

Going Digital: Testing a digital health app with children and young people with learning disabilities

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Executive Summary

Background

Healthwatch Hertfordshire worked with Hertfordshire County Council to test and evaluate a digital health app called **Hear Me Now**. Our aim was to understand whether the app could be of value to children and young people with learning disabilities as a way of managing their health in an easier way.

About the Hear Me Now app

The Hear Me Now app has been designed specifically for people with learning disabilities to support them in managing, recording, sharing and communicating information about their health.

What we did

We recruited people with a learning disability who are under the age of 25 to test the Hear Me Now app by completing several tasks independently, with the purpose of determining whether the app is accessible, intuitive and of value to children and young people with learning disabilities.

What we found

 Although the primary purpose of the app is for users to independently manage, record, and share health information and support needs with healthcare professionals, most participants were not inclined to use the app in this way.

 Participants preferred to use the app to record personal information such as their hobbies and interests. They also liked how they could customise and personalise the app to express themselves and their identity.

 All participants required support from their carer to use the app. At times the carers also found the app confusing or counterintuitive and required additional support.

 Carers of participants with greater communication needs could see the benefits of using the app to write notes and record audio and video clips to help their child communicate with healthcare professionals.

 However, carers and participants did not find it easy to share information with healthcare professionals through the app and were not convinced that clinicians would have the time or capacity to learn how to use the app.

 Carers had concerns about the safety of the app in relation to privacy, security and consent.

 Participants thought the cost of the app was too high, and difficult to justify.

 Based on this feedback, Hertfordshire County Council has made the decision to promote a range of suitable apps that will help children and young people with learning disabilities to manage their health, depending on their wants and needs. This will include apps that are free to the user.

About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HWH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

Background

We were commissioned by the Children and Young People Engagement and Digital strand of the Hertfordshire and West Essex Personalised Care Programme to test and evaluate the digital application: **Hear Me Now**.

The purpose of this work was to inform Hertfordshire County Council's decision and plans to promote the Hear Me Now app as their recommended digital application for people with learning disabilities. If selected, the app would look to complement the use of the 'Purple Folder' in cases where an electronic version is preferred over a hard copy.

This engagement was targeted towards people with a learning disability who are under the age of 25 and their carers.



What is the Purple Folder? The Purple Folder is an initiative in Hertfordshire for people with learning disabilities who are aged 18 and over. It's a tool which allows people with learning disabilities to record information about their health and wellbeing and to share this with healthcare professionals.

About the Hear Me Now app

Hear Me Now is a digital application which can be downloaded onto a mobile phone and/or tablet, and has been designed specifically for people with learning disabilities. It was developed by Maldaba, a software company specialising in web-based and mobile applications for the public and non-profit sectors. The development of the Hear Me Now app was commissioned and funded by NHS England in 2014.

Aims and purpose of the app

The Hear Me Now app was created to help people with learning disabilities to manage their health. Maldaba wanted to *"find a way for people with learning disabilities to hold on to and make sense of the information they are given about their health, and to empower and enable this community to communicate more confidently about themselves and their needs."*

According to Maldaba, the Hear Me Now app enables people with learning disabilities to:

- Capture what matters to them in a single, user-friendly place.
- Add content in their preferred format.
- Share information with carers and healthcare professionals.
- Establish better quality relationships with staff and healthcare professionals.

Key functions of the app

Maldaba promotes being able to record personal, important information about the user's health and healthcare, in a way that suits them. Examples include recording information about medication, health conditions, communication needs and support needs.

The app can also be used to include personal information such as hobbies, interests and activities. This information can be added to the app using a variety of formats – photos, videos, text and audio and by way of 'key features' within the app.

The key features are:

Key feature	Function
My Boxes	'Boxes' are created to store information that is important to the user.
Appointments	Where new appointments and reminders can be recorded.
Contacts	A place to store the contact details of friends, family, carers, and healthcare professionals, as well as sharing information between the parties.
My Week	Where the user's plans and activities for the week can be recorded.
Documents	Where documents, including letters from healthcare professionals, can be uploaded and saved.

The app can be personalised and customised to suit the user's personality and preferences, for example, by changing the font size, colours, and content.

App support

For a higher cost, Maldaba offers a training package for organisations to train staff on using the app to support users with managing information about their health.

Included in the basic cost of the app, videos and tutorials are available on the Hear Me Now website which demonstrate how to use each feature in the app. There is also the option to contact Maldaba directly should additional support be needed.

Cost

The cost to license the Hear Me Now app is £60 per year. It's worth noting that until April 2021 the app previously cost £24 each year. Organisations such as Clinical Commissioning

Groups and local authorities can bulk purchase 'tokens' which can be used to grant users free access to the Hear Me Now app.

Context and aims

In 2019/20 Maldaba worked with Hertfordshire County Council Adult Care Services to test the Hear Me Now app with adults with learning disabilities aged 25 and over.

It was agreed that children and young people with a learning disability under the age of 25 should also test the app to see if their opinions differed from the adult cohort. The aims were to:

- Identify the benefits and challenges of using the Hear Me Now app in conjunction with, or in replacement of the Purple Folder.
- Investigate whether the Hear Me Now app could improve health outcomes by helping users to “hold on to and make sense of the information they are given about their health, and to empower and enable this community to communicate more confidently about themselves and their needs” by:
 - Capturing what matters to them in a single, user-friendly place.
 - Enabling them to add content in their preferred format.
 - Enabling them to more easily share information with carers and healthcare professionals.
 - Establishing better quality relationships with staff and healthcare professionals.
- Evaluate whether the Hear Me Now app can be used independently by children and young people with a learning disability (without the support from carers being trained to use the app).
- Hear directly from those who tested the Hear Me Now app whether it would be their preferred app and method for storing and communicating information with healthcare professionals.

Methodology

We worked with Children Services, Adult Care Services and voluntary sector groups including: Hertfordshire Carer Parent Involvement (HCPI), Watford Mencap, Hertsmere Mencap, Carers in Hertfordshire, and Hertfordshire People First, to design the evaluation and recruit participants.

Following initial feedback and guidance from HCPI, we created tasks to be completed by participants independently and at their own pace, instead of holding a series of focus groups or coproduction sessions.

There were five tasks to complete, each focusing on a different key feature in the Hear Me Now app. Each task included easy read instructions and weblinks to the videos and tutorials in case they needed support.

After each task, there was a short easy read questionnaire for participants to complete so they could feedback on how they found using the Hear Me Now app. Once participants had completed all of the tasks, there was an easy read evaluation form to fill in to gather their overall thoughts and experiences of using the app, and to find out if they would continue using the app and/or recommend it to other people with learning disabilities.

In total, four people took part:

- Three out of four participants tested the app with the support of a parent or carer.
- Two of the participants were male, aged 19 and 22.
- Two of the participants were female, aged 13 and 19.
- The severity of their learning disabilities varied from moderate to severe.

We had participants who initially took part or were interested in the pilot, but decided to drop out. Reasons for this are unclear. It's also important to note that due to the small sample, feedback was limited and cannot be generalised.

Evaluation

Improving health outcomes by helping individuals to hold on and make sense of the information they are given about their health

Maldaba states that the purpose of the Hear Me Now app is to “find a way for people with learning disabilities to hold on to and make sense of the information they are given about their health, and to empower and enable this community to communicate more confidently about themselves and their needs.”

However, it wasn't intuitive to the participants that the Hear Me Now app could be used as a tool for managing their health, for example by recording information about their medication, health conditions, communication needs and support needs. Instead, participants preferred to use the app for recording personal information, such as their hobbies and interests.

Once participants were made aware of how they could use the Hear Me Now app to record and manage their health, there were mixed views as to whether the app would work well for that purpose.

“Great for putting in personal and fun information but I'm not sure about if we would use it for health reasons.”

“We would use it to record information about health, definitely.”

“I'm not sure it would be the best app for putting down health information.”

In terms of using the shared documents function, which is a tool for healthcare professionals to share information with carers and service users, all of the participants found this feature redundant.

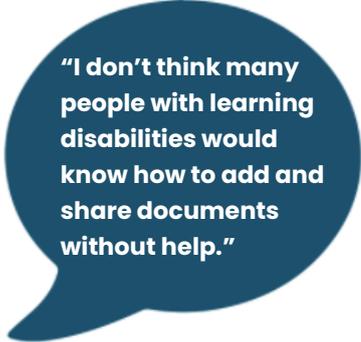
Largely this was because the participants found it difficult to use, even with support. Participants were also not convinced that healthcare professionals would use this tool, as they would need to register and log into the Hear Me Now website to use it. Participants also noted that existing ways of sharing documents such as through email, text and phone calls already works well for them.



"It was really hard to know how to share documents with someone."



"When you share a document with someone they get an email telling them to log into the website. Would staff have the time to do that?"



"I don't think many people with learning disabilities would know how to add and share documents without help."

Communicating more confidently about themselves and their needs

All of the participants liked how they could personalise the app through uploading photos, text, videos and audio clips. They also liked how the app could be customised to suit their preferences, through changing the font size, colours and content. All of the participants saw this as a key benefit of the app and a feature other digital applications and tools don't offer.



"I liked how I could add photos of my friends and things I like to do."



"I like the fun stuff I can do on the app like making videos and taking photos."

Participants primarily used the app to capture information about their personal life, interests, hobbies and activities, and didn't record information about their health unless prompted.



"We enjoyed adding photos and videos and activities and my child likes to scroll back through those to remember what we did and what we are doing in the coming days. We love it and find it very useful."



"They loved being able to put in information about their interests and hobbies. They particularly liked adding photos and taking news ones."

The benefits of the customisation were highlighted by two participants who had autism, as well as a learning disability, who shared the importance of the app allowing them to express themselves and their identity, in a way that other tools haven't been able to. One carer shared that the app provided an opportunity to start conversations between them and their child on what is important to them.

"It has been useful in generating conversations between us...about what they like and dislike and what and who is important to them."

"I want people to know what I like and don't like and what's important to me."

"I listed my family and friends and that I am autistic and have mental health problems. I think it is important for people to know."

All but one of the participants thought the app was useful in helping them to communicate their needs. For the three participants who either have anxiety and/or find it difficult to communicate their needs to healthcare professionals, this was a particularly important feature.

For the participants that used the app to better communicate their needs, they did this by recording a video or audio clip which they could play to their healthcare professional. Participants noted that this was a great way to ensure their voice was heard, especially in settings that are traditionally intimidating, as well as a way of helping them avoid having to repeat their story.

"I put in about the things I like and what makes me calm and happy. Because if I get anxious people need to know how to make me calm."

"We were thinking we could record a video explaining what they like and don't like as they can find it hard to tell the doctor this, but we could play it to them instead."

For the participant who didn't find it helpful to use the app as a communication tool, this was primarily due to them having a moderate learning disability and therefore not requiring this feature.

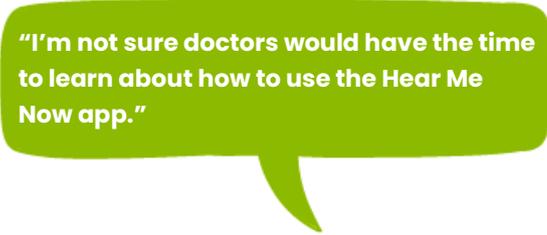
Benefits and challenges of using the Hear Me Now app in conjunction with, or in replacement of the Purple Folder

In terms of whether the Hear Me Now app could be used in conjunction with, or in replacement of the Purple Folder, participants and their carers had mixed opinions. Participants who found the Purple Folder to be impractical to take with them on a day-to-day basis felt the app could be a positive alternative. Whereas participants who used the app for recording hobbies or as a 'digital diary' felt that the app couldn't replace the

benefits of the Purple Folder. For the participant who was too young to have a Purple Folder, they weren't able to compare using the app to the Purple Folder, but did note that having a tool for storing information about their health was useful.



"The Purple Folder is so big so it's not the best. We like this as it can be on our phones."



"I'm not sure doctors would have the time to learn about how to use the Hear Me Now app."



"The Purple Folder works well for me and my doctor knows about it and how to use it."

However, all of the participants had concerns about whether the app would be used by healthcare professionals, noting the huge amount of resource that had to go into getting healthcare professionals to use the Purple Folder. They noted that even with the energy that has gone into promoting the Purple Folder, there is still more work that needs to be done. Understandably, participants had concerns as to whether healthcare professionals would also have the time or capacity to learn about the Hear Me Now app.

It's also important to note that Maldaba didn't create the Hear Me Now app with the Purple Folder in mind, meaning it's not necessarily intuitive for users to map information from the Purple Folder onto the Hear Me Now app. If the app is to be used with this intention, participants felt they would need a significant amount of support from carers and staff to be able to do this.

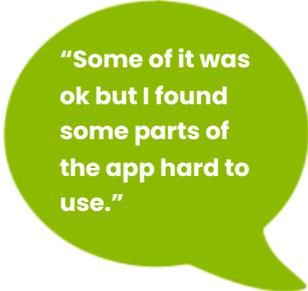
How independently users can use the Hear Me Now app

Three out of the four participants had support from their carer when testing and using the app, and for these participants they found the app relatively easy to use. However, they still encountered some difficulties when using some of the functions and features, for example the language used in the app isn't always accessible or presented in Easy Read.

For the participant who had no support from a carer, they didn't always find the app user-friendly or intuitive. What this shows is that the more independent a person is, the harder they can find the app to use. As a result, all participants felt it would be useful to have a tutorial after downloading the app to show users how it works.



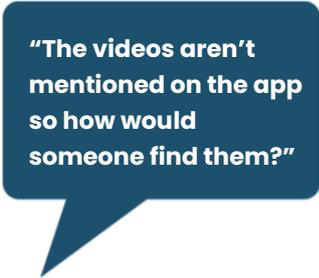
"It should come with a quick tutorial to show you what all the buttons and boxes do."



"Some of it was ok but I found some parts of the app hard to use."

The carers involved in the pilot felt that people with learning disabilities would struggle to use the app independently and would need guidance through the support of a carer and/or staff. Most of the carers felt that the videos and tutorials available on the Hear Me Now website wouldn't suffice.

Participants and carers also raised that the Hear Me Now app doesn't promote its website within the app and doesn't signpost to where users can find the videos and tutorials to guide them in using the app. Without being prompted, participants wouldn't have found the videos to support them in using the functions and features within the app. In addition, participants and carers felt the Hear Me Now website could provide more support and could be made more accessible for people with learning disabilities.



"The videos aren't mentioned on the app so how would someone find them?"



"When I went to the website it was a bit complicated."

Lastly, carers had concerns about the safety of the app in relation to privacy and the sharing of confidential information. For example, when sharing information on the app there are no warnings or information about consent, meaning a user could accidentally share private and personal information with others.

Linked to concerns about privacy, when you first download the app, the user is asked to provide consent. However, this information isn't provided in Easy Read, meaning carers felt that some people with learning disabilities might not understand what they are consenting to. Carers also felt strongly that people with learning disabilities would need support to understand what they should and shouldn't share on the Hear Me Now app to ensure their safety.

Continuing to use the Hear Me Now app

Half of the participants would continue using the Hear Me Now app as a way of recording and storing their communication and support needs. Whereas the other participants were unlikely to continue using the app, largely because they felt the Purple Folder is an already well recognised health management tool.



"The Purple Folder works well for me so I don't think I need this too."



"We use other apps which are all free and easy to use."

For all of the participants, a key barrier to using the Hear Me Now app was the cost. All participants found the price of the app very difficult to justify, this was particularly because although the app is useful to have, it's not essential, especially when there are other digital applications which are free to use, as well as the Purple Folder. One carer noted that even if they could afford to purchase the app, it wouldn't be fair if other people and families couldn't afford it, as it should be an equal system with no person or family disadvantaged.

"It needs to be free for all if it is £60 a year. Families with SEN children and adults may struggle to afford it and then it won't be accessed which doesn't help with equality of health service support."

"There's nothing I don't like about the app apart from the cost. £60 is a lot even if there is a cost but then subsidised to reduce the amount, even that would be better."

"It's not worth that price to us, not when there are other great things available for free."

Conclusion

The pilot showed that all of the participants enjoyed testing and using the Hear Me Now app, and it's clear the app has its benefits for people with learning disabilities. However, for our participants, the primary benefit was being able to record personal information, as well as being able to personalise and customise the app using the variety of formats and communication tools to suit their preferences and needs.

Although useful, the pilot indicates that users wouldn't be naturally inclined to use the app as a tool for recording and managing information about their health, and sharing this information with healthcare professionals, which is the main purpose of this app.

It's also not clear whether the Hear Me Now app could be used in conjunction with or in replacement of the Purple Folder. If this is the intention, people with learning disabilities would need support from carers or staff on how to use the app so it replicates what the Purple Folder already achieves. Participants also had concerns about how much time or capacity healthcare professionals would have to learn how to use the app, particularly as resource is still being spent on ensuring healthcare professionals use and are aware of the Purple Folder.

Another and perhaps the most crucial factor to consider is the cost and affordability of the Hear Me Now app. As mentioned, the app costs £60 every year to use, while the majority of digital applications are free or at a very low cost. Although the participants liked using the app and think it could be a valuable tool for people with learning disabilities, they didn't see the app as essential and would find it difficult to justify the high price.

Statement from Hertfordshire County Council, Children's Services, Preparing for Adulthood Board



"The Preparing for Adulthood Board would like to thank Healthwatch Hertfordshire and all the participants for their contribution in testing and evaluating the effectiveness and benefits of using the digital app, Hear Me Now. The insights provided by all those involved have helped us better understand what different service users want from an online tool aimed at supporting them to manage their health in an easier way, as well as ensured that we are promoting the right support to aid this.

The evaluation report demonstrates that although the Hear Me Now app can be used to record and share health, communication and support needs with healthcare professionals, participants were not inclined to use the app in this way. It also found that although individuals did enjoy recording personal information on the app, it required support from carers to use the app independently.

Based on this valuable feedback, the Board has made the decision to promote a range of apps that individuals can choose from depending on their wants and needs in relation to managing health information. Included within this selection there will be suitable free apps, such as the NHS app developed in the last year, as well as alternative apps that have a cost, all with the aim of improving health outcomes and independence for individuals with a learning disability. Further information will be made available on the [Hertfordshire Local Offer](#) website."

Laura Gordon and Andy Lawrence, Joint Chair of Preparing for Adulthood Board. Children's Services. Hertfordshire County Council

