Young people’s views on involvement and feedback in healthcare

Report of a brief on-line survey of young people undertaken for the Children and Young People’s Health Outcomes Forum

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Key themes

- Young people make use of a wide range of health services and feel able to rank how well they meet their needs. The primary importance of general practitioners (GPs) and pharmacies was clear.

- Young people are keen to be involved in overall design and commissioning of health services but also in practical aspects such as design of physical spaces.

- The young people responding to the survey felt they needed more information on their rights and how to complain.

- They felt helpless about their voice actually making a difference and needed reassuring that positive action would result from a complaint. As a result, significant proportions of young people would have liked to make a suggestion or complaint but did not.

- They expressed an interest in relatively private and personal ways of having their views heard (through questionnaires, anonymous complaint systems etc)

Background

Promoting young people’s participation in the design of health services is critical to the mission of the Children and Young People’s Outcome Forum (CYPHOF). The CYHOF is an independent advisory group of professionals and representatives from across the children’s sector who work together to improve health outcomes for children and young people. The evidence base suggests that young people’s involvement with local patient voice organisations is limited.¹ ² ³ Their experiences of complaints systems in some services has been reported as poor. ⁴ Yet improving their experiences is a priority for the whole of the NHS.
In particular the CYPHOF is committed to ensuring useful engagement with children and young people so that their views are asked for, listened to and acted upon, and in ensuring that children and young people’s services are accountable at a local and national level.

To support the work of the CYPHOF, the Association for Young People’s Health undertook a small online survey in September 2014 to collect young people’s views on how they like to be involved in service development or improvement, and how they feel about giving feedback or complaining about health services they have received. This was to inform the CYPHOF’s work on accountability which will feed into the CYPHOF’s Annual Report for 2014/15. The survey aimed to collect young people’s views on key accountability issues including: ‘Who designs the service?’ and ‘Who can you talk to when something goes wrong?’

Methods

A short online survey was set up using Survey Monkey, consisting of two demographic questions (age and gender), eight closed questions on how young people can be involved in service development and what they thought about complaints and accountability systems, and two open-ended questions to elicit more views.

The survey went live on Survey Monkey on 2 Sept 2014 and was closed a week later on 9 September 2014. The link was publicised using social media and email networks, specifically targeting organisations with contacts with young people interested in health issues. During this time 98 respondents completed the survey.

Sample description

The majority of the people responding were aged 15-19 (n52), with the remainder aged 20-24 (n31) and 10-14 (n15). Two thirds were female (n69), and three people did not give their gender. As we know nothing more about the sample demographics we cannot claim that they are representative of their age groups. Thirty-seven respondents were users of services for people with long-term conditions, which is more than we would expect in the general population. The results should thus be regarded as illustrative of some of the things that young people say on these topics, rather than as quantitative evidence. We have thus resisted the temptation to present percentages as this would imply representativeness. However, where the results confirm what we already know from other surveys, we can be more confident about them.

Results

The first question asked the respondents whether they used a range of health services and how well these met their needs. Figure 1 presents the number of respondents who gave a response indicating they used each service (ie, excluding those who replied that they did not use the service or the service did not exist in their area). The majority of respondents (95 out of 98) felt able to rate the services of their GP, closely followed by those who had a view on pharmacies (87 out of 98). These services were widely available and well used by young people. The services they were least likely to have a view on included counselling and sexual health or genitourinary medicine (GUM) clinics.

Figure 1: Number of respondents who indicated they used different health services
Young people were largely positive about how well each of these services met their needs, although there was some variation. Two thirds or more felt the service they received met their needs “OK” or “very well” (excluding those who replied that they did not use the service or the service did not exist in their area). Table 1 shows that pharmacies came out highest in meeting needs, closely followed by GPs and hospitals.

Table 1: Rankings for how well different services meet young people’s health needs, based on those saying ‘OK’ or ‘very well’

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Service</th>
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<tbody>
<tr>
<td>1</td>
<td>Pharmacies</td>
</tr>
<tr>
<td>2</td>
<td>General Practice (GPs)</td>
</tr>
<tr>
<td>3</td>
<td>Hospital</td>
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<tr>
<td>4</td>
<td>Specialist services for long-term conditions</td>
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<tr>
<td>5</td>
<td>Sexual health or GUM clinics</td>
</tr>
<tr>
<td>6</td>
<td>Counselling services</td>
</tr>
<tr>
<td>7</td>
<td>Accident and emergency</td>
</tr>
</tbody>
</table>

(note all services were rated ‘OK’ or ‘very well’ by two thirds or more of the respondents who used them)

Young people were given six options on how they would like to give their views about health and wellbeing. As Figure 2 shows, respondents favoured questionnaires followed by small focus groups (less than 10 people). Their least favourite options were large focus groups and meetings led by adults.
Figure 2: How do you think it’s best to seek young people’s views about health and wellbeing? (rank from best-1 to worst =6) (n98)

Frequency of response

When this question was broken down by age group (10-14, 15-19 and 20-24), all groups showed preferences for questionnaires and small focus groups, followed by meetings and activities. In the case of the younger and older age groups they said they would prefer leadership for these activities to be equally shared between adults and young people. The middle age group, in their mid-teens, expressed a preference for groups led by young people.

Figure 3 shows that respondents were keen to be involved in most areas of service design but especially in identifying the need or problem the service was designed to address. Their second and third preferences were for designing the physical space and designing publicity materials.
The majority of respondents (57 of 96 respondents) said that they had wanted to make a suggestion or complaint at some point in their contact with services, but had not done so. The others did not know or replied no. Only one fifth of the group reported having made a complaint (19), and of these more than half reported that nothing happened as a result (12). Most simply received an acknowledgement of their complaint (7).

Three people had more satisfactory experiences when complaining. In one case the service had explained how they planned to address the complaint, in the second case the service had explained that changes had been made as a result, and in the last case the young person could see that obvious changes had been made to improve the service.

When asked what would stop them from giving feedback or making complaints about services, Figure 4 shows that of the 89 respondents who answered the question most thought that nothing would change (65) and/or that no one would listen (45). Others replied that they feared repercussions, did not know that they had the right to complain, or did not know how to complain. When these results were split by age group, it was the older age group who were most concerned that they would be disadvantaged by complaining.

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1 76 young people answered the question “If you have made a complaint, what happened?” of whom 57 then ticked an option saying “I’ve never made a complaint”. The remaining 19 are assumed to have made a complaint.
Some said “I’ve already been treated like rubbish by people in power of the service I’ve complained about”, and that “I think I will be stereotyped as a complainer and that they think I don’t appreciate the NHS and my care”, and “Raised concern and told if raised another concern wouldn’t be allowed to use service again”. However, one respondent said “Nothing would stop me giving feedback”.

The key question is what would make it easier to give feedback or make complaints? The answer to this stressed the importance of anonymity and belief that something would happen as a result. Figure 5 shows that 65 of the 92 respondents to this question opted for ‘A way to complain without talking to a staff member’. Responses also stressed the importance of having clear information available to let them know what their rights were and how to complain. Again the young people emphasised that their concern that they should not be penalised or treated differently for making a complaint.

**Figure 4: What would stop you from giving feedback or making complaints about services? (tick all that apply) (n89)**

**Figure 5: What would make it easier to give feedback or make complaints about services? (tick all that apply) (n92)**
Respondents stressed the importance of “Having people actually read and take complaints seriously!”, and “Having people who actually would or have used the service being in positions to make changes and take complaints, rather than someone who is just guessing what is actually needed”.

They also asked that services should “…take us seriously. Get more young people involved in roles in these services. Ask for regular feedback, and make it easy and quick to give. Don’t be invasive (especially through sexual health services). “

One noted that “Most people won’t speak up because they don’t’ want to make a fuss, it isn’t worth it. There needs to be a mass change. A change in the way we read and interpret opinions. Not seeing the individual as someone who just wants to complain. But someone who would like to see genuine, positive change.”

**Conclusion**

Young people are keen to provide input to the design and commissioning of health services intended for them. They generally have positive opinions of the health services they use but see room for improvement and want a chance to input their views.

These responses may not be representative of the voice of all young people but they tell us that we should improve accountability systems. Their answers to our questions suggested that information for young people on their rights and the systems for complaint need to be more visible. Young people also want to be able to give feedback or complain anonymously. This resonates with what we know from other work on the primary importance of confidence in confidentiality when engaging with services in adolescence and early adulthood.

The general gist of the responses concur with the recommendations in the You’re Welcome quality criteria for providing youth friendly health services. For example, among the ten quality criteria themes are a number of references to providing clear information on how to make suggestions or complaints about the service, and how to reassure young people about confidentiality.

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**For more information please contact AYPH at**

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References


