

Listening to the Voices of Children and Young People in the Citizens Council

Consultations with Children and Young People Health, Age and Cost Effectiveness

1.0 Introduction

This is the report from the National Children's Bureau on the series of consultation events with children and young people on health, age and cost effectiveness.

The National Children's Bureau, working in cooperation with Children in Wales, approached eight schools and 12 children and young people's 'out of school' groups and youth settings to carry out 20 consultation events with children and young people throughout England and Wales on behalf of the Citizens Council. 19 consultations have successfully been completed and it is hoped that outcomes from the twentieth consultation can be presented at the Citizens Council meeting on 20 November.

A total of 198 children and young people have been consulted. Of this total 102 were boys and young men, and 96 were girls and young women. There were groups from areas throughout England and Wales including Cumbria, Cornwall, Inner London, Cardiff, Anglesey and Birmingham. Using self-monitoring forms, 28 of the children and young people described themselves as from minority ethnic groups (with 7 describing themselves as 'something else'). Six of the young people identified themselves as having a disability or special needs (with a further four young people identified by their group but not themselves as having a disability or special needs).

The consultations have elicited lively and interesting discussions around the issues of health, age and cost effectiveness. The children and young people have really engaged with the topics and seem to have enjoyed the opportunity to talk about challenging issues that are not solely connected to the lives of children and young people. There was a strong level of consistency in the responses to the questions and activities across the range of ages, locations and types of group/ settings.

1.1 Who did we talk to?

The following criteria were used in selecting the schools and groups/ settings:

1. To have broad geographical distribution
2. To reflect a broad range of ages
3. To include a range of communities

4. To include diverse groups of children and young people
5. To reflect the range of levels of young people's involvement.

The groups approached can be found in Appendix One and Appendix Two gives information on the children and young people consulted.

1.2 What did we talk about?

The sessions and activities were adapted to suit each of the groups of children and young people from the overarching question:

Are there circumstances in which the age of a person should be taken into account when NICE is making a decision about how treatments should be used in the NHS?

An outline of the sessions and activities can be found in Appendix Three.

1.3 Reporting back

In addition to this written report, there will also be a video which has been filmed by a company called Mouth That Roars. The video will contain filming from a number of the consultation events and will give the members of the Citizens Council a taste of what the consultation sessions were like and a flavour of the discussions that took place. There are also individual interviews with children and young people which give the opportunity to look more deeply into their thinking about the issues. The video report will bring the ideas and discussions to life for its audience.

2.0 Summary of key findings

This is what young people said to us:

- Ideally everyone has the right to equal treatment
- However, most of the children and young people acknowledged that this is not possible and the availability of treatments may have to be limited due largely to financial restrictions. This situation requires unwelcome but necessary decision-making.
- When treatment has to be limited, most of the children and young people did not feel that age was a legitimate consideration.
- If age has to be a consideration, general health, lifestyle (ie level of activity) and potential lifestyle should also be taken into account.
- Decisions should be made on a case-by-case basis rather than a 'one size fits all' rule. This would not be fair.
- Treatments that are provided should benefit as broad a range of the population as possible.
- Some of the children and young people felt that treatments should not be limited due to ability to pay or access to them because of where a patient lives
- Treatments that have a secondary benefit or are preventative are cost effective because they can save money in the longer term.

- If treatments have to be limited, decision-making based on cost effectiveness is the fairest way to do it because it takes into account a range of factors.

3.0 Views on age and priorities in health care

As a scene setting activity the children and young people were asked to think about what are the most important issues for different age groups when they receive health treatment. The children and young people felt that, in general, all age groups need the same things. For example, all age groups need kind, responsive staff who listen to them and can relate to them; comfortable surroundings; the opportunity to have people with them if they want (family etc); and appropriate information, advice and support which is given in a manner and language that can be easily understood.

“All the same, all age groups should get the same respect.”

Girl, Hartlepool

“Everyone needs to be listened to ...”

Girl, Inner London

Besides those needs that were common to all age groups, there were others identified as being specific to a particular group. For example, young children need patient staff who will give them extra care and an environment that is welcoming and unthreatening. For teenagers, confidentiality is particularly important especially relating to issues around sex. Not being treated in a patronising manner and being treated like an adult are both key to making teenagers comfortable using health services. Many groups felt that teenagers are a ‘lost’ group who do not fit into either the category of child or adult. They felt this made health staff unsure of how to deal with them. One group felt that it is harder for teenagers to get the help they need as they do not have as many rights as adults.

Adults need staff to treat them as they would like to be treated themselves. A number of the groups saw the needs of adults and teenagers as being broadly similar while those of the very young and elderly people were more specific to their age. It was felt that elderly people require extra respect or time and to be given the feeling that they are not being side-lined or ignored. A large number of groups identified elderly people as vulnerable to being ignored simply because of their age.

The issue of how all kinds of health staff deal with people was revisited in discussions around what treatments the children and young people were aware of. In addition to clinical treatments such as medicine, vaccinations, X-rays, operations and counselling, some of the children and young people also identified treatment as being how a service user was dealt with (or treated) by staff.

“In lots of ways the emotional side of getting treatment is more important than the physical [ie getting the medicine]”.

Girl, Inner London

4.0 Views on cost effectiveness and age

To introduce the concept of cost effectiveness the children and young people were given the following scenario:

A new treatment uses metal for a hip replacement because it lasts longer than the traditional materials used. Younger more active patients are offered the metal hip because they are likely to live longer than the traditional hip replacement would last. But some older patients might be very active and so they might wear out a traditional hip replacement and should be offered a metal hip replacement.

They were then asked to consider the range of questions shown in Appendix Three.

Across the groups there was initial discomfort in having to deal with decision-making of this kind. Generally, there was a feeling that everyone should have the opportunity to have the metal hip as it was felt that everyone should have the same opportunities regardless of age and that, ideally, cost should not be a factor. There was a strong sense that people should be treated equally because people are all the same; it is right to treat people the same; and that equality is the basis of health treatment in our society.

“Everyone has a right to the same treatment regardless of age”.

Participant, Cumbria

However, a small number of the children and young people felt that younger people should be given priority due to their age.

“Young people have all their life to live and older people have already done it”.

Boy, Derbyshire

Once they had discussed issues around limited resources, the necessity of restricting the treatments available and practical constraints on health treatments, they found the discussion easier but there was more disagreement about how decisions should be made.

“It’s difficult [to make decisions this way] but you have to do it”.

Girl, Inner London

“... can’t afford to give everyone the choice – it comes down to who’s gonna need it.”

Participant, Cumbria

Through further discussion, most of the children and young people came to feel that if there has to be some restriction in treatment available, age should not be the only consideration in making this decision and that general health, lifestyle and potential lifestyle also need to be taken into account. Even if people currently had a sedentary lifestyle, some young people thought they may become active if they were given the opportunity to have the metal hip, therefore the potential for a better quality of life also needs to be recognised.

Case-by-case

It was generally felt that decisions should be made on a case-by-case basis; that a 'one size fits all' rule is not fair; and that no segment of the population is more important than another.

"You can't just look at age [when making decisions about treatment] you have to look at everything, such as their fitness and lifestyle."

Participant, Outer London

Contribution to society

A number of the groups of children and young people touched on the idea of a person's contribution to society being a possible factor in deciding who receives what treatment. Some felt those people who contribute to society in financial terms should expect to receive the more expensive metal hip replacement while those who do not should make do with the cheaper treatment.

"Young people are going to pay taxes in the future – they should get good treatment".

"But if you're older what about the money you've already paid into the country – that should count too".

Girls, Inner London

"Old people deserve the best treatment cos of their age and what they have contributed to society".

Participant, Birmingham

Geographical equality

A number of groups touched on the issue of geographical equality of access to treatments saying that where a person lives should not have any bearing on the kind of treatment that is available to them.

"There shouldn't be a difference between cities and rural areas but all should be offered the same options".

Boy, Derbyshire

Some of the groups from rural areas talked about how a rural location impacts on access to health services and the importance of facilities being located where people can actually use them. For example, an NHS walk-in centre in one rural town was situated outside the town, next to the local hospital but not in an area that people used often, which they felt defeated the object of it being walk-in.

People with money

Some groups covered the impact a person's ability to pay might have on treatment available to them. Most of the children and young people felt that it should have no impact. However, others saw giving people the choice to pay for treatment if they can afford it as a way of freeing up more funds for those who cannot. One group felt that increased taxes could be used to provide more treatment.

*"Taxes should pay for the best treatments anyone might need
Rich people should pay more tax".*

Boy, Derbyshire

5.0 Views on choice of treatments

To develop the theme of cost effectiveness, the children and young people were asked to look at choosing treatments for smoking and the common cold. The scenarios involved role-playing as members of a local health board with a certain amount of money to spend. The consultation groups were presented with a number of choices each with a price and they then had to choose what they felt were the best choices with the money available. They had to give the reasons why they chose the scenarios they did and why they rejected the others.

Overall the children and young people wanted to choose options that catered for the whole population. However, as this was not always possible due to both the options and the money they had available, they would then consider what groups were affected most by either condition. Below we look into each scenario in more detail below.

"If you want value for money, you should go for something that affects the whole population".

Participant, Cardiff

5.1 Common Cold

The children and young people were able to choose a maximum of two of the three cures shown below.

Cure One for people over the age of 75

This drug only works on people over the age of 75. People have to have an injection every year. It also seems to help people live 3 years longer. It would cost £450,000 a year to give it to all people over age 75.

Cure Two for children aged 5 to puberty

This drug only works if it is given to children at the age of five. So at the age of five a child has one injection and the drug will protect them from the common cold until they reach puberty. There are other benefits too past puberty, it can make children's bones and teeth stronger. It would cost £450,000 a year to give it to all 5 year olds.

Cure Three for the whole population

This cure can protect people of all ages from the common cold but it only really works after 10 years of treatment, so it doesn't protect young children. It would cost £610,000 to give it to the whole population (or £450,000 to give it to the over 65's -).

Cures one and two were the most popular choices in this scenario. The children and young people generally felt that the common cold affected young children and elderly people the most as they felt they have weaker immune systems.

Cure two was also popular because it helps with other aspects of health and can help build stronger children and young people. Its multiple uses were seen to be an effective way of using funds and could help to prevent other health problems. The fact that it only requires one injection was also favoured as the general consensus was that no one likes to go for injections.

Some of the children and young people felt that because cure two would set people up to be healthier in later life there would be more chance that they would not need to use the same level of financial resources for health later on: a cost effective use of funds now to save money in future.

Many of the children and young people didn't like cure three because it does not protect young children and it would not immediately assist elderly people because it takes 10 years to work. However, most of the children and young people still saw option three as positive in that it is purported to work for the whole population, but they regarded it as too expensive and limited in its use.

"They're all good so if you had the money you'd choose all, but you don't so you have to help the whole population".

Boy, Birmingham

This scenario rekindled significant debate about age, an individual's contribution to society and quality of life in a number of the groups. Some of the children and young people felt that as elderly people are not giving money to the economy, prolonging their life is not cost effective because there is no benefit to society. Others felt that even if an elderly person's life should be prolonged the chances are that the quality of their life would be low and

money would be better spent on giving treatment to a younger person who has a greater chance of good quality of life.

“... and after 75 (and from 55) they are not giving money to the economy so in terms of cost effectiveness [cure one] is no good”.
Boy, Kent

A number of groups raised the possibility that the age of people making decisions will have an impact on their choice and they would make decisions influenced by their own age even if they are aiming to act for the good of the whole population. If the decision makers had children themselves or were getting older, these groups felt that their choices could be different.

5.2 Smoking

The children and young people were able to choose three of the five options for treatment.

Option 1

Spend it on a drug that helps people to stop but cannot be given to people under 18 because there is not a licence to do this. This would cost £200,000 a year.

Option 2

Spend it on health education in schools and youth clubs to stop young people from starting to smoke. This would cost £200,000.

Option 3

Spend it on treatment for people with smoking related diseases. This would cost £200,000.

Option 4

Spend it on local stop smoking support groups, where people can go to get support in kicking the habit. This would cost £200,000.

Option 5

Open a free stop smoking clinics in secondary schools where people can see a GP and obtain stop smoking aides like the nicotine patch and nicotine chewing gum. This would cost £200,000.

This scenario elicited a greater variety of responses than the common cold scenario. The biggest consideration for the children and young people for this scenario was about prevention for young people and through prevention making financial savings in the long run.

Options 2 and 5 were jointly the most popular. They were chosen because they are preventative options. The children and young people felt that the money was well spent on prevention particularly targeting young people as they felt that this is when people are most likely to start smoking and when peer pressure makes people vulnerable.

“...it is better to stop them before they start”. Participant, Cornwall

“The thing is to stop it before it happens”.

Participant, Cardiff

By contrast, some of the children and young people felt that these options wouldn't work because young people will not listen to health education messages and if they want to smoke they will so spending the money on them is a waste.

“... some people are not interested and won't listen and will smoke anyway”.

Participant, Cumbria

Others felt that school was not a good place to provide assistance because students tend not to listen to people who come in to give health education advice. School is the centre of peer pressure, which was cited as one of the main reasons for young people to start smoking; and getting advice in school was seldom confidential.

Option 3 was chosen by many of the children and young people because it was felt that people could get smoking related diseases from passive smoking, or just being around smokers. In general, this was the reason given rather than helping people who are smokers. However, while most of the groups felt that it was important to help people who are addicted to smoking, others felt that it was the smokers' own fault and they should not have limited resources spent on them.

“People can't take decisions for themselves once they're taken over by smoking”.

Participant, Newport

“People who smoke should be left to die anyway”.

Participant, Newport

Option 4 was generally viewed as acceptable, but it was not as popular as the above options because it did not focus on young people. It was also felt that young people would not attend a group that was not specifically aimed at them. Others felt that if people really want to stop smoking they can do it by themselves without having to go to a support group.

Option 1 was often seen as replacing one addiction with another and therefore not a viable option. There were comments about it actually encouraging young people to smoke because they could rationalise their smoking by thinking that when they are 18 they can take the drug and stop. In addition, a number of groups felt that, as most people start smoking before the age of 18, this option comes too late.

“It's bad to offer treatment to current smokers because they will think it's all right if I start because they'll cure me'.”

Girl, Inner London

Some groups recognised that a number of their choices were based not on positive reasons for a particular option but to avoid other options. They saw this as a problem in making decisions based on cost effectiveness and with a set amount of money.

“[Our] choices were made mostly to avoid certain options – so it’s a negative choice rather than positive”.

Girl, Inner London

6.0 Conclusions

The children and young people consulted engaged with the material very well and seemed to enjoy the challenge of the scenarios in particular. Initially there was some discomfort in looking at cost effectiveness in relation to health as it requires potentially difficult decisions. However, once they got used to the concept they felt that this sort of decision-making is as fair as possible and is better than basing decisions on other factors such as a person’s age.

They felt that they were being asked to be involved in complex decision-making scenarios. They also came to an understanding of how critical issues of limited resources and cost effectiveness are for the health service. A number of the groups commented that they appreciated the opportunity to be involved in consultation events of this kind and felt it was important for views from all kinds of people – including children and young people as well as adults and professionals – to be taken into account on such issues.

While it was often easier for the children and young people to concentrate discussion on their personal experiences, the strong concern the majority expressed for elderly people and how they are treated was an interesting finding. Their opinions may go some way to dispelling popular opinion that young people are only concerned with themselves.

The children and young people’s ability to think in the longer-term was also interesting and surprising that it even came from several of the primary age groups. They felt that preventative treatment was very important as a way of improving people’s health; expectations for health; and the health of future generations. They also saw it as an effective use of limited financial resources because a healthier population could save money on health treatments in future.

Rachel Monaghan
Co-ordinator Young NCB
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