

**Meeting of the APPG for Young People’s Health**

**Milbank House**

**14<sup>th</sup> November 2018, 16.00 – 17.30**

**Attendees:**

<b>Members of the House of Commons and House of Lords</b>	<b>Other attendees</b>
Baroness Massey (Co-chair)	Children’s HIV Association (CHIVA) representative – Young Person Dominic Smithies – NHS Youth Forum & Student Minds – Young Person RCPCH representative – Young Person Elaine Gibbs – Student Health Association Emma Beedon – NHS Youth Forum Samya Safaraz – NHS Youth Forum John Coleman - AYPH Emma Rigby - AYPH Ann Hagell - AYPH Vicky Robinson – AYPH Lindsay Starbuck – AYPH Marian Davies – RCGP Neil Fletcher – Bart’s Health NHS Trust Nigel Mills – Great Ormond Street Hospital Luci O’Reilly – British Youth Council Annie Morris – Redthread Steph Lamb – The Well Centre Dick Churchill – AYPH Priyanka Patel – CLIC Sargent Ruth Caleb - Wellbeing Consultant Eloise Dickens – RCPCH Alexander Lee – RCPCH Emma Sparrow – RCPCH Rachel Carter – RCN & Plymouth University Ellen Ferris – Teenage Cancer Trust Miriam Brooks – The Health Foundation Claire Bethel – Way Ahead Emily Dobson – Young Minds

**1. Welcome**

Baroness Massey welcomed everyone to the meeting.

**2. APPG business & matters arising**

The APPG will be holding an AGM and details of this meeting will be shared shortly.

**3. An overview of research on key issues in student health – Dr Ann Hagell, Research Lead, Association for Young People’s Health**

Ann Hagell addressed the meeting about research that has been carried out around student health. This is an important issue to consider as half of all 18-19-year olds are in full time higher education. Lots of young people

experience transition through university and many young people move into university with health conditions, either existing or newly diagnosed. It is also a time when health behaviours are introduced, such as smoking, drinking, etc. Finally there are issues around access and how young people get the health services that they need.

There is not much research available about student health. Most research in this area is focussed on specific conditions particularly mental health and diabetes. More research is needed to support young people. Health management is a critical area. This is a time when young people are living independently, often for the first time and there is a reduction in the amount of service contact young people have. Students are aware of services but are not accessing them. AYPH has produced a briefing on this which can be accessed from [ayph.org.uk](http://ayph.org.uk).

#### **4. Key issues in relation to student health - Dr Elaine Gibbs, Student Health Association**

Elaine Gibbs addressed the meeting about the key issues relating to student health. University based health services are attended more frequently for aged matched populations but attract less financial investment as students do not attract funding via the outcomes and other frameworks which GPs work within (e.g. QOF and Carr-Hill formula).

Long term conditions are defined as any condition that cannot currently be cured but can be treated and carry an increased risk of mental health, functional impairment and reduced life expectancy. A significant proportion of young people will have long term conditions in student practices this figure is 20-30%.

In the NHS 5 year forward view, NHS England recognised that university practices are unique in terms of commissioning. Students with long term conditions have specific emotional and social challenges. They are experiencing transitions and adapting to living independently, managing finances and their own diets, and arranging their own healthcare and prescriptions. Young people are more likely to engage in risk taking behaviours and can deny their conditions due to stigma or wanting to be equal to their peers. Students also tend to engage less in physical activity. More students are now attending university from social and culturally diverse backgrounds, who have a higher risk of dropout. 15-20% are above the threshold for counselling.

There has also been an increase in international students, who face cultural and language barriers and are not familiar with the NHS, what is available and how to access services. They can also face greater stigma around mental health issues.

Students are a transient population, they often miss appointments. There are challenges for primary care providers around finances and paying prescription charges these include:

- students tend to choose to remain with their home GP
- They are reliant on self-declaration which effects early intervention
- It can be difficult to get access to student health records
- The NICE guidelines for transition are not appropriate for students, as they assume geographic stability
- Lack of consistency, i.e. ADHD medication some parts of the country require referrals which can cause delays

#### **5. Living with the long term effects of a Cancer diagnosis/treatment at university – RCPCH**

A young person from RCPCH addressed the meeting about living with the effects of a long term condition at university. When they were 9, they were diagnosed with leukaemia, they now have a chronic pain condition and immunity syndrome. They are studying global medicine at Kings. *"I am a childhood cancer survivor. I am a chronic condition warrior."* They may look normal but are fighting behind closed doors.

Chronic illness infringes on every aspect of life. They have adapted but it wasn't until they left home to attend university that they realised how much they and their family had adjusted and what it was like to manage their condition on their own. The impact has been massive.

University offers many opportunities and they pushed themselves to do everything, which led to a cycle of trying to do everything, getting knocked down and getting back up again that was difficult to break. They received support from their peers, but many young people don't receive this and end up isolated and not having a support system. This is hard, especially if you are used to having this at home.

Their top criteria for selecting which universities they applied to was the level and standard of supportive care, not academic rankings or course offerings. At Kings plans were put in place to support them which made a difference and meant they always had someone to talk to. Having long term support was the most significant thing. If you break your leg, people will rally round to help you. If you have a long term condition people get tired of hearing about it and go back to their normal lives, you learn to hide it. Having the university acknowledge that they were not exaggerating and that long term support was needed was a big help. If they had not had this, they would not have had the opportunities that they have had. At the end of the day people with long term conditions have dreams and aspirations.

## **6. The health needs of young people with HIV when they go to university – Children's HIV Association**

A young person from the Children's HIV Association addressed the meeting about the health needs of young people with HIV at university. The experiences of people living with HIV are different to other long term conditions due to stigma and prejudice. It's connected with sex, which is a taboo subject and people remember the tombstone advert from the 80s and assume it's a death sentence. Young people feel they must keep it private, so you can't access support. It's difficult to engage with society. *"I am not HIV positive, I'm someone living with HIV. It does not define me."*

They attended Manchester University to study economics and politics and they found it very difficult. They were dealing with a chronic condition that they could not disclose and even if they did the university did not know how to support them. Even when people are trying to be supportive, they can be isolating. The first question a person living with HIV is nearly always asked is - How did you catch it? The second is - How does it affect you? They have chronic fatigue, stomach problems and cognitive impairment, but they are not believed because it is not visible.

They found it difficult to cope and tried to kill themselves 5 times, they did not want to die but could not find support and felt services were not for them. A friend of theirs who was studying at Surrey University and was also living with HIV told them about the support system there and they transferred. The Head of Wellbeing invited them to a meeting to discuss how they could support them. They were offered 1-2-1 peer mentoring, including with mentors who were not aware of their status, support for mental health and financial support. This was important because the perception of HIV can be that you take one pill and that's it, but there are co-occurring issues like the effect on mental health and other issues such as trauma and poverty.

At Surrey University they become vice president of the student union, became involved in mixed martial arts, a NUS officer and started several businesses. This was all due to the support they received. Young people who have long term conditions are often resilient and charismatic due to the difficulties they have faced. If you remove the hurdles this allows young people to be who they really are.

Universities are often reactive not proactive. At Manchester University there was a spate of suicides, which they reacted to and implemented services and support to address this, but before that the support was not there. People don't disclose their HIV status and so people don't know how to behave and there are no opportunities for the university to react.

There is an expectation that those who need help will seek it out. How can someone prove how their condition impacts them on a day to day basis and affects their ability to learn. If you wait until the conditions manifests visibly by then it will be too late.

There is so much inconsistency with levels of support in institutions. One person's bad experience can discourage others from seeking support or attending university altogether.

Recommendations for supporting students include:

- Providing training & support - understand what HIV is and how it affects people
- Initiatives that allow people to disclose – sex education, “SHAG (sexual health advice and guidance) week”, educate people
- Consider the barriers that people face
- Benchmarks, oversight with charities and specialist organisations
- Share best practice
- Get engagement at executive level – we need power brokers to engage

## **7. Managing long term conditions at university - Young people's views - NHS Youth Forum**

A young person from the NHS Youth Forum, who also works at Student Minds on policy and health inequalities, addressed the meeting on the barriers and issues affecting young people managing long term conditions at university. They worked as a sabbatical officer at York University and sat on the student mental health needs committee. York was the third ever city to look at student mental health needs at a city wide level.

They highlighted some quotes that demonstrate the issues students face from the Minding our Futures report carried out by Universities UK, that looked at the links between NHS services and support offered by universities and the gaps that need to be addressed.

*“I feel like my degree is something that I would really enjoy and something I would thrive at but being so unwell has meant that I haven't been able to fulfil the experience as I would like to.”*

*“After I was discharged from home services, I had no mental health or GP support while I was back during the holidays. Since I was home for four weeks at Christmas, and another four at Easter, this was a problem! “*

*“My mental health kept getting worse because of having to constantly retell my traumatic story to then only be told that a service couldn't help my specialist need.”*

*“Quick access to mental health services is a problem. Referrals take a long time; talking therapies take much, much longer. In the interim, students are missing classes, falling behind with coursework, and needing help. The impact on grades can be huge.”*

*“There always seems to be a lag in transferring records between GPs and my records have been misplaced more than once. “*

When you are a student you are often seeking housing or living in poor conditions. There is a lot of culture shock and home sickness and pressure from peers. Students have busy lifestyles, there are lots of opportunities which can increase pressures. You need to balance your studies, extra curricular activities and often part time or seasonal work due to financial pressures. Other issues students face include: student fees, loneliness, managing relationships and in loco parentis issues, where institutions are increasingly being forced to take on a parental role.

Some barriers to healthcare that students face include:

- Being able to manage their own records
- Unfamiliar healthcare providers
- Hidden costs of accessing healthcare – prescription costs, transport to appointments, time off work/studies to attend appointments
- Lack of knowledge – how to manage conditions

- Data sharing – GDPR, managing data across various services
- Forced transitions – CAMHS to AMHS

Their recommendations included:

- Leave of absences processes – especially for estranged young people
- Designated members of staff
- Better signposting for students before they arrive at university
- Public health initiatives – “SHAG (sexual health advice and guidance) week”, health awareness month
- Flexible transitions
- Dual registrations with primary care
- Better digital transfer
- Reduction/waiving of prescription charges
- Financial support/student support packages
- Adoption of the upcoming university mental health charter – hopefully it will make universities more holistic

## 8. Discussions & Questions

**Engaging universities:** Baroness Massey raised the issue of lack of universities being members of the Student Health Association and lack of support for students. Universities must be more proactive and flag up their services. There is a lack of links between student health and NHS.

**Dual primary care registration:** Claire Bethel raised the issue of dual registration. This was issue she had worked on previously and was interested if attendees had ideas on how it could be handled. Marian Davis said the RCGP Adolescent Health group were discussing dual registration with DHSC, NHS and Universities UK. There are some aspects of primary care practice which would seem to enable dual registration. For example, many GPs have out of hours services run by someone else, and practices are using technology more to provide solutions. Barriers remain but they are not insurmountable. We need more continuity between home GPs and university services.

A young person said that dual registration is a big issue for her. She has a lot of prescriptions for high cost medications. She is hoping to attend university next year and is worried that when she goes home, she won't have access to the services and support. The cost of prescriptions worries her. She has had a kidney transplant and if she does not take her medicine she will die. Her prescriptions should be free, having to decide between buying food and medicine should not be a decision she should have to make.

**Access and engagement – young people need to be known:** Rachel Carter raised the issue of students not accessing services. Outreach programmes should be developed to encourage engagement. There are finite services and high drop off for long term conditions. CHIVA raised the fact that everyone engages differently, we need more continuity across the board. Welcome talks when students arrive at universities are very quick and impersonal. They aren't memorable and should engage people in more creative ways, not just presentations.

Ruth Caleb raised the importance of someone getting in touch with young people. People need to be known. Universities used to have personal tutors or equivalent staff for each student. Due to the increase in number of students and lack of staff this is no longer the case. A tutor may have 40-70 students. If meetings are missed, they are not followed up. It also makes it difficult to identify when an individual is struggling, or a change takes place.

RCPCH raised the need to use the application system. They were registered as disabled and declared this when they applied to university. This meant that the disability service at all the universities they applied to contacted them in advance. We need to expand this so universities are alerted before students arrive.

**Workforce training:** Samya stressed the importance of word of mouth. Bad experiences affect take up of services. Universities should be working with VCSE sector to make sure staff are properly trained. Invite charities and experts in to speak at events. They should have a designated staff member for disabilities and health staff who have been trained to speak to young people. They don't necessarily need to be experts. Students should not be segregated into special sections. Access to services is convoluted, you can get lost in the system. It's better to see one person and not have to retell your story over and over.

**Effective transition and safe information sharing:** A young person from CHIVA said that signposting is good, but none of the departments talk to each other. Its traumatic to repeat your story, you might need to do this for several departments, i.e. counselling, additional learning support, etc. Departments should be integrated and have good communication and data sharing, between themselves not just with NHS. Transitions are important. People with HIV aren't treated by GPs, they usually see consultants. If you are transferred from a major clinic to an area with no specialist care or expertise it is difficult, and you might need to travel large distances to receive care.

Emily suggested that health passports may help support transitions between services. These are owned by health services or young people. They mean you don't need to retell your story and it holds your medical details and prescription information. The disabled student allowance should be signposted. The university can receive funding for mentoring. Ruth Caleb said that Universities UK had tried a passport approach but had come up against funding problems. The focus became the funding rather patient needs.

Steph Lamb suggested IT solutions as a way to support transitions. Apps, such as Ready Steady Go, are available to give people access to hand held record, similar to the one given to people who have babies. There is app that is used at Kings. The delay in the transfer of notes is in the remit of NHS Digital.

Emma S said that RCPCH and Well Child are developing apps for parents, children & young people with complex health conditions to help support transitions between services. There is no reason that this couldn't be used to help support transitions in other areas. We need to be mindful not to push care onto young people rather than the professionals who are paid to manage this. We need training and engagement that is not reliant on the power dynamic of you are now 18, it's your job to do this.

#### **Other:**

A young person said that they have just graduated from UCL and are carrying out research around workplace health. People do not disclose conditions due to stigma. Students often see universities as potential employers and can be afraid to disclose in case it affects their future employment opportunities. Apps should address confidentiality.

There was a discussion about HC2 certificates which can exempt you from prescription charges – however these are not automatic and are means tested. Parental income is taken into account and the application process is lengthy.

### **9. Any other business**

Emma Rigby thanked the speakers and said the minutes from the meeting would be written up and circulated to attendees. AYPH will be talking to Universities UK about the recommendations from the meeting and are carrying out a project on student health and long term conditions. They will also carry out a more in depth write up of the meeting and the recommendations to share with stakeholders and will extend an invitation to a stakeholder meeting to everyone at this meeting.

Baroness Massey thanked everyone for attending and for the productive discussion. There is a need to follow the recommendations up with parliamentarians and will submit a question based on this meeting for debate in parliament.

**End of meeting 17.30**