

REPORT OF THE CHILDREN AND YOUNG PEOPLE'S HEALTH OUTCOMES FORUM 2014/15 – Accountability Theme Group

Forum Co-Chairs:

Professor Ian Lewis

Christine Lenehan, Director, Council for Disabled Children

Dr Sheila Shribman [interim co-chair]

ACCOUNTABILITY

Summary of key questions

The key questions that the Forum suggests organisations should be asking themselves on accountability, and that their Boards and regulators should be checking as a matter of routine, are as follows:

- Are we doing enough to identify children and young people with health issues and ensuring that they are brought to the attention of the relevant part of the health system?
- Are we doing enough to ensure that children and young people are receiving health services centred around the individual which are properly co-ordinated?
- Are we providing sufficient information to children, young people and their families about the standard of services that they should expect?
- Are we making the complaints system sufficiently accessible to children, young people and their families?
- Are we engaging sufficiently with children, young people and their families to get their views?
- Are we acting on what children, young people and their families tell us?
- Are we telling children, young people and their families what changes we have made as a result of their feedback?
- Are we able to demonstrate that we are accountable to children, young people and their families and how do we respond when concerns are raised?

Challenging the system to ensure children and young people's services are accountable

In the Forum's first Annual Report we challenged the system to ensure that children and young people's services are accountable at a national and local level. The feedback that the Forum has received since then tells us that children, young people and their families often do not understand what services they have a right to expect, who is accountable for the standard of service that they receive, and what redress they can seek if they are unsatisfied.

We all want to see high quality services and agree that can best be achieved by commissioners, providers and regulators working closely together and encouraging children, young people and their families to provide feedback that can be used to further improve services. We want to avoid children, young people and their families having bad experiences of the health service but, if they do, we want services to learn about what went wrong and to ensure that it is not repeated with future patients.

The Association of Young People's Health's (AYPH) survey on Young People's Views on Involvement and Feedback in Healthcare (attached as an Annex to this document), undertaken for the Forum, highlighted the following points:

- Providing the opportunity for children and young people to feedback their views is most important – this needs a mechanism which is easy and supports open/honest feedback (e.g. anonymous questionnaire);
- Ways to encourage honest feedback: (i) providing easy opportunities for anonymous feedback; (ii) clear statement that children and young people have a right to complain and how to go about it; (iii) reinforcing belief that they will get a response;
- Strong appetite from children and young people to be involved in all stages of service development – particularly in identifying the problem;
- High proportion (60%) of respondents had wanted to make a complaint about a service but didn't – major factor is thinking that nothing will change as a result or fear of being labelled as a 'complainer'. There needs to be a change in culture so that someone who complains is not branded as a 'complainer' but rather as someone who is positive about making a difference;
- High value of having service users themselves involved in responding to feedback (i.e. someone who understands the experience of using a service is best able to interpret feedback / consider how it is applied); and

- Importance of 'You said, We did' in encouraging further dialogue and more feedback – positive reinforcement.

The Forum's discussions on accountability raised a number of challenges to the system:

1.Lines of accountability: who is responsible for identifying, referring and coordinating?

Where does the buck stop? Where a child or young person is receiving treatment from one health professional then lines of accountability are clear. However, where a child or young person requires a range of treatments/care, and these needs to be co-ordinated around them, the lines of accountability become less clear. Similarly, where a child or young person has a problem which is impacting on their health and which is not being addressed it can be unclear who is accountable for ensuring that their problem is addressed.

It is all too easy for children and young people with health issues that need addressing to avoid contact with the health service, as unlike adults they are often reliant on others to take them to their GP etc. This can result in children and young people living with unaddressed health problems which impact on their daily lives, including their education, and which get worse over time making them more difficult and expensive to treat. The Forum's view is that organisations should make pathways of referral or concern clear. That will then allow any professional, whether they be in the education or the health sector, that becomes aware of such an issue to ensure that the individual's health problem is brought to the attention of the relevant part of the health system. For example, where a teacher notices that a pupil has a health problem they need to know how to get their concerns passed to the right part of the health system which deals with it. They have a vested interest in doing so as an individual's health and educational attainment are interlinked.

It is also far too easy for children and young people in contact with the health service to slip through the gap between services. This can result in children, young people and their families becoming frustrated at the lack of co-ordination in a system aiming to provide child centred care. If a complaint is made it is dealt with by one part of the health system, missing the point that it is a complaint against how the system works together, rather than a complaint about one part of it. Health professionals all have a responsibility to ensure that a child or young person does not slip between services and that services work in a co-ordinated manner. GPs are well placed, as they are most likely to see children and young people on a regular basis, to ensure that care is co-ordinated and also to prevent unnecessary escalation through the system (the pyramid model).

2. Improve access to meaningful information about who should be doing what

There needs to be improvement in the information available to children, young people and their families about the services that they can expect to receive. They need to be able to judge whether the standard of service that they receive matches that which they should receive.

This can be addressed by making available to them information on the standards that the service being commissioned should meet. Furthermore, they should have access to the feedback that has been received from those previously using the service. Where that feedback identifies faults with the service or suggests improvements then it should be accompanied by the service's response.

3. Develop a culture of engagement

There needs to be a culture of engagement by services with children, young people and their families. Children and young people are no different to adults in having views on the services that they receive, but services need to tailor how they get feedback from them. This may take extra effort, taking into account the different age groups involved, but is not difficult. It is about being proactive in getting feedback, positive and negative, which can be used to improve services. Being positive about seeking feedback and showing that such feedback is monitored and acted upon should have positive long term results, such as leading to a reduction in complaints. However, it should not be made any more difficult for a child or young person to complain than for an adult to do so.

At all levels the system needs to demonstrate how children and young people are kept informed of their rights and responsibilities, given information about relevant services and that their views are sought and acted upon.

ANNEX

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

October 2014

Ann Hagell, Emma Rigby and Lindsay Starbuck

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

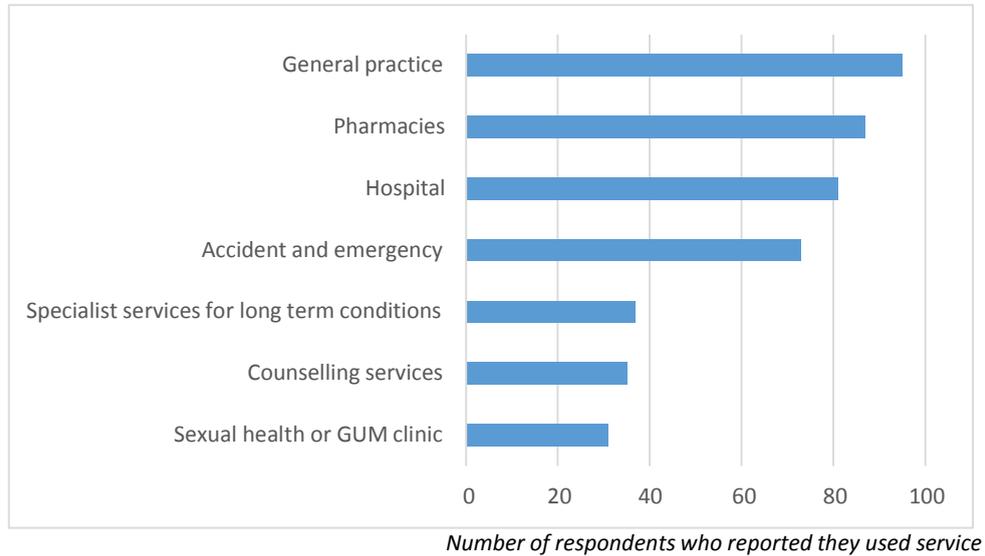
The majority of the people responding were aged 15-19 (n52), with the remainder aged 20-24 (n31) and 10-14 (n15). Two thirds were female (n69), and three people did not give their gender. As we know nothing more about the sample demographics we cannot claim that they are representative of their age groups. 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 (i.e. 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 show 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’

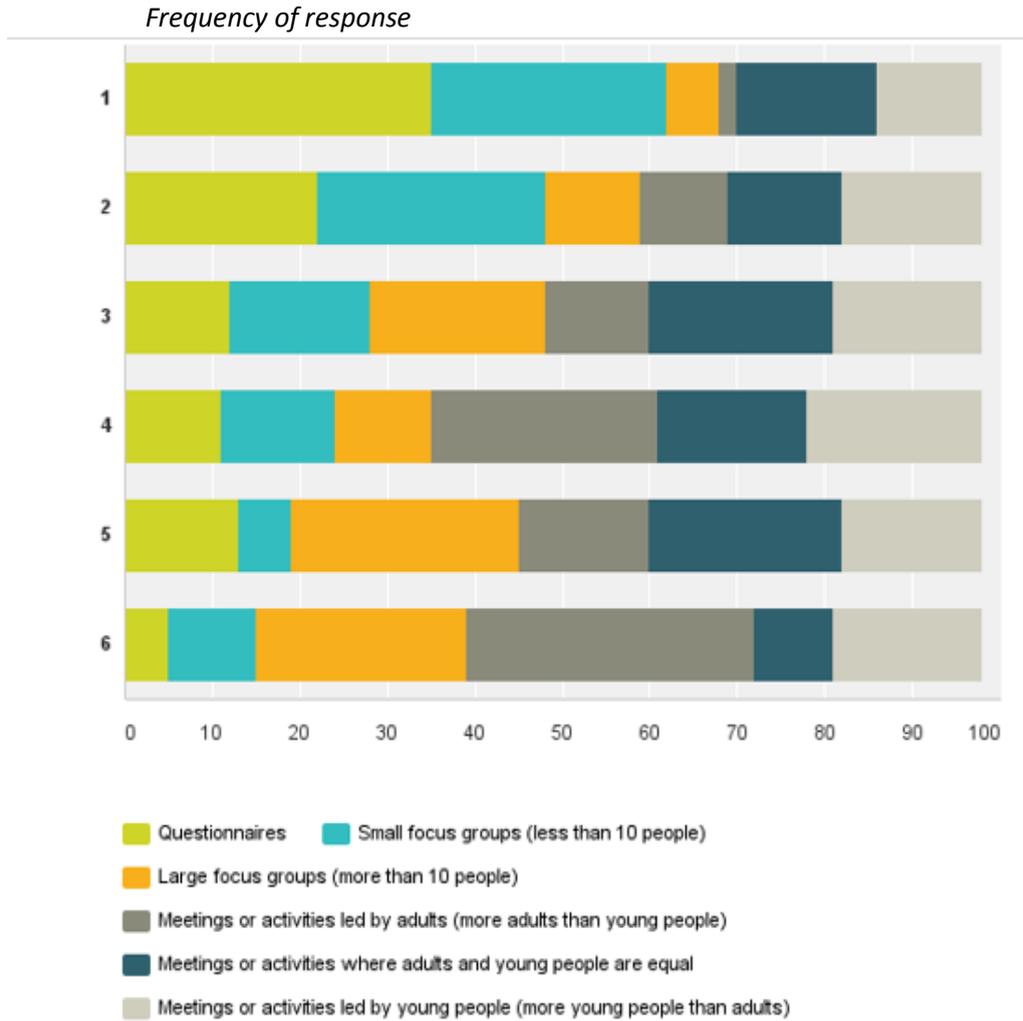
Ranking	Service
1	Pharmacies
2	General Practice (GPs)
3	Hospital
4	Specialist services for long-term conditions
5	Sexual health or GUM clinics
6	Counselling services
7	Accident and emergency

(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.

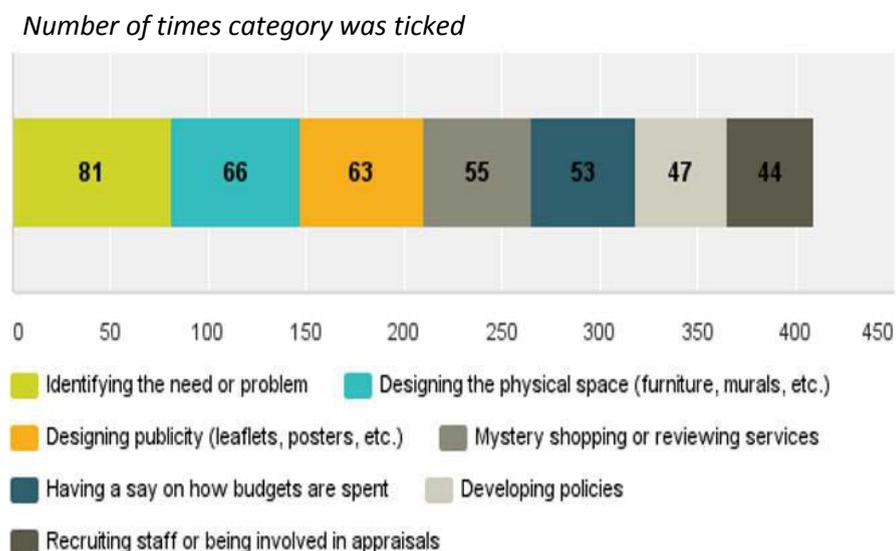
Figure 2: How do you think it's best to seek young people's views about health and wellbeing? (rank from best-1 to worst =6) (n98)



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.

Figure 3: What part of service development or improvement do you think it's useful for young people to be involved in? (tick all that apply) (n97)



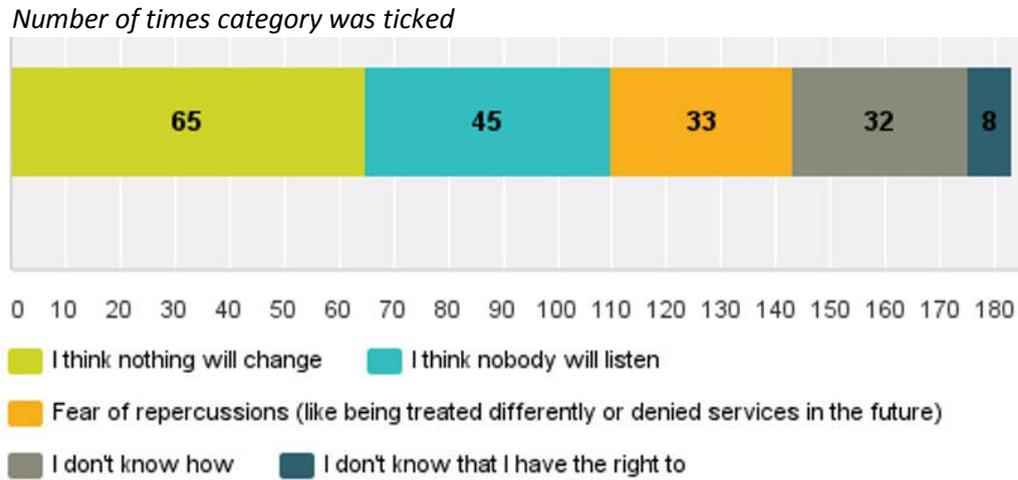
The majority of respondents (57 of 96 respondents) said that they had wanted to make a suggestion or complaint at some point in their contact with services, but had not done so. The others did not know or replied no. Only one fifth of the group reported having made a complaint (19)¹, and of these more 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.

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.

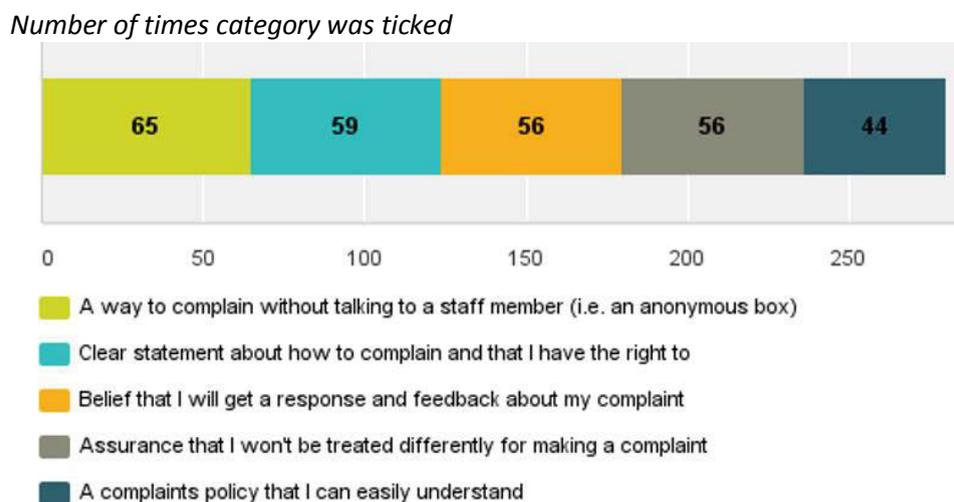
Figure 4: What would stop you from giving feedback or making complaints about services? (tick all that apply) (n89)



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 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.⁵ 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.

For more information please contact AYPH at:
info@youngpeopleshealth.org.uk

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References

- ¹ La Valle I, Payne L, Gibb j and Jellicic H (2012) *Listening to children's views on health provision*. London: National Children's Bureau.
- ² Blades R, Renton Z, La Valle I et al (2013) *We would like to make a change: Children and young people's participation in strategic health decision-making*. London: Office of the Children's Commissioner
- ³ Patient Experience Network (2013) *Improving patient experience for children and young people*. PEN/NHS England
- ⁴ Street C, Anderson Y, Allan B, Katz A, Webb m and Roberson J (2013) *'It takes a lot of courage: children and young people's experiences of complaints procedures in services for mental health and sexual health including those provided by GPs*. Office of the Children's Commissioner
- ⁵ Department of Health (2007) You're Welcome Quality Criteria, downloadable from www.ekhft.nhs.uk/EasySiteWeb/GatewayLink.aspx?allId=215250