



## **What if young people tried to change the way GPs treat them?**

*Young volunteers with the **Right Here Brighton and Hove** project decided that good research and persuasive presentation was better than just complaining*

It's an oft acknowledged fact that young people don't often get the service they want from GPs to help them look after their mental health. But what happens when a group of young people set out to do something about it?

Young volunteers aged between 16 and 25 from Right Here Brighton and Hove set out to do just that. Supported by Right Here staff, a group of young people carried out research to find out just how their peers felt about GPs services and then took what they found to local GP's and commissioners, to help shape the future of services young people actually receive.

During the Summer 2011 they developed a research methodology, created a questionnaire, carried out focus groups, summarised their findings and then used those findings to influence and support GPs seeking to meet the mental health and wellbeing needs of their young patients.

Says Dakota , one of the Right Here project volunteers: "Being a teenager myself, I was admittedly a bit sceptical about the response we would get from some of the participants and how seriously they would take it, however, when I actually took part I was astounded at how co-operative and responsive everyone was."

The GP research project built upon existing work that Right Here in Brighton and Hove had carried out. In 2010 they produced 'a young person's guide to looking after yourself', to help their peers to look after their own mental wellbeing. In 2011 Right Here volunteers developed the 'Where to Go for ...' website, an online services map for their area to help young people to navigate their way round the various sources of help and support available in their city. The decision to try to influence the quality and delivery of GP services for young people was a natural next step.

## **How did they do it?**

Two of the challenges for research work into the needs of young people are getting young people to take part and then finding out things that are useful. Taking a pragmatic approach to getting results that would make a difference both to the young volunteers themselves and to the future experiences that young people have with their GPs, Right Here secured funding to train their volunteers in the research skills that they needed to do the task well.

Prior to beginning the research project Right Here volunteers undertook a six week course (2.5 hours per week) in research and analysis skills. Provided by local social enterprise The Life Project CIC and funded by Brighton and Hove Local Involvement Network (LINK), the 'Seek and Solve' training course helped volunteers develop the skills necessary to carry out effective and meaningful research while also giving them valuable experience of research work.

Says Dakota: “Firstly [the training] brought everyone together as a group because we did the training together. Secondly it made us feel more comfortable in ourselves and more confident which obviously helped. Thirdly it made us see everything more analytically. It also helped with actually collecting the data and being more aware and more able to lead the focus groups confidently.”

The research work was split into three phases. Firstly, the young volunteers developed the research methodology for the work by identifying the key issues they wished to explore, developing a questionnaire and inviting responses. The second stage was the collection of data and responses via questionnaire and focus group sessions. The third stage was the analysis and then taking the findings to the people who make decisions. Right Here volunteers worked on all three of these stages.

Says Dakota of the design stage: “With a little input from Jo [a Right Here worker] volunteers inputted their own ideas and together we edited and designed questionnaires to be in a format that we felt would produce the most data from 16-25 year olds... Everyone openly discussed what they felt was best and together we worked to produce a number of methods which would produce evidence and data for our research into GPs services and mental health care provided to young people in Brighton and Hove.”

### **What did they find out?**

The young volunteers consulted 172 young people aged 16-25 across Brighton and Hove in the course of the research. They secured involvement from young people by inviting members and users of local projects and young people attending educational and training establishments. Particular target groups included those targeted by the Brighton and Hove project as a whole: young people not currently in employment, education or training, young parents, young carers, lesbian, gay, bisexual and transgender young people, young people with disabilities, young people on probation, black and minority ethnic young people, young asylum seekers and refugees and young people in or leaving care.

Of the 172 young people they consulted, 64% were female and 36% male, with the majority falling into the 16 – 19 age range with a mean age of 17.2. From the questionnaire responses the project found that only 52% of respondents answered yes to the statement “Would you feel comfortable talking to your GP about mental and emotional issues?” When asked “What response do you want from your GP about mental and emotional problems?” 46% of respondents said a chat or someone to talk to, 33% answered referral to a counsellor or mental health professional and 21% would like medication.

The project found that young people worried about not being taken seriously and that professionals sometimes held stereotyped views of young people. Some young people said that issues of confidentiality were often confused, with it not being clear whether interactions with professionals were confidential or not. They also found that young people did not feel that the traditional ways in which GPs surgeries operated fitted well with their expectations or wishes. They picked out appointment times that did not fit around school or other obligations and lack of continuity and lack of opportunity to build a relationship with a single GP. Young people also communicated that they were not aware of their options regarding which GP to register with. Overall, they felt that their needs were not being taken as seriously as the needs of other groups of patients.

### **Was it important that young people carried out this research?**

The combination of questionnaires and focus groups led and designed by young people allowed the project to get a broader sense of the issues that young people felt were important about their interactions with GPs. The young people involved feel that they managed to get a view of what needed to change that professionals might not have seen.

Young people see how issues around mental wellbeing affect the lives of other young people around them, rather than just seeing people when they present themselves at services. Says Right Here Brighton and Hove volunteer Jo of the different perspective that young people bring: “We see friends and people at college everyday who aren't bad enough to go to the doctors, whereas a Doctor will only see people when they're pretty bad. We see the whole spectrum of it. [We] can see how it affects everyone, not just people with mental health issues, but every single young person.”

Right Here Brighton and Hove volunteer Ryan agrees on the importance of peer-led research and that the project captured “the views of people who are going to be affected”. He feels the project had more validity and legitimacy because “the research was being done by young people rather than people who are just concerned about budget and it doesn't really affect them... [young people] are much more likely to put effort into it whereas a professional is only going to be doing it for as long as they're getting paid for it. At five o'clock they'll just go home until the next day.”

Dakota feels that as the research and the project are co-designed with young people, they are more likely to reach other young people in a way that health professionals could not: “Some of the time young people can feel a bit isolated and alienated from adults,” she says, “They're like 'I can't be completely honest with you because you might be a professional and you might report it back to someone which might lead to me getting into trouble' whereas with young people I think you can feel at ease especially if they're from your local community... They're a bit more comfortable with each other and a bit more honest.”

For Ryan, the entire research process was an eye-opening experience. “At the beginning, I didn't know loads of stuff. I thought 'you just go to your GP'. It's made me aware of how much more stuff is going on and at the same time it was a big realisation

that I didn't have any of these [mental health] problems myself... Speaking to these people who did have these problems and working with them [made me realise] that this stuff really does affect people. When you realise how severely these things are affecting people it's quite eye-opening seeing how dependent some people are on services."

### **What happened next?**

Having completed their research, the volunteers developed a set of recommendations and headline results which they then took to decision makers and service providers. The recommendations include:

- Increased use of online facilities or information young people can take away
- Young people involved in the planning of the delivery of services and actively engaged with the people who have the power to act on their views
- Services develop a cohort of 'young experts' who can lead on the consultation with other young people
- Young people inputting into the training of practice staff
- Clearer explanations and information when referrals are made, particularly to Child and Adolescent Mental Health Services (CAMHS)
- Ensuring young people are well informed about their healthcare rights, especially around issues of confidentiality.

The volunteers initially presented their findings to the Patient Engagement and Experience Lead for the Brighton and Hove Clinical Commissioning Group (CCG), the body that will be commissioning health services in their area. As a result of this the group was invited to present their findings to an invited audience of GPs and CCG members.

Says Dr Xavier Nalletamby, chair of Brighton and Hove CCG: "We had a presentation from the young people to the clinical leads at the Clinical Commissioning Group to hear about the work that they'd been doing. We were very impressed and as a consequence of that they were invited to come and talk to us at the six weekly city-wide 'teach-in'. They presented to one of the workshops. There were doctors, nurses and admin staff present. We were all really impressed in the room when they came. I thought they were really good, really articulate, and quite non-judgemental. It didn't feel adversarial. I think the feedback from the learning scheme where all the practices came was high. The staff said they'd learned a lot and it had opened their eyes. I didn't hear anything negative at all."

At the suggestion of a GP member of the CCG, the group has written a report on their findings for other GPs in the area to read as part of their own service development.

The group intends to strengthen their relationship with local decision makers and is in the process of developing an 'influencing strategy' to take the findings of their research further into the development of services for young people. Says Dakota: "We've set out quite a few initiatives and we've made out a plan. We've got lots of things that are going to happen. Mainly we made the Commissioning Group aware of the issues. We've formed a partnership with them. I think we've started down the road, hopefully, of a good partnership which helps to bring about lots of changes. They're really happy to work with us and we're really happy to work with them."

The project is also using the knowledge that they gained of young people's experiences and feelings about services to develop further projects for young people around the issues of GPs. Says Jo: "We found that people wanted to be better informed and that change needed to be more widespread... We're addressing that by making a film about confidentiality, your rights and how to get the most out of your appointments that reinforces it's a two way process. We're doing some more consulting for GPs and collaborating with practices. They said they'd like more feedback on their surgeries so what we're doing next is going into the surgeries that wanted individual feedback and telling them what they need to do to make it more young people friendly. It's a good result."

Says Dr Nalletamby: "They've crystallised what we all know but haven't thought through properly. One of the themes that come across is that young people seem to prefer a bit more anonymity; they like to deal with people of their own gender; they don't want to be seeing anyone like their mum or their dad or someone who knows their mum or their dad. Issues of confidentiality are absolutely important to get right. There were lots of themes that if you think about it are obvious; but they're not obvious until you hear it from young people themselves. If we don't invite feedback from specific groups, we think we provide a service that caters for everybody; but clearly it doesn't in this case. The more information we have; the better we can remedy it. Young people, generally speaking, aren't well represented when you're talking about interest groups so, as a specific group the actual issues related to youth itself are not well understood by us. I think the more we learn from groups like this, the better it can be."

Says Ryan of the project overall: "When I started doing the volunteering I was quite cynical and thought 'we're going to try our best but at the end of the day our voices aren't going to be heard'. When we had a meeting and there were twenty professionals at the top of their professional ladder coming to meet us I realised that our work was really being listened to by GPs. It made realise that the work we're doing actually is really important and you don't have to be a large organisation to make a huge difference."

*Mark Brown, Social Spider*