



Major Conditions and Diseases Strategy Response to call for evidence June 2023

As the UK's leading independent voice for youth health, the Association for Young People's Health (AYPH) has undertaken research and youth engagement work on a wide range of long term health conditions over many years. At the outset we would emphasise that we need to ensure we involve young people in co-producing approaches and informing the Major Conditions and Diseases Strategy itself. Meaningful participation with young people is key to getting things right.

Prevention of major conditions

Government action is necessary to ensure the specific needs of 10-25 year olds are understood and prioritised within prevention strategies. Often young people are overlooked within policies or frameworks that are either all-age or focused on the early-years of life.

We support efforts to ensure the prevention agenda is embedded within schools and education settings, where young people spend much of their time. It is important that there are whole-school approaches to promoting positive mental health and wider healthy lifestyles. Statutory RSE and health education are vitally important for embedding prevention into the curriculum and for shaping young people's understanding of health and wellbeing.

Supporting young people's health literacy is also important. These messages have been highlighted in a [recent report from the NHS Youth Forum¹](#) that stresses the need for the development of easily understandable healthcare resources for children and young people across England. Making information more youth friendly is key. Provision of youth friendly information is particularly important in "entry point" health services such as primary care and community based health organisations such as pharmacies. There is also an opportunity to ensure health literacy is a central part of good health education in schools.

¹ Baker Y, Burn G, Coulthard E, Daga, S, Nichols M, Pek, L, Prendergast M, [Health Literacy in CYP](#), NHS Youth Forum, 2023



Tackling risk factors for ill health

Young people's health behaviours include more than drugs, alcohol, smoking and sexual behaviour. Much investment to date has been in 'risk reduction' rather than in the promotion of positive behaviours in adolescence and early adulthood. We would like to see more discussions around how to promote better nutrition and food availability, more imaginative responses to encourage adolescent exercise, and more nuanced approaches to managing social media impacts for this age group.

This could be, for example, by broadening the scope of conversations with young people about their health to include more on these topics, and expanding the capabilities of staff working with young people – health care staff, but also youth workers, teachers, police etc. – so that they can cover these issues in health conversations. It also means understanding more about how healthy habits are shaped and framed by the environments in which they live – access to healthy food and green spaces are more limited in areas of deprivation.

Supporting those with conditions

Good health for young people is central to their wellbeing, and forms the bedrock for good health in later life so it is vital that a focus is given to children and young people. Within this a specific focus on young people aged 10-25 is important. There are [11.8 million young people of this age in the UK, representing about 20% of the population](#)². Although this is generally considered a healthy life stage, many long-term health conditions begin and become established between age 10-25 (such as asthma, diabetes, epilepsy and mental health disorders). Young people also form healthy or unhealthy behaviors and self-management techniques in this period, habits that they may carry with them into adulthood (such as physical activity, diet, smoking and alcohol use).

² Association for Young People's Health (2021) *Key Data on Young People's Health* www.ayph-youthhealthdata.org.uk/key-data/ Retrieved 26 June 2023



Data suggest that positive well-being in adolescence predicts good general health in young adulthood ([Hoyt et al 2012](#))³. The most common causes of death for young people are external and preventable ([ONS 2020](#))⁴ and about 70% of premature deaths that occur during adulthood result from health-related behaviours initiated in childhood and adolescence ([Sawyer et al, 2012](#))⁵. Furthermore it is the long term conditions that need focus, with data in 2019 showing that non-communicable diseases accounted for 86% of years lived with disability of young people age 10-24 in Europe ([Armocida et al, 2022](#))⁶.

Key issues that require early intervention during this period include mental health and obesity. Research has shown that [75% of mental health conditions are established before young people reach the age of 24](#)⁷. [Nearly a quarter \(23.4%\) of young people aged 10-11 are classified as obese](#)⁸. We are storing up problems for our young people, society and health services if we do not have a significant focus on children and young people's health and wellbeing.

Disparities / Inequalities

How can we better support local areas to diagnose more people at an earlier stage?

We need to help local areas to understand the population of young people that they serve so they know where to look for developing issues. As a part of this work it is important that we focus on young people more likely to be affected by inequity. As part of our programme of work on young people's health inequalities we have developed a [simple checklist](#)⁹ of questions

³ Hoyt T, Lindsay Chase-Lansdale P, McDade T, Adam E, (2012)

Positive Youth, Healthy Adults: Does Positive Well-being in Adolescence Predict Better Perceived Health and Fewer Risky Health Behaviors in Young Adulthood?, *Journal of Adolescent Health*, 50 (1) 66-73

⁴ NOMIS – Office for National Statistics (2020), *Mortality statistics – underlying cause, sex and age, England and Wales, 2019*

⁵ Sawyer SM, Afifi RA, Bearinger LH, Blakemore SJ, Dick B, Ezeh AC, Patton GC (2012). Adolescence: a foundation for future health. *Lancet*. 2012 379(9826):1630-40.

⁶ Castelpietra G, Knudsen AKS, Agardh EE, et al (2022) The burden of mental disorders, substance use disorders and self-harm among young people in Europe, 1990-2019: Findings from the Global Burden of Disease Study 2019. *Lancet Reg Health Eur*. Apr 1; 16:100341.

⁷ Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE. (2005) Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry*. 62(6):593-602.

⁸ NHS Digital (2022), [National Child Measurement Programme, England 2020/21 School Year](#), Population Health Team

⁹ AYPH



to help services think about their service and how best to meet the needs of young people and reduce health inequalities. Highlighting local data sources such as the [Fingertips Child and Maternal Health Profiles](#)¹⁰ alongside national resources such as the [AYPH youth health data hub](#)¹¹ can also support this work.

Basic training for all healthcare staff about the 10-25 age group and how conditions may show up differently in young people to other age groups is also important. Finally a youth friendly approach is central. Young people often tell us that they are not believed when they tell a healthcare practitioner about their symptoms and this is clearly something that can delay identification of health conditions for some young people. The newly published [You're Welcome criteria for youth friendly health services](#) are central to this and support for their implementation is crucial.

How can we better support and provide treatment for people after a diagnosis?

Helping people after diagnosis is all about access to services. We know these are unequal for people facing different kinds of disadvantages. Tackling these inequalities is critical for getting the best treatment for people. We call for a national strategy to reduce health inequalities. It is important that the focus is on addressing the wider determinants of health (e.g. education, employment, housing), rather than encouraging action through individual lifestyle changes.

The ways in which young people access services is different from other age groups, which can impact on their future engagement with services. Their experience is also variable and can be dependent on the appropriateness of the physical space which may not cater to their needs (e.g. paediatric departments) and the ways in which professionals communicate with them (e.g. using language and jargon that they do not understand). Barriers may be particularly notable for certain groups of young people and specific interventions may be needed (see protected characteristics and inclusion health groups). It is important that health and care services are responsive to the views of young people, by involving young people in decision making processes that affect their care. We recommend use of quality standards for youth friendly

¹⁰ Office for Health Improvement and Disparities (2023). *Public health profiles. 2023* <https://fingertips.phe.org.uk>

¹¹ Association for Young People's Health (2021) *Youth Health Data* www.ayph-youthhealthdata.org.uk Retrieved 26 June 2023



health services that are co-produced with young people, such as the [refreshed version of the You're Welcome standards](#)¹².

There are a range of services which young people interact with in their daily lives, going beyond health services. Young people often form trusting relationships and access informal support within the community, e.g. schools and youth services, which often provide a bridge for young people to access health and care services. Local Authorities need greater and longer-term investment in order to provide services that support young people's health and wellbeing (including youth clubs, sexual health services and substance use reduction services). The [public health grant awarded to Local Authorities is currently £1b lower \(in real terms per capita\) than it was in 2015/16](#)¹³, and [reductions in funding allocations have been higher in the poorest areas of the country](#)¹⁴. There was a real terms reduction of 70% of funding for youth services between 2010/11 to 2018/19 resulting in the [closure of 750 youth services](#)¹⁵ and this has probably been further exacerbated by the pandemic.

How can we better enable health and social care teams to deliver person-centred and joined-up services?

We recommend a clear commitment to youth friendly healthcare and commitment to a clear quality framework such as the [You're Welcome standards](#). In addition training for staff that is co-designed and delivered with young people on youth friendly approaches and the impact of health inequalities on young people is key. This type of training is supported by young people in the [NHS Youth Forum report](#)¹⁶ with one of their recommendations as follows: *"We believe the step forward would be to introduce in-depth, in-person training to educate all NHS staff."*

To get good treatment it is crucial that there is interoperability within NHS systems, but also across services that young people interact with. There should be routine sharing of young people's data using the [NHS number as a unique identifier](#)¹⁷. Young people often tell us that

¹² Office for Health Improvement & Disparities (2023), ['You're Welcome': establishing youth-friendly health and care services](#),

¹³ [Public health | The King's Fund \(kingsfund.org.uk\)](#)

¹⁴ Finch D and Marshall L (2021) [Why greater investment in the public health grant should be a priority](#). Health Foundation blog 5 October 2021

¹⁵ YMCA England & Wales (2020), [Out of Service - A report examining local authority expenditure on youth services in England & Wales](#),

¹⁶ NHS Youth Forum (2023) , [Health Inequalities report](#)

¹⁷ RCPC (undated), [NHS number as a unique identifier for children – position statement](#)



they don't like to "tell my story twice" and they want professionals to be "interested in more than my condition" – we need health services to take a holistic approach to young people's lives. We recommend using the [HEADSSS tool](#)¹⁸ within healthcare settings to promote a holistic view and approach to young people's lives.

There is also a need for health services to look at how accessible their structures for involving patients and people are for young people. A recent [NHS Youth Forum report](#)¹⁹ highlights experiences from young people and the important of hearing young people's experiences and ensuring these inform service design, delivery and staff development.

'I find as a deaf and disabled person with mental health struggles that if I have a concern about chronic pain, it is just automatically dismissed as a symptom of my anxiety or depression. Whereas it actually could be a progression on one of my disabilities.'

Finally it is important to remember that whilst health behaviours are an important "lever" they are dependent on environmental factors which influence an individual's ability to adopt healthy behaviours. Recognition of the complexities within the system and a range of policy approaches that address, rather than focus on individual level behaviour change could support health practitioners to take a more holistic approach in their interactions with young people. A number of relevant and useful proposals were made within '[Advancing our health: prevention in the 2020s](#)²⁰' relating to the promotion of healthy environments. We would recommend reconsideration within the major conditions strategy of the commitments already made relating to prevention.

How can we make better use of research, data and digital technologies to improve outcomes for people with, or at risk of developing, the major conditions?

It is key that data on what is happening for young people's health are collected and shared using five year quinary bands (10-14; 15-19; 20-24). Currently data tend to focus on what is available from services (such as the [Hospital Episode Statistics](#)²¹) and we need more on young

¹⁸ Dr Emma Parish (2018), [Using HEADSSS assessment](#), Paediatric Pearls blog

¹⁹ NHS Youth Forum (2023) , [Health Inequalities report](#),

²⁰ Cabinet Office & DHSC (2019), [Advancing our health: prevention in the 2020s](#),

²¹ NHS Digital (2023), [Hospital Episode Statistics](#),



people's health in the community, and more on the different experiences of sub-groups of young people such as those from different ethnic groups.

Mental health diagnoses

This response has been cross cutting looking at the health issues young people face in a holistic way. However, we wanted to highlight young people's ongoing and significant concerns about mental health and wellbeing and the need for a significant focus on solutions in this arena. We support calls to prioritise community based initiatives to further the prevention agenda. There are a number of successful models of combined youth work and primary health services. These complement wider calls to [Fund the Hubs](#)²², to provide early access to mental health and wellbeing support for young people in their local communities. [Youth Access' YIACS model](#)²³ offers wellbeing and counselling support for young people across the UK. Further resource and investment is needed to support these initiatives. Currently funding is directed towards meeting the increasing pressures in acute care, as many young people reach services at crisis level with no or limited previous access to support.

We also need more imaginative work on conceptualising what treatment for mental health in adolescence should look like, in order to lay solid foundations for early adulthood. Currently the model is firmly fixed on a short term intervention (e.g., CBT for 6 weeks), but mental ill health will often be a chronic, recurring long-term condition. Models of support that recognise this need to be developed and tested as they may be more appropriate for supporting coping and reducing health care needs in the 20s and 30s. In addition, we know very little about what a 'good' outcome means to the young people themselves, who are generally more interested in social functioning and general life coping than in symptom reduction per se.

A [recent report from the NHS Youth Forum](#)²⁴ also highlights the need for links with local level projects as well as engagement with young people and training for the workforce. Their recommendations are set out below:

²² Young Minds (undated), [Fund the Hubs campaign](#)

²³ Youth Access (undated), [The YIACS Model](#)

²⁴ NHS Youth Forum (2023), [Young People's Mental Health Experiences: Highlighting young people's experience and good practice taking place at local level](#),



- *“Co-producing all NHS mental health policies with young people and creating new guidelines on how to build more consistent mental health services across the NHS*
- *Implement shared mental health training, led by experts by experience, for all healthcare professionals working with young people.*
- *For NHS England to collaborate with effective local level projects that have delivered good practices, and to make them accessible to all service users across the nation.”*