



Alder Hey Children's **NHS**
NHS Foundation Trust



Invisible Illness Project – Part 2 Workshop Summary Report



Alder Hey Children's NHS Foundation Trust

9th April 2016

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

Introduction

Welcome to the second report of the 'living with an invisible illness' project. To recap the project was set up late 2015 by Sophie Ainsworth a young Lupus patient diagnosed in 2014 aged 15. 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. Sophie decided to raise awareness of living with an invisible illness by contacting patients through various routes including Alder Hey and college contacts. The project began with a small focus group in October 2015 to begin talks with other young people and families about what it is like for young people living day in and day out with chronic illnesses, which includes chronic pain, but they don't look any different from healthy young people all around us. Following the focus group a survey was sent out to other young people who were interested in the project to get a wider opinion of what it was like living with an invisible illness, how it affected their school/college and lives in general, what support they would have liked or would like to develop for other young people and in what format should this be communicated to other young people, families and schools. Seventeen young people with various chronic conditions including, epilepsy, chronic fatigue syndrome, cystic fibrosis, wegeners granulomatosis, large vessel vasculitis and mixed connective tissue disease, Turner's Syndrome, anxiety and mental health conditions completed the survey. Survey responses (see Appendix 1) then informed the development of a meeting with a wider group of stakeholders including, young people and their parents, teachers and health care professionals. The aim of the meeting was to create resources to be distributed to schools and colleges that will hopefully make the everyday lives of young people living with an invisible illness easier.

The meeting began with a presentation by Sophie (see Appendix 2) to inform delegates of background to the project, results from the survey and aims of the day. This was then followed by a series of interactive workshops that focused on: developing 'Top Tips' to support young people; building bridges between parents and teachers; and discussions on the most effective communication routes to reach as many people as possible. Throughout the day young people, parents and teachers were filmed talking about their experiences of living or looking after someone with an invisible illness. Finally, the young people were given the chance to name and design the official logo of the project.

Feedback from the workshops

Workshop 1

Workshop 1 was split into 3 groups (young person's group, parents group and teachers group). The young persons group were encouraged to jot down key things that would help them in their day-to-day life. They may already have this support or wish they had it? The ultimate aim was to design a 'Top Tips' resource.

Key feedback

The main Top Tips the young people felt needed highlighting was around effective communications: practical issues; raising awareness and prioritising pastoral care and respect. The following points were highlighted by young people:

Effective communications:

- Equal Communication (between young people, parents and teachers)
- Contact through email
- Phone calls from doctors to teachers
- Member of staff to talk to – approachable
- Regular meeting time with student and teacher
- Communication with medical staff
- Choose designated staff member

Respect:

- Trust
- Mutual respect
- Sensitivity
- Treat students with individuality
- Trust and Safety

Practical issues:

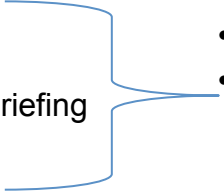
- Chill out room
- Lift Pass

- Unpredictability of illness
- Prioritising pastoral care
- Stick to plan
- A contract. What you want from them. What you will do in return.
- Research by pastoral – passed on to all teachers
- Health Passport
- Lack of education
- Better guidance - councillor not a gossip

Workshop with Teachers

The workshop with teachers discussed findings from the survey responses and explored from a teacher's perspective what where the key things they could do to support young people living with an invisible illness? The workshop explored what teachers already provide in terms of support? Did anything need to change in their associated school and if so what would needed to happen to change this?

Feedback:

- | | | |
|--|--|---|
| <ol style="list-style-type: none"> 1. Liaison Officers 2. SENCO – gets most info and need to filter it through 3. Meeting each week to think through each class – staff briefing 4. Closer work to school nurse 5. Non-teaching pastoral support 6. Lift key – 2 lift passes to have a friend 7. Rest room / chill out zone |  | <ul style="list-style-type: none"> • Patchy • Worse at high school than primary |
|--|--|---|

Workshop with Parents

What are the key concerns you have as a parent in regards to how your child/ren is treated in school or life in general? What would be the solutions to make your child's life a little easier?

Feedback:

Key concerns/issues parents had:

- Lack of understanding that everyone is different
- Ignorance of conditions
- Attendance tagged as truacy / daily phone calls
- “Missing out” – being part of activities excluding flexibility
- Medication classes
- Able to leave class
- Access – lift key – exam facilities
- Quiet Area
- Empathy / caring
- To students as well as staff – primary / secondary
- Technology
- Attendance
- Named person (right person!)
- Regular contact while away from school
- Communication
- Co-Ordination
- Spreading the message to all staff
- Accountability – sticking to agreements

Parents then discussed what solutions would resolve some of the key issues, these included:

1. Communication between staff

- ◆ New Illness – allocate a designated person e.g. SENCO, pastoral, school nurse
- ◆ Ongoing support – designated person to cascade

2. Practical Support

- ◆ Individual card which the patient holds
- ◆ Summary sheet to be held on the pupil and kept up to date by diagnosed person
- ◆ Lift key / exit card etc.

3. Coping with flares in illness / keeping up

- ◆ Extensions and prioritising of work
- ◆ Sending work home

4. Approach / interaction with pupils

- ◆ Staff training – communication and dealing with pupils with illnesses and challenging behaviour and social impact
 - ◆ Document to share
5. Empowering the young person to inform teachers about the condition and abilities
- ◆ Key Card
 - Individualised
 - Summary
 - Signed by head teacher
 - ◆ Passes
 - PE
 - Lift
 - Toilet
 - Dinner given
 - Leaving early

Workshop 2

Workshop two was divided in two groups (young person's group and a combined parent/teachers group)

The main aim of the young person's group was to come up with a name and logo for the project. Several names were suggested but the group finally decided on RAISE, which meant: **Raising Awareness of (Invisible) Illness in Schools and Education**. Figure 1 highlights some suggested logos for the project and Figure 2 is the agreed final logo.

Fig.1

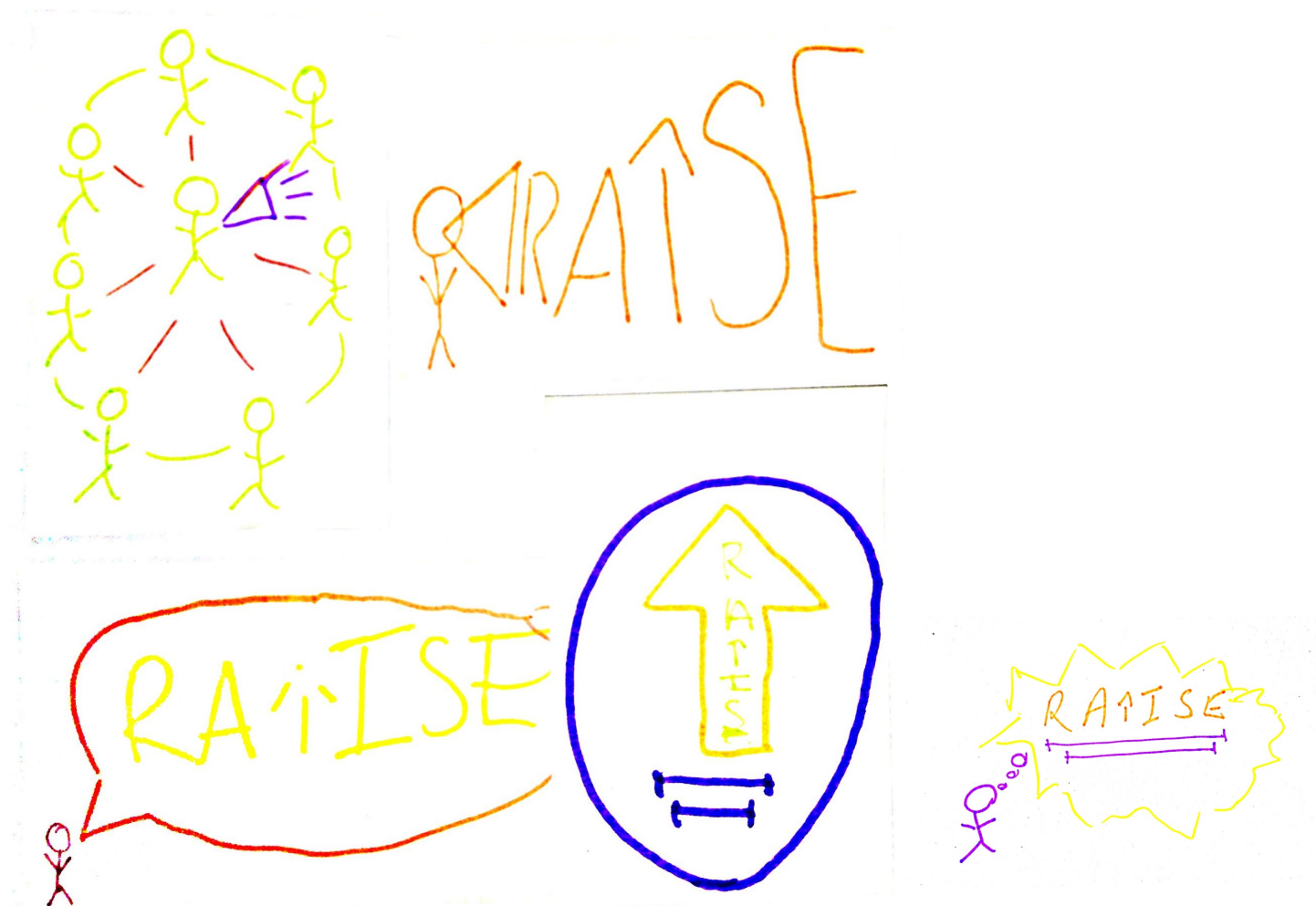


Fig. 2



The Teachers/Parent Group looked at scenarios presented by a teacher to build bridges between teachers and parents. The group discussed and debated two case studies to aid the discussions.

Case study 1.

Mark

Mark has epilepsy, he was diagnosed at 10 years old. Part of his condition means he has 'absence seizures' which means he just 'zones out' sometimes, often only for seconds. Nevertheless this creates a disruption in his concentration. His medication also makes him dizzy or drowsy sometimes.

When Mark went to High School, his teachers were made aware of his condition. His form tutor asked him to stand at the front of the class while she explained his 'problem' as she put it to the rest of the class. Although Mark had agreed to this, he actually felt humiliated and singled out, although he said afterwards that people were quite interested in his condition and he didn't really experience any bullying.

Because of his condition, Mark was not allowed to do PE, he loved swimming but school deemed it too dangerous for him to do it in school time. He also would have liked to have a go at trampolining, but he was told this wasn't possible. He felt there was an invisible barrier between himself and the rest of the pupils.

He was also constantly in trouble for not listening. Often this was because the teachers did not recognise his 'absence seizures' as they can be very subtle or because he was drowsy from medication. Mark became frustrated as he felt he was not succeeding as he should at school. Sometimes his anger came out as violent outbursts, he would punch walls or slam doors. He was accused of 'acting out' and playing on his epilepsy.

Mark left school early and only returned to sit his GCSEs. He did not get the grades he needed to go to college and felt his experience at school had been traumatic.

Case study 2

Sally

Sally has type 1 diabetes and was diagnosed at age 8 after having been very ill for six months, during which time she missed a lot of school. She is now in Year 5 of primary school although she found it hard, has settled back into school life. She has to have two injections of insulin per day, one before breakfast and one before dinner. She doesn't need to take insulin at school. All her teachers are aware of her condition and of how to spot it if she has hypoglycaemia, or a 'hypo' during the day. This has happened on occasion and has been dealt with swiftly by the teacher giving Sally a high glucose drink.


A tradition of the school is to take Year 5 away for a residential trip and the whole class has been looking forward to this since they started Year 5 in September. However, the school has told Sally and her parents that she cannot stay overnight on the trip and must return home every evening. Sally is devastated about this, as that is half the fun, getting to spend the night with all your friends. However, she accepts it and duly goes home every night and returns in the morning. She doesn't feel as though she really participated in the trip.

A few weeks later, Sally's teacher is off sick and a supply teacher is sent in to teach the class. During this time, Sally experiences a 'hypo' in class, which for her means she becomes dizzy and irritable. The supply teacher tells her off for snapping at a fellow pupil and asks her to explain herself. Sally can't do this as she also becomes disorientated during a 'hypo'. Sally's classmates try to explain to the teacher what is happening, as they have experienced this before and know what to do. The teacher will not listen. Despite this, one of the pupils gets up and leaves the room to go and get the Year 4 teacher who knows about Sally's condition. Sally is quickly given the high glucose drink she needs and there is no physical harm done.

However, after this incident, Sally loses confidence in school. She does not want to go and is classed as a 'school refuser' by the education and welfare team. Her parents are fined because of her intermittent absences as Sally is not 'sick' as such, but will not go to school from fear of being left in a hypoglycaemic state. Sally becomes isolated from her peer group and this makes her feel down and depressed.

Sally's parents decide to home educate which means one of them has to give up their job, and this means that money is tight. However, Sally's parents can't think of anything else they can do.

After some discussion the following suggestions were made to support everyone in both situations:

1. Liaison Officers – for families who need it
 2. SENCO – gets most info and need to filter it through
 3. Meeting each week to think through each class – staff briefing
 4. Closer work to school nurse
 5. Non-teaching pastoral support
 6. Lift key – 2 lift passes to have a friend
 7. Rest room / chill out zone
 8. Leaving early
 9. Skipping lunch queue?
 10. Going in late
 11. Extensions to work
 12. Computer
 13. Exit Card
 14. Pass for from of dinner queue or leaving 5 mins early of pass for friend
 15. Not being talked to in front of pupils
 16. Sending work home
 17. Interaction with specialist nurses from hospital
 18. Encouraging pupils to disclose
 19. Healthcare plan
 - In staff room in picture
 - But not read by everyone
 - Needs to show what they are capable of
 - Healthcare passport / short document which can be shown to supply teacher signed by head teacher and individual
- 
- Patchy
 - Worse at high school than primary

Workshop 3

Workshop 3 was split into three groups as the first workshop. The purpose was to come away with a clear communications/action plan. Key areas to discuss where:

- Who are the key people we need to get our messages/resources out too?
- How do we target them?
- In what format should we target them?
- What should be the project's next steps?

Feedback was similar from all groups and are highlighted below.

Communications:

Talks (assemblies)

Website with different sections

Email newsletter quarterly w/updates, stories etc

Examples of real cases

Go to teacher training conference days

Easy access to health passport and resources

Assemblies – create resources pack

Games for younger people

Compulsory teacher training section

Twitter / Facebook

Fundraising

Nurse specialists talking to them

Workshop days / teacher training

Develop a mixture of resources

Priorities to take forward

The key priorities are as follows

- Write up the report and evaluation of the day
- Set up a Twitter and Facebook account to promote RAISE
- Develop a communications plan
- Develop 'Top Tips' based on the feedback
- Fundraise to continue with the project and produce various resources in the formats highlighted above

Evaluation of the day

At the end of the day, all attendees to the event filled out an evaluation form. It asked what they thought about the format of the event and what they believed we did well, or could have done better. Of the 20 replies, everyone answered that the day was 'Very helpful' and some gave particular responses about which parts they thought were best, such as:

- Working together for a positive change
- Discussing different experiences and views of all people involved in workshops
- Meeting other people with similar experiences
- Feeling we can make a difference
- Hearing real – life stories

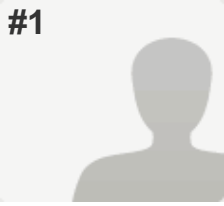
Whilst most people who answered the evaluation had no suggestions for improvement, a few thought it might have been beneficial to have the young people interacting more with the adults of the group. Whilst originally we split the groups up because we thought young people might find it easier to talk amongst a small group of their peers as opposed to a larger group of adults, upon reflection it is clear that communication between the young people and their parents and teachers would be beneficial and it is something we will do in further workshops.

Everyone agreed that the timing of the event was good (a Saturday) and everyone commented that they would be interested in attending future events.

Appendices

Living with an invisible illness

#1



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Monday, February 08, 2016 10:37:47 PM

Last Modified: Monday, February 08, 2016 10:47:12 PM

Time Spent: 00:09:24

IP Address: 86.179.74.58

PAGE 1: Living with an invisible illness

Q1: Age

16

Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)

Lupus

Q3: How does your condition affect you?

Mobility, Pain, Fatigue

Q4: How does your condition affect your school/college life?

Concentration, Attendance, Mobility,
Ability to complete work/homework

Q5: Does having your condition affect the way people treat you?

Yes

Q6: If you answered yes to Q5, please explain

Lack of understanding.
People think I'm lazy.

Q7: Can you give an example of how people have misunderstood your condition?

Seen as lazy when I didn't complete work on time.

PE teachers not understanding.

Not allowed to use the lift.

Q8: Do you feel you were supported in your school/college by staff?

No

Q9: Do you feel you were supported in school/college by your friends?

Yes

Q10: In response to Q8 & Q9 what did/didn't they do to help you?

Didn't tell other members of staff what was going on so they didn't know I was ill.

General lack of kindness from those who did know I was ill.

Friends were a lot more supportive, knew about my condition and didn't treat me differently to how they used to but just took care to make sure I was feeling okay.

Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)

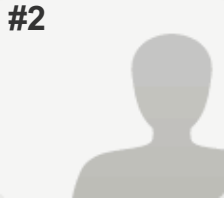
Lift key.

Living with an invisible illness

Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	<i>Respondent skipped this question</i>
Q15: How would you like this information to be presented?	<i>Respondent skipped this question</i>
Q16: If no to Q12 what type of information would you like to see?	
Pack. Videos. Talks. Online.	
Q17: How would you like the information to be presented?	Leaflet, Website, Booklet
Q18: How do you think this project should raise awareness of invisible illnesses in schools?	<i>Respondent skipped this question</i>

Living with an invisible illness

#2



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Monday, February 08, 2016 11:51:50 PM

Last Modified: Tuesday, February 09, 2016 12:15:49 AM

Time Spent: 00:23:59

IP Address: 2.99.13.75

PAGE 1: Living with an invisible illness

Q1: Age	25
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Generalised Tonic Clonic Epilepsy, Vaso Vagel Syncope, Chronic Fatigue Syndrome, Potsural Orthostatic Tachycardia Syndrome, Hypermobility, Depression and Anxiety.
Q3: How does your condition affect you?	Sleep, Mobility, Pain, Fatigue, Eating
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Mobility, Friendships, Ability to complete work/homework
Q5: Does having your condition affect the way people treat you?	Yes
Q6: If you answered yes to Q5, please explain I am treated with 'kid gloves' a lot of the time. Especially by people who are aware of my illnesses but do not understand them. I was in full time employment as a nursery nurse when I developed Epilepsy (all the other illnesses apart from depression were triggered by Epilepsy) and management demoted me because of the illness. I was called a 'safeguarding hazard' because I could have a seizure....even after 12 months seizure free!!!! Friends have stopped talking to me because they don't understand the complexity of the conditions and they accuse me of 'changing my mind' too much etc.	
Q7: Can you give an example of how people have misunderstood your condition? When I explain CFS many people say "Aww yeah I didn't sleep well last night either." When I discuss PoTS, people will assume it is a made up condition because they have never heard of it. I have a disabled parking badge and on numerous occasions, I have had older people discussing whether I am disabled or not and they often say 'She is walking, she doesn't need that badge' What they don't see is the times I am in agony and can barely stand up let alone walk.	
Q8: Do you feel you were supported in your school/college by staff?	No
Q9: Do you feel you were supported in school/college by your friends?	No
Q10: In response to Q8 & Q9 what did/didn't they do to help you? I suffered with depression and anxiety in school and college and I was laughed at by pupils and bullied because of it. The same happened in the work place. I was made to feel like a burden in work because of all my other illnesses and would not be allowed time off to go to hospital appointments. They did not wish to listen to me when I tried to explain my health to them either.	

Living with an invisible illness

Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)

I have to use a shower seat and I have grab rails to help me in and out of the shower. I also have to use a perching stool so I can get up and down easier.

Q12: Do you think there is enough information about your condition aimed at young people/staff?

No

Q13: If yes to Q12, can you explain how the information is useful?

Respondent skipped this question

Q14: Is there any other information you would like to see?

Respondent skipped this question

Q15: How would you like this information to be presented?

Respondent skipped this question

Q16: If no to Q12 what type of information would you like to see?

There is good information available online regarding Epilepsy and the stigma around mental health is slowly being broken. However, I would like to see more information and media coverage of illnesses such as PoTS and CFS. Many people are aware of CFS but are of the mentality that it is a made up illness and all in the mind. The only people I meet with a knowledge of PoTS are neurologists and other PoTS patients. I feel it needs more coverage all round as it can be fatal.

Q17: How would you like the information to be presented?

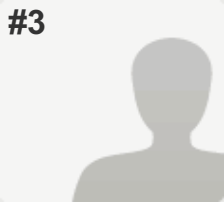
Leaflet, Apps, Website, Booklet,
Other (please specify)
TV/radio coverage and maybe famous faces
becomming involved in charities

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Posters, leaflets etc work well but also having a dedicated staff member for pupils to talk to would be helpful.

Living with an invisible illness

#3



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Tuesday, February 09, 2016 7:52:42 AM

Last Modified: Tuesday, February 09, 2016 8:01:15 AM

Time Spent: 00:08:32

IP Address: 82.132.244.25

PAGE 1: Living with an invisible illness

Q1: Age	17
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Primary Sclerosing Cholangitis
Q3: How does your condition affect you?	Fatigue, Other (please specify) Often get liver infections which cause me massive pain
Q4: How does your condition affect your school/college life?	Attendance
Q5: Does having your condition affect the way people treat you?	Yes
Q6: If you answered yes to Q5, please explain Sometimes people are very weird about it and constantly ask me questions which I don't like	
Q7: Can you give an example of how people have misunderstood your condition? They have but its hard to explain	
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you? Teachers and college tutors are very helpful with letting me know that school/college always comes second to my health and have never been concerned about my attendance	
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.) Nope, don't need anything	
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>

Living with an invisible illness

Q14: Is there any other information you would like to see?

My condition is very very rare in people my age and half of the doctors don't even know what it is never mind other people my age and staff

Q15: How would you like this information to be presented?

Other (please specify) I'm not bothered

Q16: If no to Q12 what type of information would you like to see?

I don't think I'm that bothered about people knowing about it, I don't like having it so I don't want people to know about it

Q17: How would you like the information to be presented?

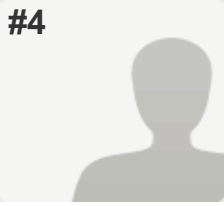
Other (please specify) Not sure

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Not sure

Living with an invisible illness

#4



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Tuesday, February 09, 2016 12:22:04 PM

Last Modified: Tuesday, February 09, 2016 12:27:34 PM

Time Spent: 00:05:30

IP Address: 212.219.118.129

PAGE 1: Living with an invisible illness

Q1: Age	17
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Lupus (SLE)
Q3: How does your condition affect you?	Sleep, Pain, Fatigue
Q4: How does your condition affect your school/college life?	Concentration, Ability to complete work/homework , Coping with exams
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	
'You don't look ill'	
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	No
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	
Many of my friends do not know about my condition because I know they wouldn't understand, and the ones that do, don't really understand either	
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.)	<i>Respondent skipped this question</i>
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	<i>Respondent skipped this question</i>
Q15: How would you like this information to be presented?	Apps, Websites

Living with an invisible illness

Q16: If no to Q12 what type of information would you like to see?

Ways to explain that it's an invisible illness

Q17: How would you like the information to be presented?

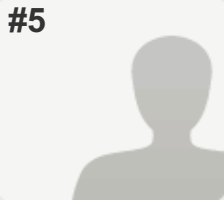
Leaflet, Apps, Website

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Respondent skipped this question

Living with an invisible illness

#5



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Tuesday, February 09, 2016 4:03:29 PM

Last Modified: Tuesday, February 09, 2016 4:12:20 PM

Time Spent: 00:08:51

IP Address: 82.35.247.172

PAGE 1: Living with an invisible illness

Q1: Age	20
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Cystic Fibrosis
Q3: How does your condition affect you?	Sleep, Mobility, Eating
Q4: How does your condition affect your school/college life?	Attendance, Mobility, Ability to complete work/homework
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	Thinking that I was capable of completing task, and conversely, not able to do anything at all.
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	They allowed me rest breaks in exams, and allowed me to leave lessons to clear my chest. My friends were just fantastic, supporting me through hospital admissions but treating me as a normal person, and keeping me grounded though jibes here and there (I reciprocated!)
Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)	Nothing more could have been done at school.
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	People won't feel so wary of me and my condition, and won't treat me differently except where I need to be.

Living with an invisible illness

Q14: Is there any other information you would like to see?

An overview of CF and how it does/nt affect everyday life.

Q15: How would you like this information to be presented?

Leaflet, Websites

Q16: If no to Q12 what type of information would you like to see?

An overview of CF and how it does/nt affect everyday life.

Q17: How would you like the information to be presented?

Leaflet, Website, Booklet

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Contacting schools through hospitals and briefing teachers.

Living with an invisible illness

#6



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Wednesday, February 10, 2016 3:54:49 PM

Last Modified: Wednesday, February 10, 2016 4:02:03 PM

Time Spent: 00:07:14

IP Address: 213.205.252.105

PAGE 1: Living with an invisible illness

Q1: Age	18
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Wegeners granulomatosis
Q3: How does your condition affect you?	Sleep, Mobility
Q4: How does your condition affect your school/college life?	Attendance
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition? People think there is nothing wrong because they cannot see it.	
Q8: Do you feel you were supported in your school/college by staff?	No
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you? Q8- PE staff would try to force me to do things I was not able to do such as running long distances despite hospital letters telling them about my condition. Q9- my friends knew what I could and couldn't do and are always understanding and supportive.	
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.) No not really.	
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	<i>Respondent skipped this question</i>

Living with an invisible illness

Q15: How would you like this information to be presented?

Respondent skipped this question

Q16: If no to Q12 what type of information would you like to see?

My illness explained in a way people can understand it.

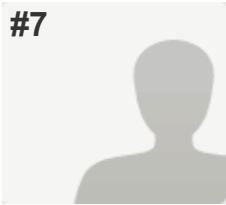
Q17: How would you like the information to be presented?

Booklet, Website, Apps

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Videos of patient story's, leaflets on invisible illnesses.

#7



COMPLETE

Collector: Web Link 1 (Web Link)
Started: Wednesday, February 10, 2016 9:17:16 PM
Last Modified: Wednesday, February 10, 2016 9:32:42 PM
Time Spent: 00:15:25
IP Address: 81.131.166.203

PAGE 1: Living with an invisible illness

Q1: Age	11
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Large vessel vasculitis and mixed connective tissue disease
Q3: How does your condition affect you?	Mobility, Pain, Fatigue
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Mobility
Q5: Does having your condition affect the way people treat you?	Yes
Q6: If you answered yes to Q5, please explain	
Some people are nicer to me because they know I'm not well. Sometimes people assume I can't do certain things, like play a game with them, when actually I can.	
Q7: Can you give an example of how people have misunderstood your condition?	
My friends sometimes question why I am off games so much and why I sometimes have to go to the health centre in school for a rest. They sometimes think it isn't fair because I seem well to them.	
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	
My teachers suggest that I have a rest if I am struggling. My friends will sometimes wait for me if I can't move quickly and they have lent me their things if I get cold.	
Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)	
Not really. I am lucky because there is a room I can go to to rest if I need to.	
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	<i>Respondent skipped this question</i>

Living with an invisible illness

Q15: How would you like this information to be presented?

Respondent skipped this question

Q16: If no to Q12 what type of information would you like to see?

i think it would help if there was some simple explanation and information for other children about my condition so that they can understand a bit about it.

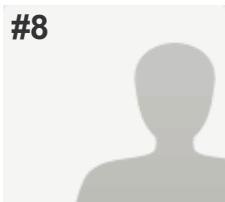
Q17: How would you like the information to be presented?

Leaflet, Website

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Perhaps by creating a website with some basic information about invisible illnesses that would be accessible to other children.

#8



COMPLETE

Collector: Web Link 1 (Web Link)
Started: Sunday, February 14, 2016 5:08:47 PM
Last Modified: Sunday, February 14, 2016 5:16:43 PM
Time Spent: 00:07:56
IP Address: 81.111.124.230

PAGE 1: Living with an invisible illness

Q1: Age	13
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Lupus
Q3: How does your condition affect you?	Sleep, Pain, Fatigue, Eating
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Friendships, Ability to complete work/homework , Coping with exams
Q5: Does having your condition affect the way people treat you?	Yes
Q6: If you answered yes to Q5, please explain	People think I'm special/ different
Q7: Can you give an example of how people have misunderstood your condition?	Think that I would die. Saying that I'm overweight.
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	Staff are really nice. Most 'friends' are supportive
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.)	lift key, leaving early from lessons, skipping the queue, going in late if needed, having extensions, being able to use the computer for work.
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>

Living with an invisible illness

Q14: Is there any other information you would like to see?

Videos more leaflets, apps.

Q15: How would you like this information to be presented?

Leaflet, Apps, Websites, Booklets

Q16: If no to Q12 what type of information would you like to see?

See above^

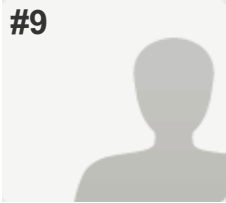
Q17: How would you like the information to be presented?

Leaflet, Apps, Website, Booklet

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Letting people know the symptoms, knowing the signs

#9



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Thursday, February 18, 2016 10:19:34 AM

Last Modified: Thursday, February 18, 2016 10:38:30 AM

Time Spent: 00:18:56

IP Address: 90.214.91.37

PAGE 1: Living with an invisible illness

Q1: Age	13
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	anxiety
Q3: How does your condition affect you?	Sleep, Other (please specify) speaking in public situations, social situations,
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Friendships, Ability to complete work/homework , Coping with exams
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	I feel like it should, but people haven't because of the lack of awareness around the issue
Q7: Can you give an example of how people have misunderstood your condition?	that only very certain triggers create panic/ the anxiety is the same of everyone else's and normal, that i can just 'stop thinking about it and everything will be fine
Q8: Do you feel you were supported in your school/college by staff?	No
Q9: Do you feel you were supported in school/college by your friends?	No
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	school was entirely unsupportive and only cared about my schoolwork/attendance/grades and my friends didn't really understand the situation that i was in
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.)	being able to get out of lesson/ not speaking in front of the class without being made guilty about it, access to a councillor sooner than 8 weeks , in which those 8 weeks your mental illness is completely ignored.
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No

Living with an invisible illness

Q13: If yes to Q12, can you explain how the information is useful?

Respondent skipped this question

Q14: Is there any other information you would like to see?

more awareness of mental health

Q15: How would you like this information to be presented?

Leaflet, Apps, Websites

Q16: If no to Q12 what type of information would you like to see?

explanation of what mental disorders mean and feel like

Q17: How would you like the information to be presented?

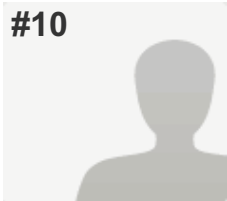
Leaflet, Apps, Website

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

tell teachers to take mental illnesses seriously instead of treating students the same as any other and ignoring their needs

Living with an invisible illness

#10



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Thursday, February 18, 2016 12:34:35 PM

Last Modified: Thursday, February 18, 2016 12:37:14 PM

Time Spent: 00:02:39

IP Address: 213.162.112.168

PAGE 1: Living with an invisible illness

Q1: Age	11
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Lupus
Q3: How does your condition affect you?	Pain, Fatigue
Q4: How does your condition affect your school/college life?	Attendance
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	<i>Respondent skipped this question</i>
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	
All teachers were made aware of my condition	
Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)	<i>Respondent skipped this question</i>
Q12: Do you think there is enough information about your condition aimed at young people/staff?	Yes
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	<i>Respondent skipped this question</i>
Q15: How would you like this information to be presented?	Leaflet, Websites
Q16: If no to Q12 what type of information would you like to see?	<i>Respondent skipped this question</i>

Living with an invisible illness

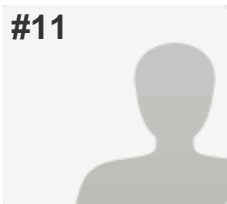
Q17: How would you like the information to be presented?

Respondent skipped this question

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

It will alert staff and pupils to various illnesses that everyone understands

#11



COMPLETE

Collector: Web Link 1 (Web Link)
Started: Friday, February 19, 2016 4:25:44 PM
Last Modified: Friday, February 19, 2016 4:32:07 PM
Time Spent: 00:06:22
IP Address: 92.40.249.107

PAGE 1: Living with an invisible illness

Q1: Age	17
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Tunes syndrome
Q3: How does your condition affect you?	Sleep, Mobility, Fatigue
Q4: How does your condition affect your school/college life?	Attendance, Mobility, Ability to complete work/homework
Q5: Does having your condition affect the way people treat you?	Yes
Q6: If you answered yes to Q5, please explain People don't understand turners as its not well known	
Q7: Can you give an example of how people have misunderstood your condition? Friends and family members	
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you? They help me cope with work	
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.) They have learning support team that support me in class	
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful? As it unknown there's not enough information published	
Q14: Is there any other information you would like to see? More information that's less medical jargon	

Living with an invisible illness

Q15: How would you like this information to be presented?

Leaflet

Q16: If no to Q12 what type of information would you like to see?

More facts about turners that people understand no medical jargon

Q17: How would you like the information to be presented?

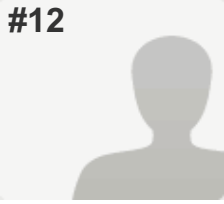
Leaflet

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Respondent skipped this question

Living with an invisible illness

#12



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Sunday, February 21, 2016 12:00:23 PM

Last Modified: Sunday, February 21, 2016 12:09:54 PM

Time Spent: 00:09:30

IP Address: 86.16.143.90

PAGE 1: Living with an invisible illness

Q1: Age	7
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Type 1 Diabetes & Coeliac Disease
Q3: How does your condition affect you?	Sleep, Mobility, Fatigue, Eating
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Friendships, Ability to complete work/homework , Coping with exams
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	<i>Respondent skipped this question</i>
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	<i>Respondent skipped this question</i>
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.)	<i>Respondent skipped this question</i>
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	more information needed to explain the difference between type 1 and type2 diabetes
Q15: How would you like this information to be presented?	Booklets, Websites, Apps, Leaflet

Living with an invisible illness

Q16: If no to Q12 what type of information would you like to see?

more information needed to explain the difference between type 1 and type2 diabetes

Q17: How would you like the information to be presented?

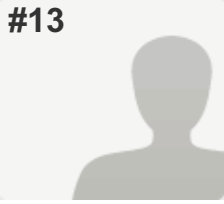
Leaflet, Apps, Website, Booklet

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

by making it part of student teacher training

Living with an invisible illness

#13



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Wednesday, February 24, 2016 7:33:17 PM

Last Modified: Wednesday, February 24, 2016 7:43:27 PM

Time Spent: 00:10:09

IP Address: 90.202.182.193

PAGE 1: Living with an invisible illness

Q1: Age	14
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Under investigation
Q3: How does your condition affect you?	Sleep, Mobility, Pain, Fatigue
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Mobility, Ability to complete work/homework
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	They don't understand how I look well but feel like hell inside
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	They carry my bag around school when I'm on crutches and they try to understand what I'm going through
Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)	They should send work home instead of expecting me to look for it
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	No

Living with an invisible illness

Q15: How would you like this information to be presented?

Booklets, Websites, Apps, Leaflet

Q16: If no to Q12 what type of information would you like to see?

I think there should be more information for teachers so they can understand what I'm going through and help me with work when I've been absent

Q17: How would you like the information to be presented?

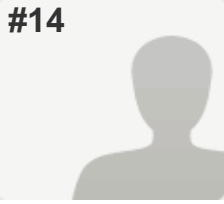
Booklet, Website, Apps, Leaflet

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

I believe that this would help in schools because it can give teachers and pupils a better understanding of what people with invisible illnesses go through

Living with an invisible illness

#14



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Wednesday, February 24, 2016 10:44:32 PM

Last Modified: Wednesday, February 24, 2016 10:53:43 PM

Time Spent: 00:09:11

IP Address: 86.150.2.101

PAGE 1: Living with an invisible illness

Q1: Age	17
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Beçhets
Q3: How does your condition affect you?	Fatigue
Q4: How does your condition affect your school/college life?	Attendance, Coping with exams
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	teachers assuming I miss school for no reason.
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	They help me catch up on work that I have missed .
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.)	No.
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	<i>Respondent skipped this question</i>
Q15: How would you like this information to be presented?	<i>Respondent skipped this question</i>

Living with an invisible illness

Q16: If no to Q12 what type of information would you like to see?

Information on how to talk to young people with an illness and how it can be difficult for them to cope with the workload.

Q17: How would you like the information to be presented?

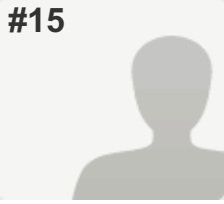
Leaflet

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

I think it should give advice on how to talk to young people with an illness.

Living with an invisible illness

#15



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Wednesday, March 16, 2016 11:14:13 PM

Last Modified: Wednesday, March 16, 2016 11:26:31 PM

Time Spent: 00:12:17

IP Address: 151.229.203.227

PAGE 1: Living with an invisible illness

Q1: Age	17
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Primary sclerosing cholangitis
Q3: How does your condition affect you?	Fatigue, Other (please specify) Sometimes Itching, liver infections (very painful), jaundice
Q4: How does your condition affect your school/college life?	Attendance
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	<i>Respondent skipped this question</i>
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	Teachers were very good to me at bowland I always felt like I was in good care and that I could talk to teachers that I got along with
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.)	Nope
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>

Living with an invisible illness

Q14: Is there any other information you would like to see?

Not really

Other (please specify) I don't

Q15: How would you like this information to be presented?

Q16: If no to Q12 what type of information would you like to see?

I don't think there is any need as I know no one with the disease I have and it isn't life threatening so there is no need for people to know about it unless they have it

Q17: How would you like the information to be presented?

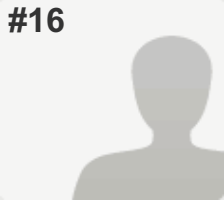
Respondent skipped this question

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

As I said i haven't had a bad time with teachers/tutors mistreating me or misunderstanding me so for me there isn't much need but for other young people with possibly life threatening diseases then people should go and talk about their experiences with other schools to get a 1st person account about what it's like for someone with a life threatening disease as I would feel id learn most this way

Living with an invisible illness

#16



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Thursday, March 17, 2016 1:54:31 PM

Last Modified: Thursday, March 17, 2016 2:06:26 PM

Time Spent: 00:11:54

IP Address: 138.253.15.72

PAGE 1: Living with an invisible illness

Q1: Age	20
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Juvenile Dermatomyositis
Q3: How does your condition affect you?	Pain, Fatigue
Q4: How does your condition affect your school/college life?	Concentration, Ability to complete work/homework , Coping with exams
Q5: Does having your condition affect the way people treat you?	No
Q6: If you answered yes to Q5, please explain	<i>Respondent skipped this question</i>
Q7: Can you give an example of how people have misunderstood your condition?	
People don't know what it is and don't always correctly judge the seriousness of it. They don't understand the affect my medication has on me and my ability to carry out day to day activities.	
Q8: Do you feel you were supported in your school/college by staff?	Yes
Q9: Do you feel you were supported in school/college by your friends?	Yes
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	
Exam support but day-to-day support is more difficult and its hard to keep using your illness as an 'excuse' for your struggling My friends understand that some days I dont feel well and need to rest. They help me out if they can.	
Q11: Do you have any simple things that could help your everyday school/college life? (e.g.having a lift key, etc.)	<i>Respondent skipped this question</i>
Q12: Do you think there is enough information about your condition aimed at young people/staff?	No
Q13: If yes to Q12, can you explain how the information is useful?	<i>Respondent skipped this question</i>
Q14: Is there any other information you would like to see?	<i>Respondent skipped this question</i>

Living with an invisible illness

Q15: How would you like this information to be presented?

Leaflet, Booklets

Q16: If no to Q12 what type of information would you like to see?

More up to date leaflets and more online resources

Q17: How would you like the information to be presented?

Leaflet, Website, Booklet

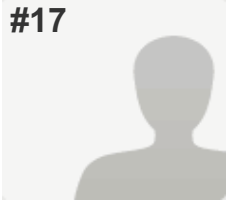
Q18: How do you think this project should raise awareness of invisible illnesses in schools?

Packs which can be distributed to schools

Online resources

Visits from medical staff and patients to explain to students and staff

#17



COMPLETE

Collector: Web Link 1 (Web Link)
Started: Monday, March 28, 2016 5:22:18 PM
Last Modified: Monday, March 28, 2016 6:30:52 PM
Time Spent: 01:08:34
IP Address: 109.158.1.25

PAGE 1: Living with an invisible illness

Q1: Age	16
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Eosinophilic colitis
Q3: How does your condition affect you?	Sleep, Pain, Fatigue, Eating, Other (please specify) INTENSE nausea and weight loss
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Friendships, Ability to complete work/homework , Coping with exams
Q5: Does having your condition affect the way people treat you?	Yes
Q6: If you answered yes to Q5, please explain	
Especially in high school i was seen as the 'ill' kid and nothing else. Since I have started college i have told only one of my friends that I am so poorly in order to try and achieve some normalcy.	
Q7: Can you give an example of how people have misunderstood your condition?	
A lot of the time I don't like looking as ill as I am, so I try and just get on with things. People often hint you are pretending to be ill, whereas in reality you're spending every second outside of the house pretending you are well and okay.	
Q8: Do you feel you were supported in your school/college by staff?	No
Q9: Do you feel you were supported in school/college by your friends?	No
Q10: In response to Q8 & Q9 what did/didn't they do to help you?	
My high school experience was terrible. The staff in charge of my care made no effort to understand my situation or to help support me in anyway. They were not educated on how to deal with cases such as mine so they made no effort. Their only approach was to criticize how little I attended school, even though my doctors and specialists and my medical needs team had made them aware that it was a miracle i attended school at all.	

Living with an invisible illness

Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)

Since I have started college this year the staff have been amazing and I have a proper support network. I have access to lifts, a fridge for my medicines, a chill out zone for me to use whenever i am ill and a pastoral care team which I have access to whenever I am in need. It is a complete change from my time at high school.

Q12: Do you think there is enough information about your condition aimed at young people/staff?

No

Q13: If yes to Q12, can you explain how the information is useful?

Respondent skipped this question

Q14: Is there any other information you would like to see?

Respondent skipped this question

Q15: How would you like this information to be presented?

Respondent skipped this question

Q16: If no to Q12 what type of information would you like to see?

I have never talked to another teenager who suffers with a disease like mine. It makes dealing with it very hard, and talking about it even harder. I am aware there are leaflets, support groups and websites for people suffering with colitis. However my condition is never included or even mentioned. My condition means my white blood cells attack my colon but I only know the details of my condition from my doctors and even they can vary with it being such a rare disease. I think it would be helpful for people suffering with my disease, especially children, to be able to inform people with a leaflet or website. Being a teenager and having to explain a complex illness to your friends is very difficult especially when there is almost nothing to refer to.

Q17: How would you like the information to be presented?

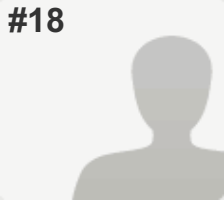
Leaflet, Apps, Website, Booklet

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

I believe, as a teenager who has gone through what many teenagers will have to in the future, there has to be more put in place in order to support the child in need. I came out of school with four GCSE's after dropping 6 as i couldn't cope with the work load. I wouldn't have been able to achieve the grades i have if it hadn't been for my hard work and family support. My teachers were uneducated, unreliable, unmotivated and frankly insensitive to a child with an invisible illness. Many support strategies were put in place following meetings with the staff at my school. Each meeting being attended by my medical needs team and my hospital representative. All of which was agreed was never upheld and left me feeling desperate and alone. The staff made no effort to help me with my courses or with friendships I was losing. I wasn't even notified of my last day at school. I managed to get the grades i needed, but I came out of school exhausted, sick of fighting and with no friends or memories. It is so sad as so much could've been done for my school experience to be so different. Schools need to support children with invisible illnesses at school. Children living with an invisible illness have it tough. It can be a struggle for us to get out of bed in the morning, never mind attend a hospital appointment. That is why it so enormously important that when children with invisible illnesses attend school they can feel happy, supported and most importantly, understood.

Living with an invisible illness

#18



COMPLETE

Collector: Web Link 1 (Web Link)

Started: Thursday, April 07, 2016 11:18:14 AM

Last Modified: Thursday, April 07, 2016 11:41:21 AM

Time Spent: 00:23:06

IP Address: 51.9.152.66

PAGE 1: Living with an invisible illness

Q1: Age	17
Q2: What type of chronic condition do you have? (i.e. Diabetes, Lupus, etc.)	Mental health issue
Q3: How does your condition affect you?	Sleep, Fatigue, Eating, Other (please specify) Low mood
Q4: How does your condition affect your school/college life?	Concentration, Attendance, Friendships, Ability to complete work/homework , Coping with exams, Other (please specify) Confidence
Q5: Does having your condition affect the way people treat you?	Yes
Q6: If you answered yes to Q5, please explain People who don't know me well either tiptoe around me as if I'm extremely fragile or they roll their eyes and say I'm being pathetic and seeking attention and being ungrateful. My close friends do support me if I need it and treat me the same though.	
Q7: Can you give an example of how people have misunderstood your condition? If I'm panicking or anxious people tend to think I'm being paranoid and stupid because they don't understand that I can get worked up over small things and I get accused of faking it to get out of doing things I don't want to do.	
Q8: Do you feel you were supported in your school/college by staff?	No
Q9: Do you feel you were supported in school/college by your friends?	Yes

Living with an invisible illness

Q10: In response to Q8 & Q9 what did/didn't they do to help you?

I received a little support from staff but the wrong kind, they didn't fully understand that mental illness affects each person in a different way so they treated me as they treated everyone else which overall didn't help. I appreciate them trying but they lacked understanding which would sometimes lead to me being in trouble for being unable to do work etc. as they didn't see how I was trying when they couldn't see it through my work or social groups.

My friends understood me as they knew me well because any illnesses came along so they knew it wasn't my fault and they felt comfortable with me to ask me questions about what was going on and find ways to help me. They cared more about my health than my grades so they wouldn't push me too hard as school work was/is one of my biggest low mood and anxiety triggers. They would help me at a pace they knew was right instead of forcing me to continue to try and excel in school.

Q11: Do you have any simple things that could help your everyday school/college life? (e.g. having a lift key, etc.)

At college my teachers are much better and are your friends as well as your teachers, if I have a problem I can leave the room or go outside for a few minutes to calm myself.

Q12: Do you think there is enough information about your condition aimed at young people/staff?

No

Q13: If yes to Q12, can you explain how the information is useful?

Respondent skipped this question

Q14: Is there any other information you would like to see?

People should get to know a person before getting to know the illness so instead of being looked at as a mental case you get looked at as a person who want a to do so many things and tries to but can't because of their illness and instead of trying to push the person out of their illness by pressuring them into doing things they can't manage, try to guide the person through and take it easy while finding ways to get things done. Understand how the illness limits someone, don't just jump to the conclusion that they're lazy or rude or pathetic or an attention seeker.

Q15: How would you like this information to be presented?

Booklets, Websites, Apps, Leaflet,
Other (please specify) Presentations, meetings

Q16: If no to Q12 what type of information would you like to see?

Refer to Q14

Q17: How would you like the information to be presented?

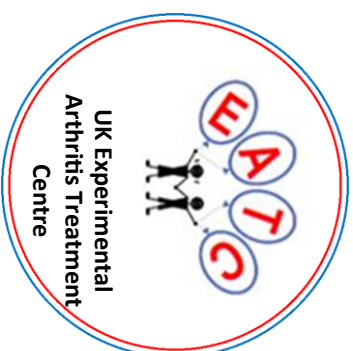
Booklet, Website, Apps, Leaflet,
Other (please specify) Presentations, meetings

Q18: How do you think this project should raise awareness of invisible illnesses in schools?

In every way possible to reach as many people as possible. Websites and apps for the younger generation and booklets, leaflets, posters, etc. As they can be distributed anywhere. Talks and meetings for those who think it's not that important to read the leaflet or look things up. Presentations as they engage people more with visuals and sound and questions can be asked and answered straight away.



Alder Hey Children's **NHS**
NHS Foundation Trust



NHS
*National Institute for
Health Research*

Invisible Illness Project

9th April – Workshop

Institute in the Park

Sophie Ainsworth

Introduction/Background

- Lupus – An autoimmune disease in which the immune system is hyperactive. Causing damage to healthy tissue.
- Symptoms:
 - Fatigue
 - Brain fog
 - Chest and joint pain
 - Breathing difficulties
 - Muscle weakness
 - Nausea

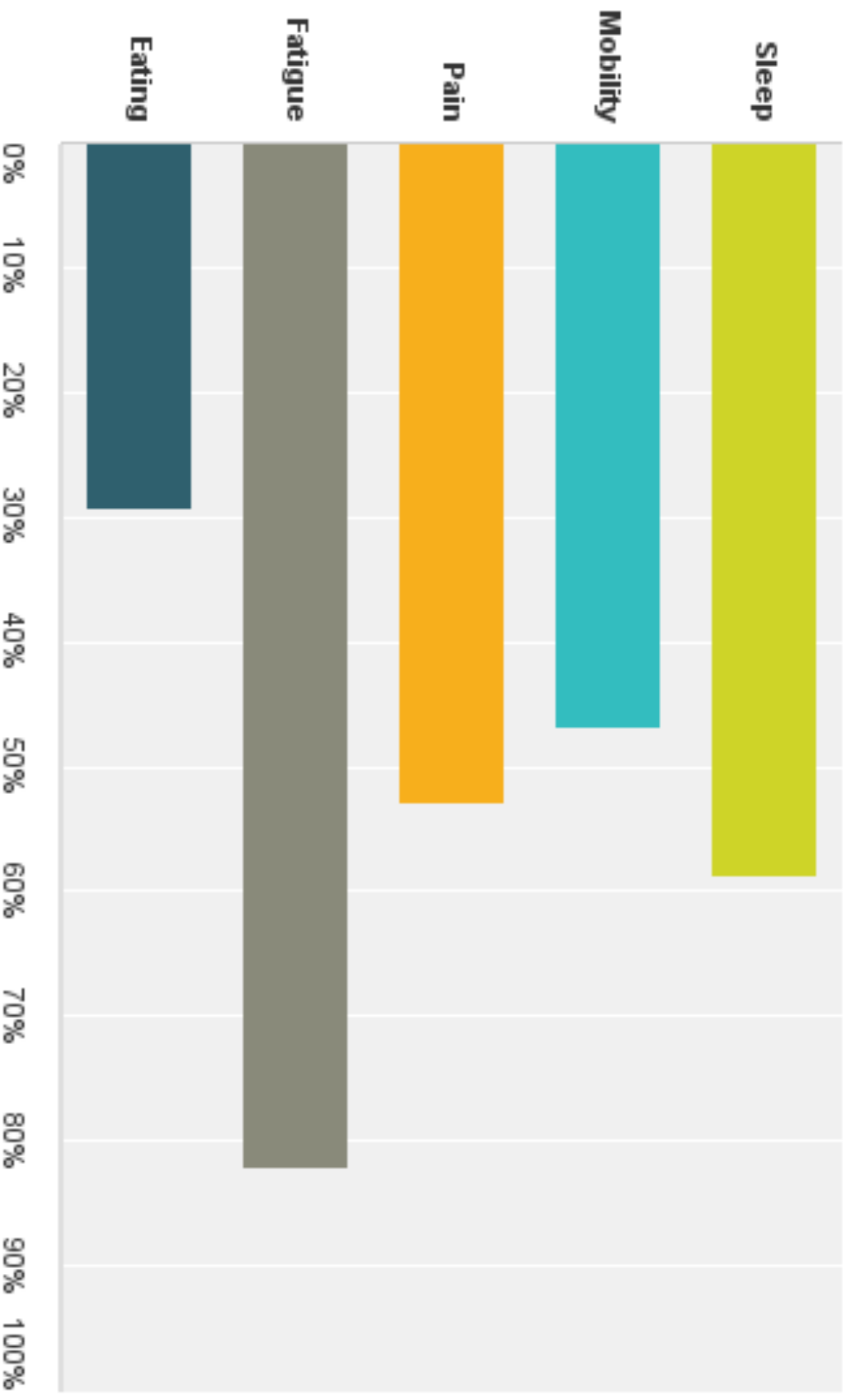


Survey results



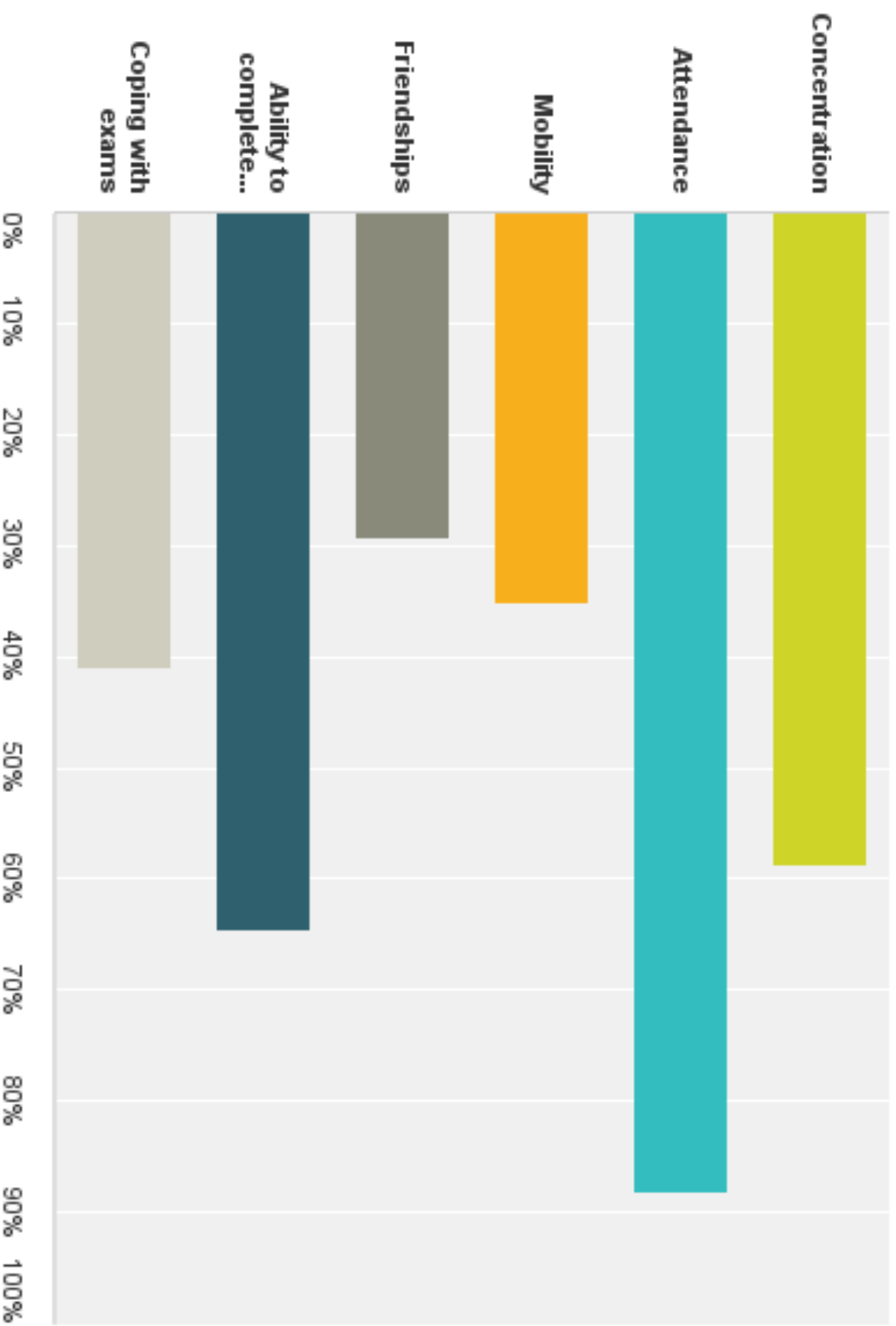
Q3 How does your condition affect you?

Answered: 17 Skipped: 0



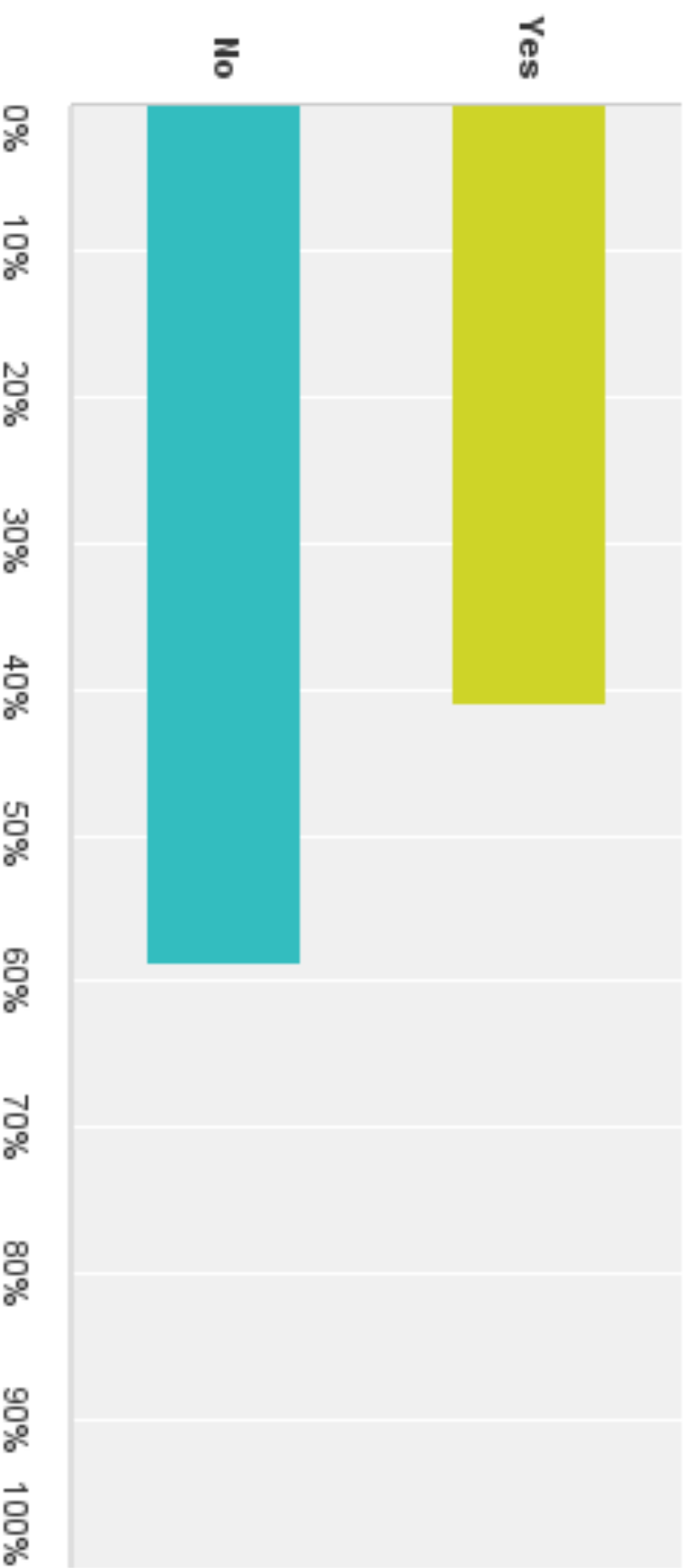
Q4 How does your condition affect your school/college life?

Answered: 17 Skipped: 0



Q5 Does having your condition affect the way people treat you?

Answered: 17 Skipped: 0



How?

'Constantly ask
questions I
don't like'

'Both
overestimating
and
underestimating
me'


'Calling me
overweight'



'Treated with
'kid gloves''



'Treated as 'the
ill kid''



'Assume I can't
do things'

Misunderstanding your condition

'You don't look ill'

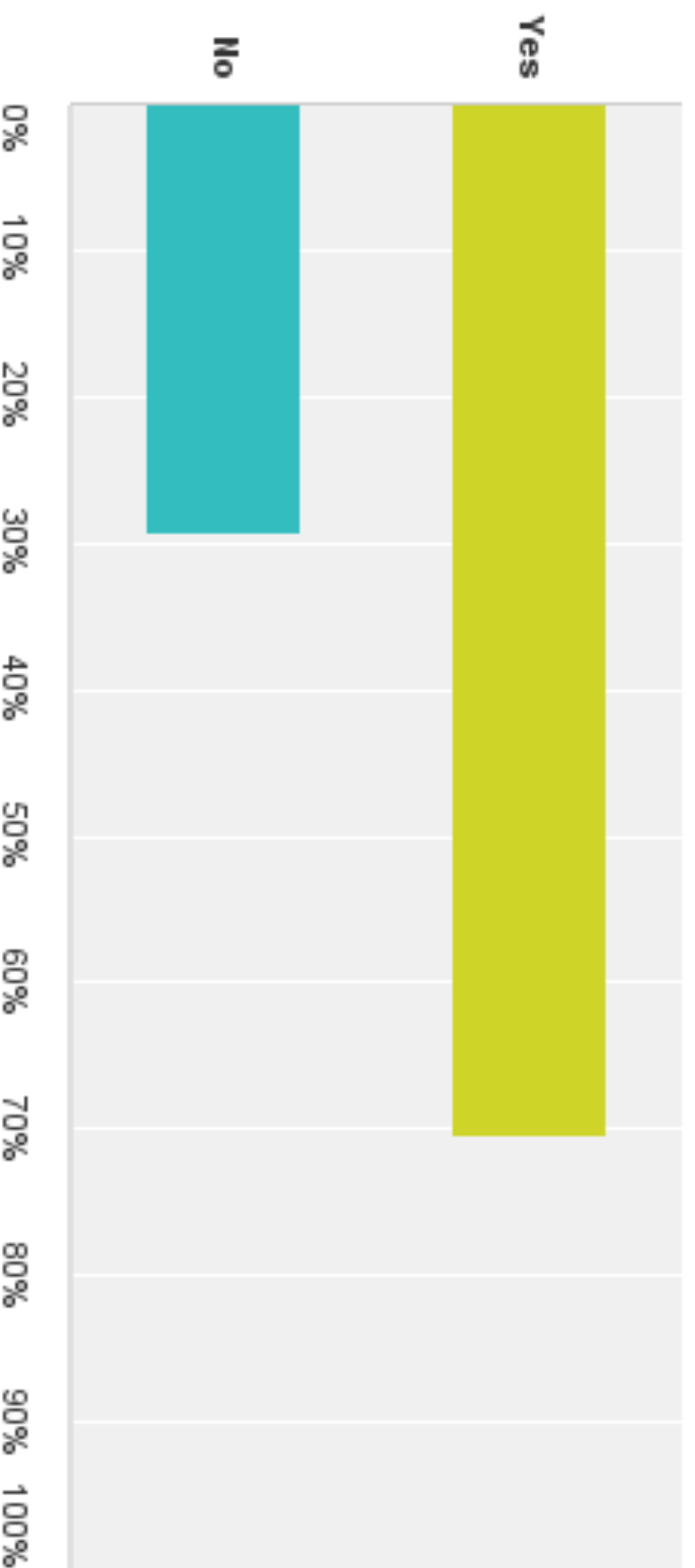
'Don't understand the seriousness of my illness'

'Changing my mind-set will make me better'

'Criticised and made to feel lazy'

Q8 Do you feel you were supported in your school/college by staff?

Answered: 17 Skipped: 0



What did they do to help you?

'Reassured me
my health was
more important
than school'

'Allowed me to
leave lessons
without
questioning'

'Exam support'

'Helped me catch
up on work'

'Teachers were
kind and
approachable'

What didn't they do to help you?

'Made no effort to understand my rare condition'

'Ignored information from me and my doctor'

'Only cared about my work and grades'

'Didn't communicate to other members of staff what was wrong'

'Forced me to do things I couldn't do'

Simple things to help

Lift key

Leaving early
from lessons

Exam
support

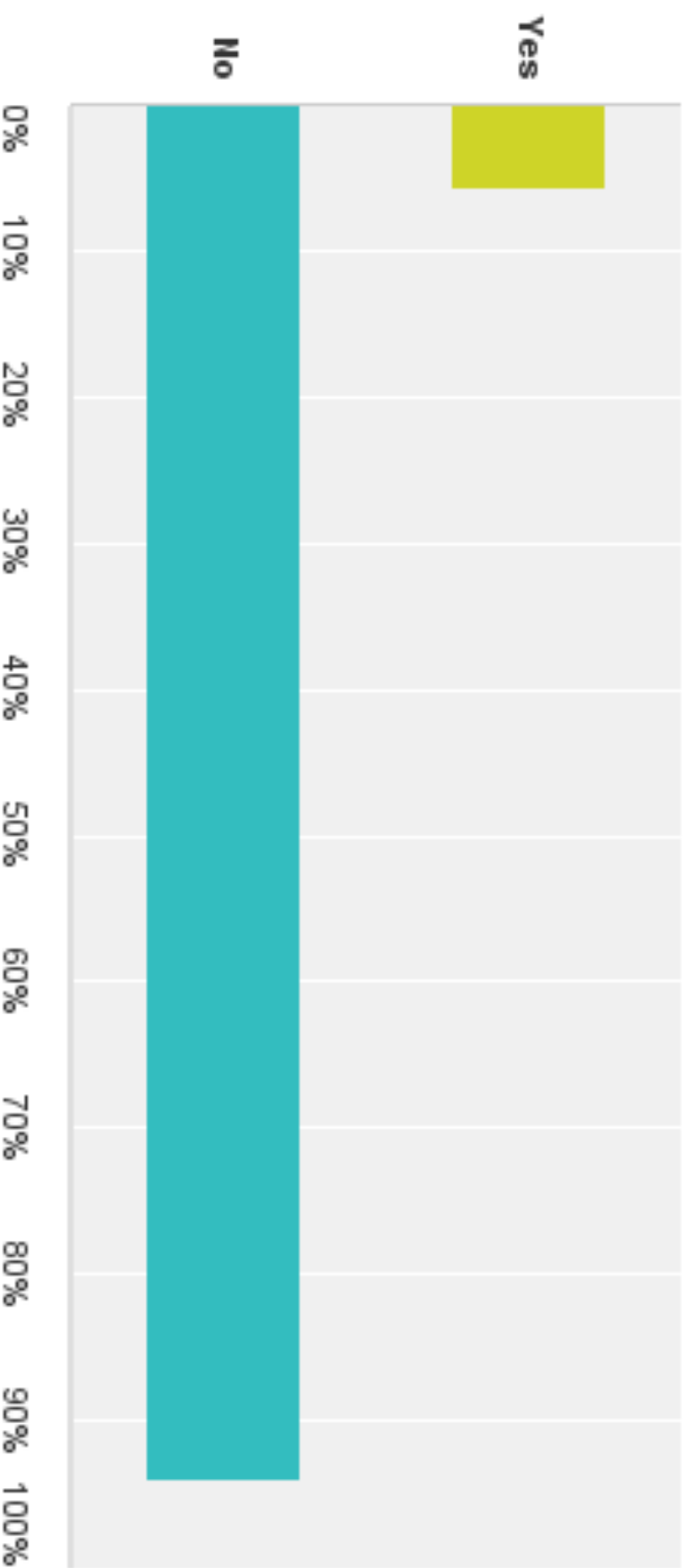
Skipping the
queue

Extensions
on work

Learning
support

Q12 Do you think there is enough information about your condition aimed at young people/staff?

Answered: 17 Skipped: 0

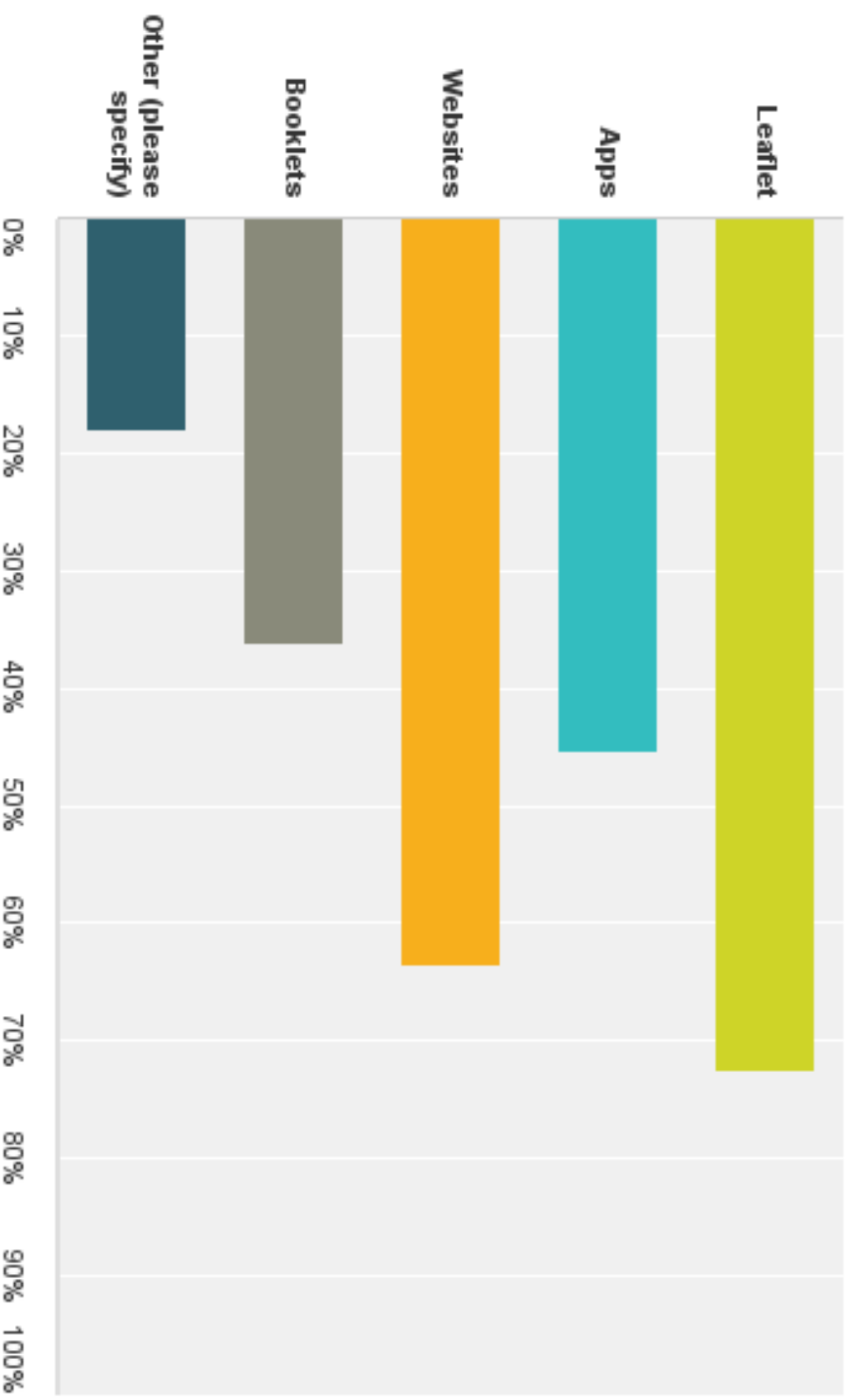


What would you like to see?

- Information pack
- Videos
- Talks
- Online

Q15 How would you like this information to be presented?

Answered: 11 Skipped: 6



Raising awareness of invisible illnesses in schools – How?

People talk
about their
experiences with
schools

Advice on how to
talk to young
people about
their illness

Understanding
that every
student is
different

Visits from
medical staff

Make it part of
the student
teacher
training





Workshop 1

- What are your Top 10 Tips which will be most useful for you in ensuring a child gets the support they need?
- What support is already provided/do you provide?



top 10





Workshop 2

- Young people – Designing a logo and choosing a name for the project.
- Parents and Teachers – Building bridges. Read the scenarios and discuss how best to handle the situations.



Workshop 3

- Who are the key people we need to target our information at?
- How do we do this?





A

ACTION

C

CHANGES

T

THINGS

