NHS Digital Strategy Consultation

Aim

The Association for Young People's Health (AYPH) was commissioned to support the engagement of young people and parents in the development of the new NHS Digital Strategy For Children and Young People. The aim was to ensure their views were captured so the strategy responds to their priorities and perspectives. AYPH described the main concept of the strategy as 'an interactive virtual space that could include young people's GP appointments, visits to hospital, vaccinations, school health information, as well as blood test results,' adding 'it could also include information about local health services and could tell them if there was a flu outbreak.'

Methods

The consultations with young people and parents were carried out separately and involved a mix of online surveys, focus groups and individual interviews. The parents and young people were not related.

Young people's survey and focus groups

AYPH conducted a survey to find out young people's views about the NHS digital strategy. The survey ran from late January until the end of February 2016. 30 young people completed the survey and many gave detailed written responses to questions. The proportion of respondents' ages were 11-14 (3.33%), 15-19 (40%) and 20-25 (56.67%). 56.67% also identified themselves as having a longterm condition.

In late February, the AYPH Participation Coordinator conducted a focus group at Young Minds, a voluntary sector organisation that supports and involves young people with mental health issues. The group had a general discussion about the concept of the digital health record for young people as well as an in depth discussion about confidentiality, an issue that come up repeatedly on the survey. The Participation Coordinator also conducted a phone interview with a young person supported by the organisation Together for Short Lives and a focus group with CHIVA, a charity offering support and services for families with children affected by or infected with HIV and AIDS.

A summary of the findings from the survey and focus groups is presented below. It includes both quantitative and qualitative data. There is also a brief analysis of the results at the end. This report focuses primarily on the concerns of young people. We have done this not because the young people were overly negative about the digital strategy but because in the context of this strategy already having been agreed, we felt it was more important to highlight the concerns of as many young people as possible, especially those from marginalised and stigmatised groups to ensure they are being addressed as it is developed. The full results of the survey can be provided on request.

Survey and focus group data

How do young people think the system currently works?
- There is a lack of clarity/awareness about where information is currently stored and what is actually shared between medical professionals.
- Only 7% of respondents thought nothing was shared
- But only 10% said that when they see a health professional 'they know all about my health condition' and 37% said 'they know nothing about my health condition and I have to repeat my story'.
- When asked about the entire concept of accessible digital health records, one commenter said 'I thought it was already accessible'

Accessing information through the child digital health records:

Accessing my own information

- Good
- Bad
- Wouldn't make a difference to me
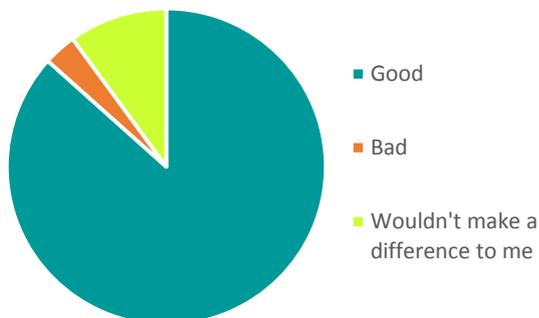
- Almost 87% of respondents thought having access to their own digital health record would be a good thing for them. The number of positive responses decreased to 50% when asked about parents accessing this same information.

- Amongst the 50%, one respondent wrote, 'They would be armed with all the information and facts, as I would be, and could support me in the best, most effective and safest way possible.'

- Of the 39% who responded it would be bad, one wrote, 'Some things are

Parents accessing my information

Good · Bad · Wouldn't make a difference to me
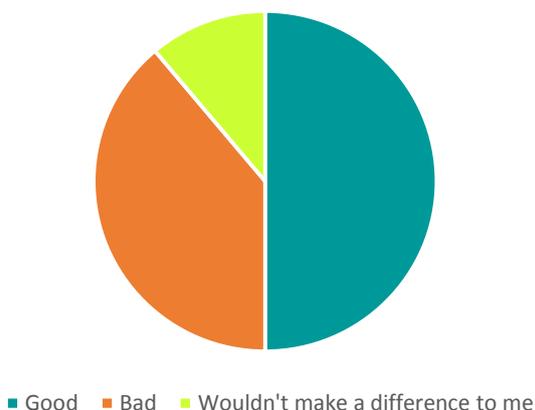
private and I don't want them knowing, such as things to do with gynae issues. I'd want to be selective so they only could see what's relevant with my permission'

'Any system that automatically spreads information to the parents of an individual without the individual's permission *cannot* claim to be confidential, regardless of whether that individual is a young person' – young person

How much information do young people want?
- 80% of respondents said they would want to have access to everything on their medical records
- In focus group and on the survey though, more than one young person with mental health issues expressed concern about having all this information.
- A survey respondent said 'I'm also worried that seeing what they are saying might impact my mental health negatively or be triggering.'
- A participant in the Young Minds focus group talked about the fear of 'becoming obsessive' about looking through the notes.
- Another Young Minds focus group participant said it could actually ease the anxiety of not knowing what's being said about you in your medical record.
- There were also questions about existing laws as young people with mental health issues understand that they aren't currently allowed to see *everything* written about them.

We asked young people what they thought the app/service should allow them to do? The options were: *book appointments, get test results, Control what information about me gets shared and with whom, write my own notes about how I'm feeling between appointments and find out about local services.*
- Young people responded positively to all the suggestions on the survey.
- They also suggested that being able to give feedback about services should be easier and should be incorporated into it.
- One focus group participant was hopeful that this could be a useful tool for young people who are transitioning into adult services, making it possible to take more control of their own treatment/condition and work alongside parents to do this.
- Freedom from having to repeat their personal story was another positive benefit.
- Several respondents wrote about how they feel unable to take everything in or remember everything that is said to them at an appointment and thought this could help.
- One respondent wrote that it would be good to be able to share the information with voluntary sector organisations that support on specific conditions.

What are young people's concerns?
- There was widespread concern amongst respondents about a lack of security, information being leaked or hacked. This was asked as an open question with no answer prompting.

- There was also a general concern about who this information would be shared with and who would be deciding who has access.
- There were more specific concerns about the information being shared (or leaked) where young people don't want it going, such as schools, insurance companies and even journalists.
- There was also concern about which medical professionals have access.
- A young person in one focus group expressed concern that some young people are unaware about how much they already share online i.e. giving their facebook password to friends. There is a general lack of awareness/attention paid to privacy settings on the internet.
- What kind of language will this be written in? Medical terminology and jargon? Will it be young people friendly?
- Who decides when a young person is ready to take control? What happens to a young person's right to confidentiality before this time?
- Who would this be useful to? Someone who goes into hospital once for tonsillitis might not engage the way someone with a longterm condition will. But then if it includes things like sexual health and mental health, everyone needs to be made aware of all that information being out there about them.

> 'I wouldn't want my dentist to know about my sexual health history' – young person

Suggestions to make young people feel safer/more at ease:
- Lots of security measures! Passwords etc.
- Young people should grant access to medical professionals they trust – opting-in instead of opting-out as a starting point
- Young people with long term conditions were keen to be able to add their own information and notes – they felt like experts on their own conditions and felt they could inform medical staff
- Add an easy to use glossary of terms to decipher any medical language

> 'Technology is good but you never know' – young person

Communication is key according to the Young Minds focus group!
- Work with young people from an early age to help them understand how this works and how it affects their rights. This could be done through schools and youth clubs as well as through NHS services.
- The right to confidentiality and the available security features need to be explained over and over to help young people understand how this system is different.
- Train peer educators to explain this information to other young people.
- Provide very simple and clear tutorials on how to use that explain all the security functions
- Needs to be some way to speak to someone 1-to-1 about this when you have concerns
- Also needs to be a way to complain/give feedback when things go wrong! As one participant said

Young people's response to the suggested names (Digital Child Health Hub or Health and Wellbeing Hub)
- Not great names. They are clinical and too long!
- Why child? What about youth/young people?
- It should be easy to remember and catchy – an acronym would be better
- The name does matter and it needs to sound less corporate for young people to use it

- It should have the word 'my' or something similar that makes it clear that the person/patient is at the centre

CHIVA focus group 29/03/16

10 young people and 2 workers, led by AYPH Youth Participation Coordinator

CHIVA is a national charity for HIV positive young people. The young people who took part in the focus group are members of the CHIVA Youth Committee.

All the young people said they would want access to their medical records and generally thought it was a good idea to centralise and digitise the records.

The young people were worried about their HIV status being visible to all medical professionals they see, even if they were getting help for something completely unrelated. They'd already had a variety of negative experiences, such as feeling judged or stigmatised when medical professionals found out they were HIV positive. This was especially a problem in primary care settings where it was felt that a whole host of assumptions about their lives were made by GPs and other doctors when they found out their HIV status. They also talked about the unnecessary sympathy/pity that often comes when professionals without much knowledge of living with HIV find out.

As privacy and confidentiality were such important issues to the participants, we spent the session talking about what protection could be put in place to make them feel safe with the new system.

We discussed privacy settings on social media as a way of thinking about how this should and shouldn't be managed.

The good re: privacy online:

- On Facebook, you have to actively accept a friend before they can see your timeline – you can choose to accept or decline
- There are periodic reminders on FB to check your privacy settings
- Other websites ask for a password and a security question

The bad re: privacy online:

- Default setting on FB is public – you only get privacy once you do something about it
- Having to opt-out of data sharing
- Privacy information on Facebook is in a long list of terms and conditions that "nobody reads"
- Youtube is really difficult to make private – you have to be persistent

The participants felt strongly that their current right to confidentiality and privacy needs to be rigorously maintained with the new system. One participant said that her parent asked her GP for some information and the GP wouldn't share it without her giving consent. This made her feel good about her GP and is how information should be shared.

We had a long discussion about the potential conflict that might come up with parents/carers having access to medical records. Some felt there should be a strict age cut-off and others felt it should be up to young people to decide with their doctor.

The participants came up with the following ideas and suggestions about how the good aspects of online privacy could be applied to the digital health records to meet their right to confidentiality:

- Privacy settings should be very clear and easy to understand – bullet points or something that is easy to read – not buried in terms and conditions
- There should be reminders sent about privacy settings, especially to teenagers who might not want their parents/carers to see everything
- There should be passwords + security questions
- Medical professionals access to the records should be controlled by the young person – like accepting a friend request
- Each aspect of health should be controlled separately (physical, mental, sexual, etc.) and young people should have to grant permission for medical professionals to see each one - "Dentists can only see dental records!"
- Young people should also have a say on whether medical professionals can share information about them with each other – at the very least, they should be informed when anything is being shared (like a FB notification)
- One participant gave an example of a card designed for HIV+ people that stated what would conflict with the medication they were taking instead of listing the medication the card holder is actually on (this would immediately disclose their HIV status). Everyone thought this would be a better idea than listing their prescriptions on their digital health record.

Parents' survey and case studies

The parents' online survey ran from late January until the end of February 2016. There were 159 responses. AYPH also conducted phone interviews with parents to gain more in depth qualitative data. The results of both the survey and the interviews are presented below.

Respondents' children were aged 11-14 (51%), 15-19 (58%) and 20-24 (23%). 68% also identified themselves as having a child with a longterm condition.

SURVEY

Which of the following bits of information do you think are currently shared between different health professionals (doctors, nurses, etc?) Tick as many as you think apply.

GP records – 76%
Hospital records – 73%
School health, eg height and weight – 35%
Medicines they're taking or are allergic to – 51%

When your child/young person sees a new health professional, the health professional...

Already knows all about their health condition(s) – 0%
Knows something about their health condition(s) – 35%
Knows nothing about their health condition(s) and you or they have to repeat their story – 62%
This doesn't apply to my young person – 3 %

How do you feel about having one virtual space containing all your child/young person's health information?

Positive – 89%
Negative – 10%
Can't see any advantage in it – 1%

If health professionals could share and see all of my young person's information in one place that would be...

Positive – 94%
Negative – 6%
Can't see any advantage in it – 1%

At what age do you think young people should take control over their own health records?

When they feel ready – 30%
When a health professional thinks they are ready – 13%
When they are 16 – 12%
When they are 18 – 46%

What is it currently like trying to help your young person manage their health?

Straightforward – 12%
Difficult – 83%
Doesn't affect me – 5%

Which of these would your young person find it useful to do online? (tick all that apply)

Book appointments – 85%
Get test results – 75%
Control what information about them gets shared and with whom – 69%
Find out about local services – 86%

Other suggestions from parents:

- Being able to email a health professional
- Have access to their list of prescription medications, allergies, inoculations.
- Information leaflets and even chat support groups etc, information about healthy lifestyles, contraception, relationships, managing stress.
- Emergency button for help in a mental health crisis
- Have some appointments online ie over Skype

- Status of referrals and reports

> 'Having all the information in one place will avoid having to repeat it' - parent

> When asked if parents would benefit from having easier access to their young person's health information with an online digital hub, 113 (91%) said yes and 11 (9%) said no

137 parents responded to a question on whether they had any concerns about all their young person's health data being stored in one place.

45 respondents (33%) said 'None'.

50 (37%) cited security as a concern, including hacking and data protection, and the safety of data on mobile devices which are easily lost.

24 (10%) said information sharing was a concern, including who the info is shared with (which professionals, what information might be shared, and 3rd parties eg govt/insurance companies having access to the data.

5 parents (4%) said they were concerned about the editing of data on a digital hub, including who has control and could errors be amended.

63 people responded to the question on whether there was anything else they wanted to say.

There were very varied comments, including:

- 'Right direction, can't believe it's not been done before, the benefits would be huge!'
- 'Might speed up mental health help'
- 'There would be very different responses from young people of different ages'

CASE STUDIES

> **Mother of 15-year old with Type 1 diabetes**
> Personally I think this is a great idea as we are struggling with her condition and my daughter is not compliant with her treatment. But I would be very concerned if she got sole access to it as things could really spiral out of control, medically, if I didn't know what was going on with her results and treatment. I could see access to the app being a source of further conflict. Having said that, to get results online would be very handy.

Conclusion

It is clear that young people do not have uniform views about the digital health strategy. Young people with longterm conditions and those who have regular encounters with health services were in general agreement that having centralised records and not having to repeat their story at each appointment would be beneficial. But even the category of young people with longterm conditions can be misleading because there were very different views from young people with different types of conditions.

> '**I wouldn't be a carrier pigeon between professionals like I am now'** – young person

Concerns about confidentiality were highest in relation to health conditions and issues that are stigmatised, such as mental health, sexual health and gender identity. The biggest concern was in relation to parents having unregulated access to a young person's medical information and this also highlighted the conflict of views between the two groups.

A total of 46% of parents said they wanted to maintain control of the digital hub until their young person is 18, which is not in line with current health practice, but 30% did think young people should take control when they felt ready.

Parents were overwhelmingly positive about the concept, with 94% thinking it would be good for health professionals and 89% saying they would personally find it useful. A total of 83% said they currently found it difficult to manage their young person's health.

Parents also raised key questions, including:

- **What happens to the digital hub at transition to adulthood? And what age is that?**

- **Who will present the hub to young people and teach them how to use it?**
- **What about young people who don't have the capacity to use the hub?**

To conclude, there is strong support for the strategy concept from both young people and parents, but there needs to be further thought to key issues highlighted above including ownership and control of the digital 'hub' and both delivery and communication of the concept. Fear of a lack of confidentiality remains a major barrier to young people seeking health advice and using services, so it is paramount that this is acknowledged and addressed as the strategy progresses.