Whether young people's views should be listened to, and to what extent they should be allowed to take part in decision-making, is widely accepted as a key element to impactful patient engagement. But many young people, especially the so-called 'hard-to-reach', feel their views are given little more than lip service when it comes to their healthcare - and they feel overlooked.

Are we really valuing young voices?
Fixers, the national charity which gives young people a voice on the issues that matter to them, is working with policy makers and service providers alike to give a truly meaningful and impactful means of engaging. What is more, the charity is setting out to show it is not the people who are 'hard-to-reach' but the institutions. This follows its UK-wide studies which uncovered a worrying trend showing that young people believe healthcare professionals are failing to listen, act and report back on their concerns and experiences.

In addition, a Care Quality Commission Children and Young People’s Survey (2015) on inpatient and day surgery experience, highlighted that 43% of 12 to 15-year-olds were not as involved in decisions about their care as they wanted to be.

Similarly, in a key Fixers report, 50 Fixes for Mental Health (2015), young people said their lived experiences and views about mental and emotional wellbeing were disregarded, or trivialised, by healthcare professionals.

After surveying 300 young people across the UK with personal experience of mental ill-health, Fixers discovered that they felt at best-misunderstood and at worst ignored in every aspect of their lives.

Empowering young people
Since it was established in 2008, Fixers has enabled some 20,000 young people aged 16 to 25 to ‘use their past to fix the future’ and launch a campaign to tackle any issue that matters to them.

The young people are trusted to be experts in their own experience and work with an in-house creative team, to arm themselves with a high-quality resource which helps them articulate their message. They are supported to start a new dialogue with their target audience, they see change happening as key professionals take away their ideas and messages, and they create new networks to keep building on their campaigns. Interestingly, 69% of the projects they have developed are focused on mental health concerns and place wellbeing at the core of their work.

Whether at home with family, in education with their peers and teachers, at work with colleagues, interacting with health services, socialising and engaging with all forms of media, the young people signing up to be Fixers find that people just don’t ‘get it’ – that is appreciate and understand what they say they are living through.

They say that in every area of their lives they feel isolated and are battling stigma. At the top of their list of things that need to change is that we all do more to listen, put ourselves in their shoes and learn to empathise. This, they say, will help them to help themselves and assist future generations to build a more mentally robust society.

Identifying solutions
Maggie Morgan, Director of Communications and Stakeholder Engagement at Fixers, says: “Young people see and experience things in different ways, so taking the time to listen to them is essential to any care professional’s role. ‘We find their voices can drive change by identifying solutions that are based on their personal experiences, rather than on the assumptions of adults. ‘It has been found that the more young people are listened to, the
‘My film encourages HCPs to show more empathy to child patients’

When I was nine, I became incontinent. My GP sent me and my parents to the hospital. He just put it down to attention seeking.

The doctor pulled down my trousers and pants. I quickly tried to pull them up, but the nurse told me they had to examine me. I felt exposed and humiliated. The doctor was scary. He treated me more as an object than an actual person.

I look back now and it still upsets me. My mum wasn’t with me. No-one was introduced; no-one told me what was happening. I was completely powerless. As a child I could do nothing. I had no control.

I want health care professionals to realise it is scary for children and young people to go and seek advice sometimes and they need to treat them with the respect and dignity that they treat adults with.

My Fixers project was to make a film encouraging health professionals to be more empathetic with patients, especially children. The film has been shown at a conference about children’s health. I have also shown it to medical students and they have said they’re still seeing things like this happen, even with younger doctors.

It shows there’s a need for patients to share their experiences so medical professionals can learn from mistakes. I’m happy that the film is having an impact on health professionals and it is creating positive change. It makes me feel very proud that I have actually made a difference.

I’ve been heard and believed; you can’t believe just how powerful that is for a young person.

‘Jayme Leigh’, 18, Shropshire

‘Our film highlights communication difficulties’

I was born with a rare disorder called Cat Eye syndrome - a disorder which affects the brain and causes varying degrees of physical and mental impairments.

He has to communicate using an app, but it takes a long time to write things down and show people. Apps can’t express emotions and explain the nuances of things. You can make somebody understand you’ve got a pain in your arm but that doesn’t exactly describe how it feels - you can’t describe that it’s a burning pain or where it’s located. As a result, I’d like to see interpreters attending GP appointments.

Unlike deaf people, patients like Eddie and I who have speech, language or communication needs are not entitled to an interpreter. We can apply in advance for an interpreter to attend, but must give plenty of notice.

If there is an emergency you can’t get a speech and language interpreter to come in instantly, so it would help to already have those rights there.

With Fixers, Eddie and I have made a film showing the struggles we face communicating with healthcare professionals.

Lara Goring, 18, Hellingly, East Sussex

‘My voice is helping to improve mental health care for others’

When I was 16 I started experiencing mental health problems.

I’ve battled an eating disorder, borderline personality disorder and the urge to self-harm.

It’s hard to describe just how low these conditions can make you feel and how difficult everyday life can become. At times during my treatment I felt powerless and that no-one was listening to me.

I became fed up of hearing that Cognitive Behavioural Therapy (CBT) is the answer to everything. Borderline personality disorder doesn’t respond to CBT, but I’ve been offered it four times.

It was then suggested that I try Dialectical Behavioural Therapy (DBT), but 200 people were interviewed for 20 spaces and I didn’t qualify because they thought I didn’t want to recover. The treatments need to be suited to each individual, age appropriate and varied; CBT doesn’t work for everything.

I got through the tough times, but it was only when I came across Fixers that I felt empowered again. As part of my campaign with Fixers I took part in a workshop and conference with other young people aged 16-25.

This was a unique opportunity for those of us with experience of mental illness to tell our stories, explain our viewpoints and share the issues we faced, such as barriers for treatment and support, with an audience of practitioners and policy makers.

Crucially, we also came up with practical solutions to the problems. Finally, I was being listened to and so were hundreds of other young people.

The tables were turned – we were the experts and the doctors and psychologists learnt from us.

We came up with 50 recommendations to improve mental healthcare and they formed the Fixers report, 50 Fixes For Mental Health. We delivered this to ministers because we needed to be heard, recognised and understood for the sake of all generations.

Sarah Harmon, 22, Presteigne, Wales
There needs to be a lot more awareness and empathy amongst NHS professionals. For a start I would like general nurses and psychiatrists etc to be more sympathetic. They also need to know who it is best to refer you to, they don’t always know. Some kind of training with a young person with lived experience would help professionals to understand what it’s like for us.' Natalie

Fixers recommendation: NHS professionals who do not specialise in mental health to receive mental health training as part of their initial training. The training should be co-produced and delivered, in part, with young people. Mental health professionals should also receive the young person-led training to benefit from their ‘lived experience’ to improve empathy and understanding.

‘It took me 4-5 trips to get diagnosed. GPs try to push you out the door. There should be a special first point of call, like a nurse to take you through your treatment from start to finish, so we don’t have to repeat ourselves all the time.’ Iqbal

Fixers recommendation: Designated mental health nurse practitioner to be a central point of contact to young people through their treatment and recovery plan, empathy and understanding.

‘School counsellors are such a good idea. There wasn’t actually a counsellor assigned to my school when I was going through problems in my life. But in my last year there were two counsellors who joined and they did alternate days. I only saw one of them, but I really opened up to her and she ended up knowing everything that I’d gone through. But that being so late through my school life, I only got to see her for a few months. If she’d have been there from the beginning of my school life, I could have gone to her and I probably wouldn’t have gone so far with the self-harm.’ Alwen

Fixers recommendation: Access in every school to a mental health trained professional, such as a counsellor.

‘Schools need to stop treating students as a number, e.g. attendance, appearance, and grades given for high performance. It would be good for more time to be dedicated to building a relationship between pupil and teacher. More holistic time, hugs and chocolate!’ Silvie

Fixers recommendation: Schools to take a more holistic view of students’ needs and not just focus on grades and outcomes.

‘PSHE classes, if you get them, never have lessons about mental health. Schools can spend weeks on other topics like alcohol awareness and drugs, but nothing on mental health. PSHE should be mandatory and taught at a younger age to teach acceptance and understanding of mental health issues.’ Ryan

Fixers recommendation: Department for Education and all devolved administrations to make PSHE a statutory requirement in their curriculums, with a specific element of the programme dedicated to mental health teaching in all schools, starting before senior school.

Breakout on 50 fixes for mental health report

The Fixers report, 50 Fixes for mental health: It’s time you ‘got it’ (2015), calls on parents, grandparents, teachers, fellow students, employers and colleagues, journalists and other media professionals to all play their part in creating greater understanding and reducing stigma.

The easiest way to achieve this, according to the report, is for everyone to make it their business to listen to young people living with mental ill-health and learn from them.

The young people who took part in the study (see some of their comments left) call on employers, educators, healthcare workers and family support services to help them open a new public dialogue by inviting them to speak at workplaces, in schools and colleges.

The 50 recommendations for policy and practice include:

1. All medical professionals to use simplified literature and language to explain the child and adolescent mental health system and what to expect.

2. Employers to offer employees more flexibility by providing return-to-work plans, which may include flexible hours, regular breaks, time off to attend treatment appointments and a buddy support system.

3. Confidence and assertiveness techniques should be taught as part of mandatory PSHE lessons to improve young people’s low self-esteem and lack of confidence from primary school upwards. The techniques should develop positive social skills, be creative, and should be taught in small groups.

4. There should be a code of media guidance, which outlines what words and images can be used to describe and portray mental health conditions, regulated by the Independent Press Standards Association and OFCOM.

5. A new public health campaign for all parents and carers on spotting the signs of mental illness and advice on where to go for support.

6. All teachers and support staff should be mental health trained during their training and it should be an ongoing part of teaching development.

To read the 50 Fixes for Mental Health report (2015) in full, visit: www.fixers.org.uk/50fixes
more they will engage with health services, and the more likely they will be to pursue a healthy lifestyle.

‘But the young people we are working with say that while many service providers and policy makers are willing to sit down at the table with them, the real listening stops at the end of the conversation. They might get their voices heard in a practical sense, but they feel like it’s a box ticking exercise and what they are saying is not really valued.’

In a ground-breaking partnership between NHS England and Fixers, patients are being enabled to detail uncomfortable truths, in powerful short films which are now being used to change the way health professionals work.

Conveying vital messages

In one, a student nurse of 18 tells how she has been haunted for nine years by the memory of a medical examination which left her feeling exposed, humiliated and scared as a child with incontinence. The film has been shown to more than 500 commissioners and health providers at conferences and workshops around the country.

Karen Higgins, of Shropshire Clinical Commissioning Group, said: ‘I feel the film has been hugely beneficial in so much as so often we treat a complaint or a concern as an administration process.

‘What this film has actually shown is by listening to what the person wants to achieve we can actually create something that will bring about an action or bring about change.’

The film has also been released on social media for local trusts, clinical commissioning groups, higher education institutions, strategic clinical networks, health watch regulators and health and wellbeing boards, to use on a local level.

Kath Evans, Experience of Care Lead for Maternity, Newborn, Children and Young People for NHS England, says such projects bring ‘patient experience’ to life in a high quality, engaging manner.

She said: ‘Cultural shifts are needed in the NHS to move us from paternalism to true partnership in care and we need creative methods to get there.

‘Fixers not only provides that creativity but critically the support to the person involved and expertise in disseminating the key issues and messages. Narrative engages the heart and mind to complement the data regarding patient experience.

‘Young people and families are given a voice working with Fixers and flourish in having their experience validated and can see action is resulting by them having courage to speak.’

Young people around the country are getting together to write a prescription for the NHS… so that it’s fit to serve their needs in the future. Here we highlight the experience of four Fixers, who explain how their projects with the charity empowered them to help others by encouraging effective engagement with healthcare professionals.

‘I campaign for child sex abuse victims, to show they are not alone’

I was sexually abused by my father from an early age.

It ended when I was 15 after I told my mum about it and we went to the police. Fifteen months later my dad was sentenced to three years in prison.

I became a Fixer when I was 17, to create a website to share my abuse story and invite other survivors to speak out. I felt it was important to speak candidly about my experiences to let others in similar situation know that they aren’t alone and that there is hope.

Since then I have appeared on television, radio and in magazines. I’ve studied Law at the University of Exeter, given motivational speeches to young people and won two national awards.

Today my life’s purpose is to support those who have endured child sexual abuse, to speak up about this taboo issue and to find ways of making the system better for vulnerable children.

If it wasn’t for Fixers, I would not have started on this path, or at least not as early as I did. They gave me a medium to reach out to other people and I always knew Fixers had my back.

One of my current key aims is to raise awareness of the need for mandatory reporting legislation in the UK. Such a law would place a legal requirement on staff working with children to submit a report to a local authority when abuse is observed or suspected on reasonable grounds.

Shockingly, there is currently no legal requirement to report child abuse in the UK. In my opinion this means that many incidents go unreported, and may only be discovered later, when the child has had to suffer more abuse.

The NHS has provided funding for me to do a second Fixers project to raise awareness of the need for this legislation. Watch this space! It will be coming soon and I am determined to be heard!

Siobhan Pyburn, 25, London

Further information

www.fixers.org.uk

Fixers choose the issue they want to fix and, using the skills of a team of creative experts, they work out how to make sure their message is heard by the right people, that’s through a unique film, a leaflet or poster campaign, a website, an event or workshop. Then they use digital, print and broadcast media to make their voice heard as far and wide as possible.

To find out about Fixers work on patient engagement, go to: http://www.fixers.org.uk/supporting-fixers/public-sector-organisations/help-us-fund-trust-me-i-m-a-patient.php

To find out how you can support Fixers, go to: http://www.fixers.org.uk/supporting-fixers.php

http://www.mefirst.org.uk/resources/

Me first has been developed in partnership with healthcare professionals and children and young people. It is a resource hub that aims to collect and grow a range of resources to share ideas and expertise in communicating with children and young people. The hub also aims to promote peer-to-peer learning and contains resources that healthcare professionals have told us they have found helpful in their practice.

http://s215637369.websitehome.co.uk/our-work/young-peoples-participation

The Association for Young People’s Health (AYPH) run a variety of projects that amplify the voices of young people in the health and wellbeing sector.