

Meeting of the APPG for Young People’s Health

11th March 2019, 16.00 – 17.30

House of Lords

Members of the House of Commons and House of Lords	Other attendees
Baroness Massey (Co-chair) The Earl of Listowel	Gabrielle – NHS Youth Forum – Young Person (Speaker) Rachel - RCPCH representative – Young Person (Speaker) Owen - RCPCH representative – Young Person (Speaker) Jacqueline Cornish – NHS England (speaker) Richard Owen – NHS England (Speaker) Emma Rigby - AYPH Ann Hagell - AYPH Vicky Robinson – AYPH Isabella Perales – PLMR Hannah Baynes – King’s Adolescent Outreach Service Philippa Watts – National Children’s Bureau Maria Sykes – British Youth Council Stephen McKeever – Southbank University Paul Jarvis-Beesley – StreetGames Angela Wright – Bart’s Health Angela Thompson – Bart’s Health Neil Fletcher – Bart’s Health NHS Trust Luci O’Reilly – British Youth Council Steph Lamb – The Well Centre Emma Sparrow – RCPCH Tina Lond-Caulk – The Nutrition Guru Isabel Inman – Brook Ryan Nibloe – National Children’s Bureau Liz Ainsworth – Teenage Cancer Trust

1. Welcome

Baroness Massey welcomed everyone to the meeting.

2. APPG business & matters arising

The APPG will hold an AGM next week. Baroness Massey thanked AYPH for their work as the secretariat for the APPG and congratulated them on the recent publication of the International Comparisons report published with the Nuffield Trust.

3. What Young People Wanted from the NHS Long Term Plan – Young People representing RCPCH & Us

Rachel and Owen, representing RCPCH & US and the Epilepsy12 project addressed the meeting about the engagement work they carried out with the Young People’s Health Partnership, British Youth Council and NHS Youth Forum to get young people’s views on the long term plan (LTP). Work included: a survey, webinars, a roadshow across England and events, some of which were targeted towards young LGBT people, young people in care, young people with long term conditions and seldom heard groups. Over 300 young people engaged with

the work and we then analysed the key themes across all the groups. The results were launched on World Children's Day.

31% of young people told us they wanted child & youth friendly services, 25% wanted improved mental health support, 21% wanted support on skills for health, 16% wanted their voice and rights in healthcare to be listened to, understood and included and 6% wanted improved support for transitions.

Rachel sits on the Epilepsy12 programme board. They are working to improve care and services and the engagement work around the LTP echoed what young people involved in Epilepsy 12 have said they want: better mental health services and transitions and advice on self-care. They want guidance on how exercise and diet can help manage long term conditions (i.e. eating spinach to get extra iron). There is no guidance in schools on how to improve your general health. Young people stress the importance of mental health, you live with the effects of this every day and it is just as important as physical health. There is not enough support for mental health in epilepsy care. 75% of young people they spoke to receive no mental health treatment during their care. We need to offer good care from the beginning to ensure support in the future. We can see increasing problems for young people affected by obesity and diabetes, young people want support to take care of themselves. Physical and mental health are connected, we need to treat the whole body. And this is not just a request, young people have the right to this as stated in Article 24 of the UNCRC, which says that children and young people have the right to be both physically and mentally fulfilled and have a right to information about their health and how they get this.

Owen also sits on the Epilepsy 12 programme board. As a young person with epilepsy he knows the impact of long term conditions on everyday life, such as the practicalities of transitions, support and services and how specialist nurses who know young people can help you come to terms with your diagnosis. The general public is more knowledgeable than people think, they know a diagnosis when they see it. Whilst in a pub, he dropped a drink and the people there came to help him and spotted that he was epileptic without him disclosing this. Everyone needs a voice. Stigma needs to be challenged and education is particularly needed to find the best answers to support those with long term conditions. The LTP promises to establish youth friendly services up to the age of 25. This is great news. Young people he has spoken to don't want to start again at 16 or 18. We need to listen to young people to improve the future.

4. Overview of proposals in the NHS long term plan

Richard Owen, Head of Quality Strategy at NHS England addressed the meeting and offered his thanks to the young people for their contribution and the organisations that supported them.

There were 18 work streams for engagement that went into the LTP. It was important that the NHS got this right and got an insight into what people wanted from the NHS. The content of the plan would not have been so strong if young people had not engaged with the process. Policy can be created from evidence and data but having young people's voices had a huge impact. It was an opportunity to look at the life course and the experiences of 0-25s. This is an exciting time that will influence how the NHS move the plan into delivery. Co-production and voice will play an important part of the implementation.

Jacqueline Cornish, National Clinical Director for Children, young people and transitions to adulthood at NHS England addressed the meeting. She thanked the young people for their engagement. Their voices were powerful and the evidence they provided helped to shape the LTP. She stressed the importance of investing in early years and to cross-services and the life cycle. The UK is in the 19th position for neo natal mortality. We need to increase the safety of services, numbers of nurses and enhance the experiences of families, including accommodations for parents.

1.2 million children and young people suffer from mental health disorders. 25% of mental health disorders are diagnosed by 14, 75% by 24. Early intervention and better opportunities are needed for young people to have a

healthy adulthood. Poor investment, 21st century living, social need, adverse childhood experiences, and poor infrastructure, including lack of staff and long waiting times all hamper young people's health. All the recommendations from Future in Mind, the 5 year forward, the children & young people's mental health green paper have been incorporated into the LTP to give a policy context. There will be a whole system approach, so everyone will be working together. The LTP will have ring fenced funding and a commitment to increase children and young people's funding and services. The NHS will be working with schools and colleges. The 0-25 offer will address the cliff edge young people face at 18. There will be increased crisis support and new standards to help reduce suicide. There will be a prevention focus to help reduce obesity rates. Local services will be family friendly, with practice offering programmes and support for weight management, sleep apnea, diabetes, mental health, etc.

Service design is important to the LTP. 5 million young people under 20 attend A&Es. More acute and initial care services are needed at a community level, working with health community nurses so that hospital admissions only occur when really needed. The UK does not perform as well as Europe on managing long term conditions. Young people are developing early conditions. We need to enhance existing networks and improve outcomes.

Epilepsy 12 carry out an audit of services annually, but 2 parameters are not measured: safe transition and mental health. We need to establish networks to support young people living with complex disabilities and life limiting conditions.

The UK is also behind Europe on cancer rates, due to late diagnosis, clinical trials and diagnostic ranges. We need to develop networks of care. Transitions must be handled in age appropriate ways and services must be youth friendly and service specifications must be included in specialised commissioning. This should be rolled out into all areas and we will continue to engage with young people.

5. Young people's reflections on the plan: Gabrielle Mathews, NHS Youth Forum

25 young people with long term and complex conditions engaged with the long term plan creation via workshops, stakeholder events and surveys and this made us feel very valued and heard. We need:

- increased focus on mental health
- children and young people friendly services based on the You're Welcome standards
- focus on transitions – moving away from support to managing individual health & self care

This should be a holistic process that will require parity of esteem and relationships between young people and professionals. Young people need to be heard and not just listened to. The increased focus and funding for mental health services, learning disabilities and cancer in the long term plan is positive.

Chapter 1 of the plan talks about person centred care and includes a great quote from National Voices about the importance of 'what matters to someone' not just 'what's the matter with someone'. This is important for children and young people.

The recent AYPH & Nuffield Trust international comparisons report shows we are not doing as well as other European countries on diabetes, asthma, etc. There are gaps. How will the transformation board be set up, will young people be involved? We need new ways of working, it's important we work with young people and not just in their own services. Obesity is an issue that affects children and young people, but also the wider general population. We need to work with young people to help train professionals, to learn how to have conversations with young people, to co-design and co-deliver services. We must acknowledge the differences between need in rural and urban communities. Alone we are not a representative group, we had to work together to get broad view for our engagement and we must continue to work together to ensure this view is not lost.

Accessibility is an issue around young people and A&E use. There is a lack of understanding on what is available and where. We must pull the NHS and services closer together, include pharmacies, urgent care, etc.

Being heard, not just listened to is vital. It can't just be tokenistic, tell young people how things will happen. The plan promises a model of comprehensive care for 0-25 year olds, how will this work? How will paediatricians feel about working with over 18s? The NHS will be holding a youth voice summit to address these issues and will be recruiting young people shortly.

Can existing work be tailored to support young people, i.e. Obesity tiers – focus on family, what campaigns can be tailored to young people and to consider accessibility?

6. Discussions & Questions

Young People Friendly Services: Baroness Massey raised the issue of the importance of how professionals treat young people. Services should be holistic such as services in Sweden.

Experienced Clinicians: Lord Listowel is a Trustee of a charity that supports the mental health of children and adolescents and welcomes the high priority in the long term plan for mental health. We have excellent clinicians but there is concern that we have lost jobs. Cheap interventions are available widely but these are not sophisticated, we need to retain experienced clinicians. The mental health of looked after children must be supported, we can't have a low qualified workforce supporting highly vulnerable young people and must avoid young people becoming criminalised. We must reflect on the relationship and respond in more positive ways to challenges.

Workforce: Stephen McKeever commended the long term plan for its focus on parity of esteem. When talking about neonatal services the plan did not mention paediatric intensive care services. Jacqueline Cornish said there is a national review on intensive care services, surgery and paediatrics that is nearly complete and will be published in the next 6 weeks. The review looks at transport mechanics, ECMO and development of networks of care. These are all dependent on nursing workforce. The workforce are most important at all levels. We need a wide variety of professionals in mental health services, schools, care homes and other institutions. There will be a drive to recruit and a level of quality of people. We don't want to lose well qualified staff. It's critical to get right, we must work with partners. Richard Owens said that the review will feed into the transformation board so they are aligned and will be part of the wider programme. The transformation board will consider everything. The timeframe and how this will be done will depend on facilities and funding. We must have a distinct work programme and must ask young people how it should work. The board will oversee delivery and local transformation services for children and young people. Sarah Jane Marsh, the Chief Executive Officer of Birmingham Women's and Children's Hospital and Chair of the NHS England Maternity Transformation Programme and will be responsible for getting the national and local level right. Young people must be at the heart. Some areas need more development and some areas already have a solution, such as the You're Welcome standards. How do we make sure these are used? As to the questions of paediatricians caring for older young people, the key is getting Drs to work together with young people in the middle. This can be tricky due to the sheer volume of adult practice. Transition should take place when young people are ready, at a developmentally appropriate stage.

Emma Rigby said we are delighted that children and young people are so prominent in the long term plan. When we consider how the transformation board will hold 0-25, young people asked what the particular strategy will be to address the move to independent use of services? Lots of programmes are focused on younger children, how will the board sustain focus on the whole age range?

Paul Jarvis-Beesley said that this is not pitched as children & young people programme. Will it include link workers in primary care and social prescribing? All ages, including young people benefit from mental health

prevention and self management. Richard said that social prescribing has a massive potential and links to the new primary care networks. The key is integrations and how we bring together young people. Some programmes are pathways of disease population groups, segmenting across life course and across the age ranges. Different children and young people have different needs.

Jacqueline said that clinical quality, long term conditions and transformation board for 0-25 were all issues. We need to keep focus on services. The continuation of care for young people is very important, as age appropriate treatment. Richard said the NHS need to be reminded of this, it's easy to focus on bits. Young people face lots of transitions, not just 18-adulthood, but school, university, etc.

Has there been any thought to parenting and the support on mental health issues and how this impacts on young people's lives?

Steph Lamb said that as a GP she is interested in self care. The RCGP AHG has discussed how feasible it is to talk to PSHE curriculum, it's important to impart particular understanding of health, diet, etc. The Well Centre is a young people health hub, which is co produced with youth workers to provide models of care. Unfortunately there is not the investment to replicate this model. Primary networks need drive and investment. Response to care and access to care for young people. Jacqueline said these are great examples, the Southwark model at Evelina is also great. Now is the time to spread these out further. Richard said that at the moment it's in pockets, we need to evaluate and learn so we can get to a place where we can say that all areas should be doing x why aren't you? This has to be done through SDPs. We hope SDPS will come and ask how to do this. As to parenting we work with health visitors and local maternity.

Emma Rigby said that AYPH has carried out some work with parents of young people that showed there is a lack of focus on parenting work. They have published a briefing and are developing a resource. A focus on the parents of young people is really important as we move forward.

Tina Lond-Caulk said that as a nutritionist who works with 60 schools, they all want information on what keeps them well. This needs to be brought into PSHE. It is not there as much as is needed especially in state schools. There is more work to be done in the community at a state level.

Baroness Massey said that departments need to talk to each other more. We have to make this as good as possible and it needs the input of the kind of people in this room.

Maria Sykes said that diversity and inclusion is vital. It can be neglected and we tend to access young people through particular means which means that we don't get a true range. We need a commitment from NHS and stakeholders to understand what it means to have diversity of engagement. At the youth voice summit we will ask for a commitment to hold inclusive engagement and how we can create an environment that will be more inclusive.

Owen said that families are an integral part of children and young people from a mental health and long term condition view. RCPCH in the process of establishing a small group tackling 6 main areas. The most important is tackling the main anxieties of young people and families from clinics across the country. It's important that young people have the choice to see clinicians with parents and also without.

Jacqueline said it is fundamental to ask young people what they want. This must be part of transition. We must make sure clinics do not breach confidentiality. Richard said that it is not just NHS executives discussing integration, they are asking DFE, etc. so they can have a rounded discussion with the system. Local roundtables, not just the NHS, but wider service providers. They will be missing a trick if they do not get the right stuff on the curriculum. Jacqueline said schools and the NHS were working on resilience and early interventions but funding was pulled. The mental health green paper establishes mental health workers not just in schools to provide a continuation and preparation of young people to leave home and take the next step where they are independent.

Terry Austin said he is Head of Wellbeing at Nuffield, who have been working on a school wellbeing programme with 150 sites. They have been working with local schools, particularly primary to ensure wellbeing can be incorporated as part of the curriculum, covering subjects such as emotional wellbeing, nutrition, sleep, etc. How can we expand this?

7. Any other business

Baroness Massey thanked everyone for attending and for the productive discussion. She also thanked the speakers and said the minutes from the meeting would be written up and circulated to attendees. Key issues will be highlighted and we will continue to feed into the NHS and inform co-production with other organisations.

End of meeting 17.30