

Student Health Project: Models of good practice for supporting students with longterm health conditions

August 2019

Contents

- 1. Background**
- 2. Why is this important?**
- 3. The process**
- 4. What the students told us**
- 5. Feedback from the stakeholders**
- 6. Solutions and suggestions from the stakeholders**
- 7. Recommendations and next steps**

1. Background

The Association for Young People's Health (AYPH) has long had an interest in promoting student health, because of the large proportion of the population that continues as students into their late teens and early 20s, and the interest in this as an age of transition from child to adult health services. This transition is potentially complicated by managing longterm health conditions, as well as environmental challenges such as geographic changes and changes to living arrangements that further and higher education can bring. There may also be some disincentives built into the health system particularly around the development of flexible, appropriate primary care services for this group. Yet this is a critical time for establishing self-care habits and for influencing later health outcomes.

Funded by the BUPA UK Foundation, and working with students under 25 and those delivering health services in higher education, this project aimed to improve understanding of the needs of students with longterm health conditions to identify and share good practice. This report explains how we undertook the project and the key themes from student and stakeholder feedback. It will be followed by a good practice guide later in 2019.

2. Why is this important?

A larger number of young people are going into further and higher education than in previous decades. In 2017/18 there were 2.3 million students at UK higher education institutions.¹

The advice and care that young people receive at this age could affect their current health and could have longterm consequences for how they manage their health in later adulthood.²

³ In an earlier review of the research literature on the topic, we concluded that there was a need to know more about how the needs of students with longterm conditions may differ from the general population of university students. We also highlighted the gaps in understanding how students make use of services and the barriers to full participation that may face them.⁴ Most work to date has focused on specific conditions (particularly diabetes and mental health) and has not drawn attention to other conditions or looking at solutions that might help a wider range of students. This project sought to fill in some of these gaps.

3. The process

In order to identify the main challenges facing students from different perspectives and collate examples of good practice, AYPH carried out a number of scoping and engagement exercises throughout 2018 and 2019. These included conversations with students via participatory workshops, an online survey and a small number of one to one interviews. Following the engagement with students we held a stakeholder event for all those involved in supporting student health and wellbeing.

Engagement with students

The participation workshops took place in Liverpool and Plymouth. Workshop participants were drawn from the Young People's Advisory Service Liverpool (YPAS) and the University of Plymouth. We ran two workshops with each group. The first workshop focused on the challenges of managing a longterm condition in higher education. This included practical issues ranging from accessing lectures and seminars to utilising universities online learning portals. The second workshop focused on best practice, what support had been useful to

¹ Bolton P (2019) *Higher Education Student Numbers*. House of Common's Library Briefing Paper 7857. London: HoC

² HoytL, Chase-Lansdale L, McDade T, Adam E 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 (2012) 66–73

³ Universities UK (2018) *Minding our Future: Minding our future: starting a conversation about the support of student mental health*. London: Universities UK

⁴ Hagell A (2017) *An overview of research on key issues in student health* London: Association for Young People's Health

students as well as 'top-tips' they would pass on to new students managing a condition. We also asked whether managing their conditions affected the social aspects of their life at university.

In addition we conducted one to one interviews in London with an additional group of students to complement the workshops, and created an online survey which was completed by 45 young people from thirteen different institutions. The interviews and survey also included a focus on both the challenges and practical solutions, mirroring the workshops.

Over 60 students were engaged in total, of whom 45 were students under 26 years old and 44 were living with a longterm health condition.

Despite the good level of engagement we achieved there were a number of challenges which delayed the process and are important to note for context and learning. AYPH approached a number of universities to undertake face to face student workshops. Many universities felt that subject of the project was too sensitive given current issues that they were dealing with in relation to student mental health and suicide, and as a result declined to host workshops. In addition, several universities defined the workshops as 'research', which had implications involving their research ethics. The nature of participation workshops is that they adapt and change, depending on the group or individuals. This made it difficult to fit the proposal into standard research ethics applications.

Other challenges arose when undertaking workshops outside of universities. To complement the sample from higher education sites, AYPH approached several charities working directly with young people. The feedback from youth charities was unanimously positive, however very few charities worked with a large population of higher education students, or they worked with students who did not consider themselves to have a longterm health condition.

Stakeholder event

After the scoping exercises with students, AYPH presented the findings at a stakeholder event in 2019. This was hosted at London South Bank University and included an audience of healthcare professionals, educators, university staff and youth workers. In total 30 stakeholders attended. As well as a presentation of the findings from engagement with students, presentations were delivered by two GPs working within university health service settings and two students with longterm conditions providing further examples of good practice as well as potential challenges.

4. What the students told us

Student feedback loosely fell into three different categories: practical challenges, emotional or motivational challenges and what higher education institutions do that helps them.

Practical challenges:

Students raised a number of practical challenges presented by trying to fit into standard university provision while managing their longterm condition. For example, students managing longterm conditions felt that longer lectures were challenging for them. One student had wheelchair access, but the limited number of accessible spaces made it difficult to leave the lecture if they needed to manage a bladder condition. Many students managed multiple conditions and felt that only one of their conditions was fully supported by their university.

Most students who took part felt that clinical appointments had clashed with their timetable at some point in their learning and that they felt anxious about catching up with their studies. Many students shared stories of having to choose between attending classes or going to clinic or GP appointments.

Traveling to college or university was challenging for students with longterm mental health issues. Anxiety around public speaking or working in smaller groups inhibited some students which led to them feeling unable to leave their homes and travel into seminars. Students with physical conditions highlighted that classrooms could change last minute, meaning traveling to them could take longer than anticipated, making them late or that once they arrived at the building, there was no access equipment or lifts.

In some cases, students found that their medical records could take months to transfer from their home GPs to the university GP practice. This could mean that they went without their medication or had to commute back home, costing time and money, in order to get prescriptions.

Often university GP practices (both practices in the student's new university town and specific student practices) were reluctant to give students prescriptions for multiple medications or medication for serious conditions, such as severe painkillers or serious mental health conditions, without explaining why to the student. Many of the young people we spoke to had been denied their daily medication.

Emotional or motivational challenges:

Students shared a range of issues that impacted their ability to engage fully in the social aspects of university life. This included universities not providing accessible sports or activities that could be adapted for physical conditions. Societies also often met up in inaccessible places without suitable toilet facilities.

Some students felt unable to join in the social side to university because managing their condition required a restricted diet or limited their alcohol consumption.

Students also shared the challenges of joining certain activities due to the commitment required (sports teams, regular socials). Clinic appointments or fatigue meant they were unable to commit to ongoing activities

Students felt like their peers and university staff would not understand their condition. This often resulted in students feeling isolated from university life or anxious about engaging both socially and with their studies. This was particularly significant for students with rare and/or non-visible conditions.

What higher education Institutions do that helps:

Students who were able to access mental health or wellbeing services found they were much better able to manage their physical health. Recognising the overlap between physical and mental health (and between physical and mental health services) was important to them. The distinction between physical and mental health was not clear cut for many of the students, almost all of them sharing examples of their mental health suffering due to difficulties in managing physical health: a theme often raised in AYPH's work with young people generally. When their mental health needs were met they felt more able to manage their physical health.

Many of the students we spoke with struggled to catch up with their studies after missing lectures due to clinic or GP appointments. Students struggled when they were not able to talk with staff or find PowerPoint presentations of classes through their university's learning portal. Being able to talk to staff outside of lectures and seminars and access regularly updated learning portals with PowerPoint slides, lecture notes and reading is hugely important.

Students who could access extra assistance to support their course work and lecture notes found it invaluable in helping them to stay on top of their work load and manage their health.

Many students found that being able to speak openly to doctors, nurses and wellbeing staff about the practical elements of managing their condition particularly important. In addition they found it important that university care teams communicated with each other, so that a plan could be implemented effectively. In situations where this was not the case students found that consistently having to explain their condition, or why they could not access their learning like their peers, became exhausting and anxiety inducing, resulting in their studying or health lapsing.

5. Feedback from stakeholders

We shared the findings from our group and individual consultations with students at a stakeholder event which included two students presenting their personal experience together with presentations from the Student Health Association and a GP from a student health practice. Many of the themes raised by the students were endorsed by the stakeholder group, who contributed similar and additional examples of issues and challenges posed when trying to support young people with longterm conditions.

From discussions and reflections about the work some key additional themes arose:

- **Communication with students can be challenging.** Students can be reluctant to talk to professionals until they are at a point of crisis. At this stage it can be difficult to support the student in the most effective way.
- **UCAS forms are too general when asking about health conditions,** and do not alert universities to the issues. Words like 'disclosure' and 'disability' do not feel applicable to a student managing a longterm health condition. Professionals have found that some students do not disclose a condition when starting university, because they do not want to define themselves as the condition and see university as the opportunity to have a 'fresh start'. They also do not think to disclose a condition as they are not at a point of crisis and are well managed at the time of application
- **The cost of prescriptions was highlighted by both professionals and students.** Some professionals gave examples of students having to prioritise which medication they needed most and which they could ignore due to having insufficient means to buy all their prescribed medication. Students also noted that some longterm conditions prevent them from having part time jobs while studying, meaning that even with a student loan, they are particularly unstable financially. Prescription costs, as well as buying over the counter medication can present a very serious financial challenge.
- **The role of personal tutors could be developed:** Professionals felt that the move towards more electronic communications between staff and students has potentially impacted the development of supportive relationships, meaning personal tutors face time with students should be nurtured and encouraged. Personal tutors having a better understanding of links between mental and physical health, access to training, as well as a more comprehensive knowledge of signposting to wellbeing services or local charities, could also help students with longterm conditions manage.
- **Support for students who develop a longterm condition during studies:** Universities needed to be aware that students who develop a longterm condition while studying will need help to find the support they need and may not have any previous experience of disability services or health professionals which could be a barrier to accessing appropriate services.

6. Solutions and suggestions from stakeholders

Stakeholders (including students) contributed a range of solutions and suggestions to improve support for students. These included:

- **Improving communication:** Students said they felt disability support services and wellbeing services were not aimed at them because they do not consider their condition as a disability. This means they miss out on support they could be entitled to. Using specific terms – such as disabled - to advertise wellbeing services can be unhelpful. Using language that reflects a student's experience is more helpful, ie. 'supporting access to lectures' is more helpful than 'Disabled student support'.

Students often fail to engage with support services as they are not aware of where they are or what support they provide. It may be that relying extensively on Freshers' Week or the admissions process creates some barriers for those who may not be attending events, or may be too anxious at the start of university to be able to absorb the information - and relying on Freshers' Week will also miss those who develop their longterm condition after arrival at university, or whose condition gets worse after arrival.

A solution to this might be making students aware of support services before starting higher education. This could include university open days, online information as well as sources of support outside of universities, through trusted routes such as GP practices, schools and colleges, youth centres. This could empower students in advance of the transfer to university, helping them to know what help is out there and where to go to get that support, as and when needed.

- **Improving sources of support:** Creating more opportunities for peer to peer support among students would help those who are managing longterm conditions. This may include encouraging better day to day care and support through peer learning to reduce isolation and students only seeking help at point of crisis. All university staff could be enabled to have a better understanding of referrals to internal university wellbeing services and other local support services. This should include clear signposting to external services, such as Third Sector organisations, Young Person Drop-in's at GP Practices and support groups. Information for staff on how to make meaningful interventions and encourage better lines of communication would also be helpful.
- **Best practice and shared learning:** Examples of best practice by student GP practices, university staff and others could be circulated to demonstrate how better support can lead to more successful students.
- **Improving the application process:** Language on UCAS forms should be revised as a matter of urgency, in order to reflect a wider spectrum of needs and not isolate students who may have less well known conditions or those who would not consider themselves a candidate for disabled student support. Those with mental health problems are particularly unlikely to see themselves as disabled, and overall only a very small minority of students with longterm conditions tick this box.

- **Improving access to primary care:** Stakeholders had various different suggestions about improving access to primary care. Some suggested allowing dual GP registration for students leaving home for university, to not only ensure they have access to medical professionals in and outside of term but also to help the transfer of medical records and communication between medical staff. Other suggestions were encouraging students to set up an account on an NHS app where they would be able to manage their own medical records and prescriptions. Other proposed reforms to how the NHS is accessed, including digitally, could support students and these should be explored.
- **Improving understanding of student mental health issues:** Students often do not see physical and mental health as different, as one supports the other and vice versa. Training could be offered to higher education staff around supporting students, particularly around mental health, such as Mental Health First Aid Training.
- **Understanding stigma:** Students are often worried about perceptions and stigma, saying that they are not understood or taken seriously enough by academic staff and their peers. A greater understanding is needed across the further and higher education sector of the challenges students face when managing a longterm condition. This should include mental health impacts and fatigue and issues for students with multiple conditions some of which may not be visible. Good communication among staff as well as students about students' needs within higher education can save students a lot of emotional strain. If lecturers already understand a student's needs in classes, seminars or lectures, students will not have to explain their condition on multiple occasions. This saves students a lot of stress, which can make them better able to engage with studying.

7. Recommendations and next stages

This report explains the process of the project and the key themes from student and stakeholder feedback. From the feedback we are developing a set of good practice recommendations for universities, youth workers, health professionals and young people to help practically support students which are managing longterm conditions. This will be launched later in 2019 following agreement with stakeholders and young people.

The Association for Young People's Health is the leading independent voice for young people's health in the UK. We bridge the worlds of policy, practice and evidence to promote better understanding of young people's health needs, and to advocate for youth friendly health services.

For more information about our work please visit
www.youngpeopleshealth.org.uk

Jeremy Sachs and Emma Rigby, August 2019