

NHSE 10 year plan - Children and Young People's Sector Stakeholder Event

13th September 2018

About the meeting

On the 13th September 2018 a stakeholder meeting was held in London for organisations working with children and young people, in order to consult on proposals for the NHSE 10 year plan. A total of 71 people attended the meeting including 57 professionals and 14 young people. Professionals represented a wide range of organisations including the voluntary sector, professional bodies/royal colleges, NHS England staff, clinicians, local government.

The [Young People's Health Partnership](#), part of the Health and Wellbeing Alliance set up and facilitated the meeting working together with the NHS England Children and Young people's team. President of the Royal College of Paediatrics and Child Health Professor Russell Viner chaired the meeting.

Professor Russell Viner opened the meeting and welcomed those attending. He outlined the process of consultation for the NHS 10 year plan and how the Maternity and Child Health workstream fits alongside 14 other workstreams. Emma Rigby, Chief Executive of the Association for Young People's Health, shared feedback from young people to date and plans for further engagement with young people. Dr Jaqueline Cornish Clinical Director for Children, Young People and Transition outlined current NHSE thinking when setting priorities for babies, children and young people. Matthew Dodd, Policy Lead at the National Children's Bureau, outlined consultation work with the children and young people's sector which had already taken place.

Delegates attended two half-hour roundtable discussions from a choice of six topics, and themes from these discussions were fed back to everyone attending. A final discussion identified some headline issues which are set out in this document.

The overarching question for roundtable discussions was: ***What do you think should be included in the 10 year plan to improve the health and well-being of babies, children and young people and ensure their experiences of the NHS are positive?***

Delegates were asked to think across the **0-25 life course** and focus on tackling **inequalities, innovation** and **children and young people's voice** as cross cutting issues. The six groups focused on the following issues:

- Maternity and neonatal services
- Early intervention and prevention work
- Cancer in Children and Young People
- Ongoing health needs / long term conditions
- Mental Health in Children and Young People
- Transition from children's to adult services

Visual minutes were taken of the meeting and it was agreed that a note of the meeting highlighting the feedback from all discussions would be drafted and circulated to those who attended and shared with the NHSE Children and Young People's Team.

Themes from the meeting stakeholder discussion

<p><i>Rights and experience</i></p>	<p>We need children, young people and their families to be at the heart of the NHS with effective systems for participation, co-production, and gathering / learning from their experiences. It should be about what we do with children and young people not what we do to them.</p> <p>There should be a focus on the rights of families, children and young people to care. A refreshed constitution for children and young people and families would be an important first step to achieving this.</p>
<p><i>Access</i></p>	<p>In order to tackle health inequalities early in the lifecourse we need to improve access to what is already provided for children, young people and families. An NHS endorsed co-produced Library of Resources & Interventions for professionals and people would be welcome.</p> <p>We also need to focus on improving access for marginalised children and young people with greater health needs and less access to services.</p>
<p><i>Personalised Care</i></p>	<p>Personalised care for all babies, children and young people with mental and/or physical health needs is essential.</p>
<p><i>Workforce</i></p>	<p>We need more targeted training and support for NHS staff working with babies, children and young people.</p> <p>We have to think more widely about the workforce and look outside the NHS to for example youth workers, VCSE partners etc.</p>
<p><i>Accountability and data</i></p>	<p>We need better accountability across the NHS about how much is spent on health services for babies, children and young people and the impact of this spend.</p> <p>Routine data collection about the experience of children, young people and families and the outcome of health interventions is important to support better service provision and drive a culture of continuous improvement.</p>
<p><i>Working together</i></p>	<p>To get it right for babies, children and young people we need to work together – across health specialties, across health and education, with VCSE partners, with parents and carers whilst maintaining the child, young person and family at the heart of all conversations.</p>
<p><i>Thinking 0-25</i></p>	<p>Delegates supported a plan that focuses on 0-25 years and taking a developmental approach. For this to work the implications for the adult workforce as well as the child and maternal workforce needs to be built into plans.</p>

Feedback from young people attending the meeting

The young people attending the meeting represented a number of different organisations and brought a range of perspectives. They attended some of the plenary sessions and also held their own parallel discussion group during the proceedings. Young people in the conversation were from: Step Up to Serve, Street Games, UK Youth, South Bank University and an NHSE intern.

In their parallel discussion group, the young people highlighted the following issues:

What we want from the NHS service providers: Tokenistic engagement is not good enough. If a YP comes to a doctor with a problem, just because they may not be a specialist in that area or don't have an answer, they should still make an effort to provide help or support, even if it is just showing empathy. ***"I went to a GP with mental health problems, all they did was tell me to go to a website, I felt really disappointed"***

Preventative measures are crucial and the NHS should take a bigger role in education, particularly with physical health

Understanding the impact of social change: NHS providers need to understand that today's young people are living in a vastly different world to the one doctors and healthcare professionals were when they were young. It is important for professionals to understand each new generation will have specific difficulties that relate to their time and place.

Understand that developmental stages are unique to each young person and they need to be treated as individuals rather than just a 'life stage'.

The group agreed some final questions to feed back to the plenary session:

- How will the 10 year plan be communicated to us (young people)?
- How much of an impact / input do young people have in the 10 year plan?
- Are you REALLY listening to us, how can 'tokenism' be avoided?

Feedback from roundtable discussions

Maternity and neonatal services

- **Vulnerable mothers** including teenage mothers are better reached by VCSE BUT these services are not currently well funded – e.g. smoking cessation services have been cut.
- **Young parents need specific support** – peer support is important as well as linking to existing support resources e.g. Little Lullaby website and social media support. Family Nurse Partnership is less widely available and can be too rigid – we need to be clear on definitions of what its for. Prevention is vital for young mothers – we need to invest to save.
- **More choice and more personalised care** – e.g. personal budgets, single point of contact, text appointments etc. Giving women control over where they have their baby.
- **Making parents partners in their babies care** – for attachment and development parents need to be caring for their baby as much as possible. This is also vital for parental mental health. To enable this there is a need for space for parents to stay overnight for babies in neonatal care, to remove barriers including costs of travel and parking, support for parents.
- **Workforce: Working with the community and VCSE sectors** Maternity and neonatal support can be delivered via community / children's centres by VCSE organisations who know families and follow them through to primary schools. Developmental checks could be done in children's centre setting by nursery nurses – doesn't have to be NHS Health visitor led.
- **Workforce: Neonatal services need more specialised training for nurses** – there is a huge shortfall in neonatal nurses as babies need 1:1 care. As well as recruitment (new scheme at South Bank Uni) we need to focus on retention – many nurses experience stress and burn out leaving the profession.

Early intervention and prevention work

- **Parenting** – upskilling parents and supporting them to be part of the team caring for children and young people
- **Making the first point of contact with a child, young person or family count** – health services are in contact with families before education. For SEND early diagnosis with additional support in place as soon as possible is vital.
- **Working together is vital** – cascading and reaching out from the NHS and sharing expertise so that messages are consistent, joint commissioning – removing divisions between arms length bodies etc.
- **Primary care has a central role** we need to develop new models, homes, hubs with wide range of staff and outreach into the community.
- **We need to improve access in order to reduce inequality** – You're Welcome quality standards are part of this and primary care is central

Cancer for children and young people

- **Improve diagnosis of childhood cancers** – improve training for primary care so all GPs have the basic skills they need, we should also educate children at school – time to diagnosis is very important
- **Improve treatment systems for children and young people** – treatment is already specialised but systems for children and young people are less established, young people may not be offered specialised services and its important that 19-24 year olds are offered options. We need to improve access to radiology and we need effective pathways and cultural change. Skin cancer has a good clinical pathway because its visible – hidden cancers are less so.

- **Personalised and holistic care is vital** – particularly important in transition from child to adult services. Clinical nurse specialist important as are youth services which have been significantly cut. Personal budgets for patients with cancer.
- **Access to innovation and clinical trials for children and young people** so that they can benefit from new advances
- **Improve palliative care for children and young people** We also need to consider life limiting diseases following cancer and improve referrals to palliative care with perhaps access to an advanced care plan. Physicians should approach palliative services in tandem with curative care. More resources are needed to support palliative care.
- **A greater focus on children and young people’s experience is important** – e.g. National Cancer Patient Experience survey. We need to ensure children and young people have the opportunity to feedback. Wifi access is really important for children and young people’s experience.
- **Recognise the wider impact of cancer on families** – the financial impact on families is huge including travel – could the NHS have a travel fund and free parking?

“we need strong networks with a strong mandate to implement new service specifications”

Ongoing health needs / Long term conditions

- **Personalised care** – e.g. personal health budgets
- **Access to services** – 24 hours
- **Wider support for children and young people with long term health needs** – Peer support groups, better support and training for early year settings, schools and colleges, clearer roles and responsibilities for meeting needs in education settings.
- **Better communication with CYP and families** – accessible information, health information passport, information in advance of meetings, a single identifying number wherever you go, information in advance of all important appointments so you know how to prepare, different and accessible means of communicating - particularly for those with special educational needs, key worker or lead professionals as a single point of contact.
- **Accountability measures** – outcomes that matter to children, young people and families, outcomes that go beyond health needs, the development of new and better indicators.
- **Joint planning and commissioning of services** - A common understanding of data and the needs of the local population, arrangements for agreeing provision across education, health and social care, new primary care home model can support integrated working, linking commissioning for CYP with long-term conditions, SEND and mental health needs.

Children and young people’s mental health

Three groups discussed children and young people’s mental health. They raised the lack of parity of esteem insufficient funding and lack of access. Within this challenging context a number of suggestions were made to inform priorities.

- **Building emotional literacy for children, young people and families and linking to PSHE:** Children, young people and carers need emotional literacy to be able to self-help and build resilience. This could be delivered in schools in PSHE (personal, social, health education) lessons and as early as possible to help prevent the development of mental health. Work across health and education is an absolute must to help prevent mental health issues and to build resilience.

- **Research:** We need to identify what the triggers are that lead to mental health issues. Research will help prevent development and subsequent impact on things as reasonable adjustments can be made. Poverty is a big issue.
- **Workforce:** Increase the competency of all staff working with children and young people about mental health and emotional wellbeing. In schools, charities and health settings – e.g. increased access to Mental Health First Aid for those who work with CYP, access to appropriate support and supervision for staff.
- **Person-centered treatment and support plus integrated care** - We need an integrated child health service with a variety of roles supporting a the child or young person at the heart of the issue. Thresholds for support or treatment are set very high and are getting higher. This contradicts ‘early intervention’. Crisis care is of poorer quality than for adults. It needs to be more accessible and less restrictive.
- **Accountability** There should be ‘whole system accountability’ to young people. Regular prevalence survey
- **A greater focus on navigation and social prescribing** - We don’t have efficient use of current models or provisions. There needs to be an NHS endorsed co-produced Library of Resources & Interventions for professionals and people.
- **A greater focus on inequalities** There are still inequalities in access as not all who need help get it. Young carers, care Leavers, young people not in education, employment or training (NEET), the children of parents who abuse substances or are involved in crime often get missed out. Eg. There should be mental health support workers in ‘leaving care teams’.
- **New ways of accessing services** When there is a gap between face to face MH appointments and a child or young person needs help, there should be a self-help app or video appointments made available.
- **We need whole system co-produced support made available early.** The rights of children and young people need to be better communicated and enforced. Youth Access has a recently co-produced Young People’s Charter.
- **Peer support and volunteering:** Learning from peers can lead to effective strategies for self-management or prevention. Volunteering can also help overcome mental health issues.

Transition from children to adult services

- **Personalised care for young people is a must.** “Nothing is easy as a young person” “it’s a scary place I’m in”. Young people need compassion – the relationships they have with health professionals matter. Co-production with young people and hearing young people’s voice as part of the transition process is fundamental to good care.
- **We need to learn from services that focus on 0-25 years.** It’s not a one size fits all across this age range we need overlap of services, choices for young people and flexibility.
- **We need to have medical records shared.** Digitalisation, links, not repeating narratives.
- **Young people should have a single named contact who they identify** to support their transition and provide continuity
- **All services including primary care need standards for transition** – ‘You’re Welcome’ quality standards should be followed
- **Workforce** – youth workers and primary care are really important for good transition providing continuity for young people

Next steps

Professor Viner and Dr Cornish thanked the group for the timely and useful discussion and outlined the next steps in the development of the plan. The NHSE team would be drafting a full version of the Maternal and Child Health workstream by the end of September, and the full plan was due for completion by the end of October 2018. There would then be discussions in relation to the next Spending Review and the allocation of funds to different workstreams to take the plan forward.

If you would like more information about the Young People's Health Partnership or the Health and Wellbeing Alliance please contact info@youngpeopleshealth.org.uk

For more information about the NHS 10 year plan contact england.ltp@nhs.net or visit www.england.nhs.uk