBTQ+ people felt that their lifestyles, sexual identity or gender were not relatable to older generations, therefore mental and physical health issues that can arise might not be understood properly.

Young people told us that this generational difference existed within their families and communities but also within the health services they accessed. This included interpreters who may not have the vocabulary to effectively explain certain health issues. Primary Care Networks could take more positive steps to help to break down these barriers.

- **Primary Care Networks should be using technology to communicate with young people and share health information, however in some instances young people prefer to remain anonymous**

Being able to ask questions of healthcare professionals anonymously and via apps or online was highly valued by young people. Young people acknowledged that there were times they would want an app, like NHSGo, to have their medical records and other times where they would prefer to remain anonymous.

The young people we spoke to wanted Primary Care Networks to communicate and keep them up to date via app and online technology,

"If they could send me a text letting me know where I was on a waiting list that would be very reassuring"

Young people also felt that different technology platforms would be a good way to seek peer support. This might include creating ways of talking to other young people and finding psychosocial support from those their age, linking to the point about peer to peer support above.

- **Primary Care Networks have the potential to support young people to get involved in health by supporting volunteer positions etc.**

Young people told us that they would value ways of being involved with Primary Care Networks beyond seeking consultations with professionals about their own health. It was felt that having volunteering schemes or placements in primary care would help them understand services as well as benefit young people's long-term management of health, their health outcomes and careers.

8 Recommendations

Primary Care Networks have the potential to play an important role in improving the health outcomes of young people and supporting them to manage their health and wellbeing. Services have a duty to think about how to support young people to engage with them effectively and how to commission youth friendly models of care. This could include:

1. **Youth friendly information and outreach:** Primary Care Networks should aim to be simple and easy to navigate, with youth friendly information. Information should not only be provided within health services but shared broadly to make it as accessible as possible within young people's communities. Doing outreach where young people are, as well as supporting Continuing Professional Development (CPD), help young people know what is out there. Rainbow flags in services and posters in community centres / mosques are good examples of how young people within Tower Hamlets are made to feel comfortable, welcomed and listened to.
2. **Youth friendly staff:** Youth friendly skills from staff are crucial for young people to engage well with services and manage their health effectively
3. **Awareness of different communities of young people:** Primary Care Networks need to be aware of different communities of young people within their local area.
4. **Local engagement with young people:** Each area will come with different groups of young people. It is important to carry out local engagement to understand what particular issues there may be for young people. This local engagement should inform services and commissioning models. Key questions for this engagement should include:
 - *What do we already know about young people's needs in our local area?*
 - *What are the gaps in our knowledge and which are the groups of young people we need to engage with?*
 - *How will key local stakeholders be involved and support the engagement work so that what young people say can influence change?*
 - *How will we seek to engage young people on an ongoing basis?*

With very many thanks to the young people and other stakeholders who have taken part in our project so far and shared their perspectives with us, and to the youth organisations who helped arrange the workshops.

This briefing was written by the Association for Young People's Health (AYPH). AYPH is the UK's leading independent voice for youth health. We work to improve the health and wellbeing of 10-24 year olds. For more about our work please visit www.youngpeopleshealth.org.uk, or contact us at info@youngpeopleshealth.org.uk.