



Invisible Illness Young Person's Focus Group Summary Report



Alder Hey Children's NHS Foundation Trust
30th October 2015

Report by Jenny Preston (Patient and Public Involvement Manager Alder Hey Clinical Research Facility) and Sophie Ainsworth (young person)

Background

On the 30th October 2015 a focus group was undertaken to talk about what it is like for young people living day in and day out with chronic illnesses, which includes chronic pain, but don't look different from healthy young people all around us.

The focus group was organised by Sophie Ainsworth who is 16 years old and was diagnosed with Lupus in 2014. Living with Lupus generated all sorts of symptoms like fatigue, joint pain and breathing difficulties that affected daily school life and her school where really unsupportive with it. Constant letters about attendance due to hospital appointments and comments about avoiding PE due to laziness was quite stressful. So Sophie decided to raise awareness of living with an invisible illness by contacting patients through various routes including Alder Hey and college contacts. The aim is to eventually create information packs that can be distributed to schools that would give them information about invisible illnesses and raise awareness.



Quite a few young people expressed an interest in the project but only three young people could attend the focus group. One other young person and his parent joined the focus group on the day after hearing about the group whilst waiting for an appointment. The focus group took place in the psychology department at Alder Hey Children's NHS Foundation Trust. Jenny Preston, Patient and Public Involvement Manager for the National Institute for Health Research (NIHR) Alder Hey Clinical Research Facility (CRF) co-facilitated the workshop with Sophie.

Focus Group Session

The session began with an Introduction to the project by Sophie. Jenny then explained to the group how the workshop will work. She explained to the group that it would be a 2hr workshop using an innovative interactive



kit call Ketso which allows individuals to be asked a question on a particular topic and write down their thoughts, place on the relevant section then discuss as a group. Consent was taken for the session to be audio recorded and for photos to be taken.

Feedback

Q1. What is it like living with your condition?

I am / I feel / I have/ I find.....

- dependant on substances
- isolated
- Self harm
- Self destructive impulses
- Lower school/college attendance
- Nobody takes you seriously
- Lack of motivation
- Lack of energy
- Stressed because nobody understands
- Don't feel any different
- low mood and manic episodes
- lack of sleep
- difficulty concentrating
- anxious
- low self esteem
- frustrated
- many hospital visits
- fatigue
- breathing difficulties
- accused of laziness
- pressured not encouraged
- fear of approaching people who shout
- teachers difficult to approach
- teachers don't seem to believe that people struggle
- joint and muscle pain/weakness
- uncomfortable at not being allowed out of lessons
- People get angry about school my school work
- to be more open with friends I can trust
- some teachers are scared
- friends see you as human beings
- peers encourage you to look after yourself
- pressured by teachers to get good grades



- some days teachers treat you as a special case, the next day it changes.
Inconsistency
- staff are ignorant
- embarrassed at school because of scars
- peers are more understanding than staff
- I miss out
- angry at being made to show legs in P.E and take blazer off

Q2. Support - what support do you need?

- education of invisible illnesses in PSHE lessons
- trust your students
- students should choose a mentor that they can trust
- talk to students and make sure that you communicate
- a lift pass
- helpful teachers

Q3. Information & Raising awareness - How do you do it? How can it be done?

- Inform teachers and people that hidden illness is real and can affect people a lot.
- Teach self-respect to students throughout school.
- Spread the word via information packs, films and talks in school
- Show people that everyone is different
- people need treating as individuals

Priorities to take forward

Young people felt it was a really important topic and appreciated the opportunity to get together with other young people living with invisible illnesses. The group felt that the key priorities to take forward, include:

- There will be another workshop in the New Year, which will provide an opportunity for the people who couldn't make it and maybe some teachers to come too.
- Develop an online forum for young people to chat to each other (could possibly do this via GenerationR website www.generationr.org.uk)
- The group want to develop information about what it is like living with an invisible illness and a possible resource for teachers to support young people

- Young people to deliver talks to school staff.