

FINAL EVALUATION OF THE DOWN'S SYNDROME ASSOCIATION'S HEALTH SWAP APP



M & E Consulting December 2019



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Final evaluation of the Down's Syndrome Association's Health Swap App

1. INTRODUCTION

1.1 The Down's Syndrome Association

The Down's Syndrome Association (DSA) is a UK-based charity that aims to help people with Down's syndrome live full and rewarding lives. Since 1970, it has grown from being a local parent support group into a national charity with over 20,000 members. As well as working closely with local support groups throughout the UK, the DSA:

- runs a helpline providing information about all aspects of living with Down's syndrome including specialist advice on benefits, education and health and social care
- delivers training for professionals and carers and advice for parents and carers of people with Down's syndrome
- runs an employment programme to help people who have Down's syndrome to find appropriate employment opportunities
- and, through the DSActive programme, provides opportunities for people with Down's syndrome to lead active and healthy lives.

1.2 The Health Swap App

In 2018, the DSA received funding from the Department of Digital, Culture, Media and Sport (DCMS) to develop an App that would enable people with Down's syndrome to eat more healthily and be more active. The App is designed to help users plan for the week ahead by giving them recipe ideas and creating shopping lists so that they plan and shop for healthy meals. It then gives step-by-step instructions on how to prepare and cook the meals they have chosen. The App also aims to help users to track their physical activity and awards badges and points as users make positive changes to their health. At the At the same time, it was envisaged that using the App would improve user's digital skills, thereby reducing their digital exclusion.

1.3 This evaluation

M & E Consulting, a research and evaluation agency were commissioned by the DSA to carry out an evaluation of the App's development and effectiveness.

Aims

The aim of the evaluation was to investigate the effectiveness of the App in terms of reaching its target audience and meeting its intended outcomes of:

- enabling people with Down's syndrome to make healthy lifestyle choices
- improving the physical and mental wellbeing of people with Down's syndrome
- reducing the digital exclusion of people with Down's syndrome.



Methodology

The evaluation was carried out in three phases.

Phase one:

- We worked with the project team to design an evaluation framework that set out the project's intended outcomes and processes and the ways in which these would be measured.
- We carried out a rapid literature review to explore relevant research around how people with Down's syndrome use smart phones, tablets and apps, their health and eating behaviour as well as their involvement in physical activity. We also explored what good practice existed in developing apps for people with learning disabilities.
- We conducted baseline face-to-face interviews with seven people with Down's syndrome in order to learn more about their eating behaviour, engagement in physical activity and use of smartphones and apps.
- We designed an online survey which was sent to relatives and carers of people with Down's syndrome in order to learn from their experience of living with people with Down's syndrome and gather their views on their relatives' eating behaviour, engagement in physical activity and use of smartphones, tablets and apps. This was completed by 230 people.

In addition, we worked with the project manager to ensure that data gathered through the App would enable us to track whether people were using the App to support healthy lifestyle choices.

Phase two:

- We reviewed data collected from the App on take-up, engagement and outcomes to check the process of analysing the App data.
- We carried out an interview with the project manager to review the development of the App and draw out learning from this.

Phase three:

- We carried out in-depth telephone interviews with seven people with Down's syndrome and three carers.
- We designed a follow-up survey to carers of people with Down's syndrome which was completed by seven people.
- We analysed data collected through the App to provide an overview of the number of people downloading and how they were using it.
- We carried out a final interview with the project manager to capture his perspective on the project and draw out learning from this.



The interviews were recorded with participants' permission and subsequently transcribed and imported into NVivo, a software package that supports the analysis of qualitative data. The interviews were then coded against the key outcomes identified in the evaluation framework as well as other themes that emerged during the interviews. Analysis of the quantitative data from the App and the survey was carried out in Microsoft Excel.

Limitations

There are a number of factors which have affected the results of this evaluation and our ability to report on the project's outcomes:

- We were only able to get feedback, either through interviews or the survey, from a small number of people. As a result, the evaluation may not be representative of the experiences of the wider group of people who used the App. It is therefore possible that those who did not take part in the evaluation had different experiences of using the App from those who were included.
- Furthermore, people who took part in the evaluation may have done so because they felt more positively about the App than those who decided not to take part, resulting in some potential bias in our findings.
- The App software only captured limited information about who used the App, how it was used, what people thought of it or whether people benefited from using it.
- As contact details were not gathered through the App, we had to rely on the DSA to send out email requests to the people on their database to take part in our evaluation activities. This meant that we were only able to get feedback from a small number of App users.
- Finally, some of the people with Down's syndrome found it difficult to answer our interview questions.

1.4 This report

The rest of this report is organised into five main sections:

Section 2: Developing the App

Section 3: How the App was used

Section 4: Profile of users

Section 5: What difference the App made to people with Down's syndrome

Section 6: Conclusion and recommendations.

In reporting the data, percentages have been rounded up to the nearest whole number. In addition, due to varying sample sizes, we have indicated the numbers on which percentages are based on using "n" and missing data (i.e. where respondents did not answer a question) have been excluded from the percentages given. It should also be noted that quotes have been anonymised and some have been edited for clarity.



2. DEVELOPING THE APP

This section provides an overview of the design and development of the App and summarises what worked well in the development process and the challenges faced.



2.1 Background to the App

Funding from the DCMS enabled the DSA to begin developing an app for people with Down's syndrome which would support them to live healthier lives. Prior to this project being commissioned, the DSA had previously produced a prototype app which had been tested in a focus group with people with Down's syndrome. The development of the Health Swap App was informed by this initial piece of work as well as by the subsequent research carried out at the start of the project.

2.2 Initial research

The literature review

A rapid review of literature at the start of the project was carried out to gather information on the kind of food that people with Down's syndrome choose to eat, their levels of physical activity and their digital capabilities. The review found that:

- Over 70% of people with Down's syndrome are reported to be overweight or obese, and only 16% of adults with Down's syndrome in the UK meet the Government's weekly recommendations for weekly physical activity.
- Food choices are particularly important for people with Down's syndrome as they have a lower basal metabolic rate than that of the general population and burn fewer calories at rest or while active, than most people. ii
- However, families struggle to help their relatives with Down's syndrome to make healthier choices iii and people with Down's syndrome find it difficult to navigate the complex world of nutrition and healthy eating.
- The majority (81%) of people with Down's syndrome reported that they ate foods high in fats and sugar on a daily basis and, when asked to construct a "healthy lunch", chose fizzy drinks, burgers and chips. Only a quarter of participants chose fruit.



The review also found conflicting evidence around levels of physical activity among people with Down's syndrome. While one American study found that 60% of adults with Down's syndrome were exercising daily, vi an Australian study found that adults with Down's syndrome were typically sedentary, and many did not participate in the recommended levels of physical activity per week. vii

The review also found that previous research into the design of an app to help people with Down's syndrome to manage their nutritional habits had revealed the importance of providing positive reinforcement. For example, earning stars were found to be motivating for people with Down's syndrome. However, the researchers had also found that creating an app to influence the nutritional choices of people with Down's syndrome was a complex task and they recommended limiting the use of pull-down menus, minimising password requirements, making use of familiar icons, and designing with visual strengths of people with Down's syndrome in mind.

Baseline research

The development of the App was also informed by a survey sent out to parents and carers of people with Down's syndrome. The survey was completed by 230 parents and carers and revealed that the majority of people with Down's syndrome:

- were living at home either all the time or sometimes (73%)
- needed help planning and cooking their meals (96% 97%)
- had a fairly or very healthy diet (84%)
- took part in physical activities at least once a week (85%)
- used a smartphone and /or a tablet (87%).

The survey also showed that nearly half (46%) of people with Down's syndrome did not take part in shopping for food and nearly a fifth (16%) had an unhealthy diet:

[She likes] anything high in fat, sugar and carbohydrates.

His favourite foods are chicken, fried foods, sweet foods, basically unhealthy food craving.

Nonetheless, some described how their relative liked eating healthy foods:

[His favourite dish is] salmon with either potatoes or wholemeal pasta and salad/green beans.

He likes most foods, including vegetables and fruit.



Respondents suggested that an app could help people with Down's syndrome to eat more healthily by providing information on whether food is healthy or unhealthy, ideas for healthy snacks and reminders to help them stay motivated to eat healthily. Equally, respondents felt that providing information on local activities and a daily or weekly planner for recording physical activity as well as encouragement for being active could help people with Down's syndrome to do more physical activity.

2.3 Designing the App

The development of the App also involved bringing together a team of DSA staff with consultants from an app development team, to discuss the results from the initial research and how they could achieve the aims and objectives of the project within the three months allocated for designing and testing the App:

We hit the ground running, taking all the information [gathered] and then working through a five-day process ... there was a business analyst, myself, the DSActive project manager, a creative person and a marketing person. We got into small teams and worked on ideas and solutions of how the App would work.

These discussions resulted in the development a paper-based prototype App which was presented to a small group of people with Down's syndrome who made suggestions for its development. At the same time, an App development company was selected and given a brief to design a test version of the App, based on the feedback on the prototype. In parallel with the App design process, the project manager started developing the content for the App by creating a range of healthy meals that were appropriate for people with Down's syndrome. As a result, the project manager and other DSA staff spent a great deal of time cooking and photographing meals:

One of the things we found in our research was that many people with Down's syndrome have gluten intolerances ... We tried to find recipes that veered more towards healthy fat and good sources of protein, fruit and vegetables.

However, the project team found that many of recipes presented nutritional information in a complex way, used ingredients that could be difficult to source or were overly complicated:

As the project went on, we had to think about how we could simplify things ... thinking about when it is okay not to use a home-made sauce and actually buy a jar of something that will do and will be healthy.

Once the App was developed, a small group of people with Down's syndrome were asked to test the App and to try out the recipes and, as a result, further changes were made:

We've added multiple categories to each recipe ... so that you can find things quicker. We refined the menu so it's not so complex in terms of cuisine styles.



2.4 Promoting the App

Once the App design had been finalised, the project manager focused his time on promoting the App through writing blogs and tweeting photos with a link to the App. A series of roadshows were then organised in London, Birmingham, Manchester and Exeter where the App was promoted and people were shown how to find it and download it. The project manager reported that the roadshows were well attended and that the roadshow in Exeter worked particularly well because the local DSA branch helped to promote the event:

There was a real mix of people. We even had a physio for a group of people with Down's syndrome. Carers and parents came too, along with people with Down's syndrome. They were really interested and there was a lot of discussion afterwards. (Project manager)

2.5 What worked well

Our interview with the project manager revealed that the baseline research had been an important element in the development of the App:

The work on the research phase ... is almost 100% responsible for [the App] being so successful. (Project Manager)

In addition, the project team had a mix of relevant skills and experience which included knowledge of nutrition and psychology as well as experience of working with people with Down's syndrome and app design. Having this range of skills and experience within the team helped the project keep to its tight deadlines:

The agency was brilliant and responsive and we managed to get [the test App] out amongst a few people to do some internal testing. (Project manager)

The support and guidance provided by both the DSActive project manager and other staff at DSA were also greatly appreciated by the project manager:

[He was] a sounding board to reason and pragmatically work through anything that needed resolving. He was brilliant. And ... as a trained nutritionist ... whenever it came to content and approach, he verified that the recipes and the content that we were putting in were bang on. And then there was a lot of support from people who work at the DSA, who helped to create the recipes and take photos of the [various] stages.



2.6 Challenges

The project manager reported that the main challenges in developing the App were the constraints on time and budget which had limited the extent to which the App could be modified. He had also found managing the project on his own difficult:

It's the first time I've ever really gone almost solo on managing and planning a project of this scale ... it was hard. There was a lot of hours of just pragmatically project managing and working through it and planning.

The other main challenge faced by the project manager in developing the App was designing an App that was user-friendly and engaging while supporting people with Down's syndrome to change their behaviour around healthy eating and exercise:

Having something in your pocket that you can literally pull out in the supermarket and say, "I'll have that" and you can plan a shopping list in moments. And once you've bought the ingredients, you've got recipes and step-by-step instructions, you are ready to go. [It's all] there in one thing that is very personal to you and individual in design. (Project manager)

This was particularly difficult in terms of trying to address the varying capabilities of people with Down's syndrome in terms of their dexterity and vision. As a result, the project manager concluded that more time and resources would have been beneficial for the development of the App:

The timeline of the project should have been doubled and ... I would have slowed down the launch date and got [users] involved in creating recipes that are more suited and customised to them, and I would have used a chef to work with them to perfect the recipes.



3. USING THE APP

This section describes the uptake and use of the App, including information on how many people used the App, how they used it and what they thought of it.

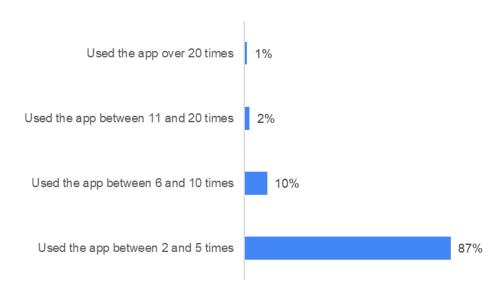
3.1 Number of users

Analysis of the App data revealed that 1,273 people downloaded the App. However, 750 people did not go on to use it further, giving a total of 523 App users.

3.2 Frequency and type of use

As Figure 1 shows, the vast majority of people used the App between two and five times, while a small percentage (10%) used it more than six times and 3% (18 people) used it more than ten times.

Figure 1: Frequency of App use (n = 523)

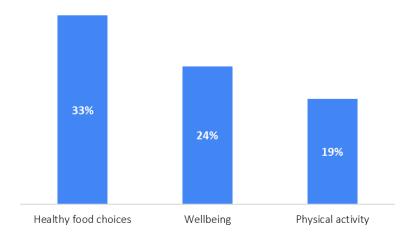


Further analysis of the data relating to the 18 people who had used the App more than ten times revealed that 12 of these users were people with Down's syndrome, suggesting that the App was in a format that was particularly suitable for people with Down's syndrome.

As Figure 2 shows, analysis of the App data also revealed that a third of users had entered data into the section relating to healthy food choices, while a quarter had entered information relating to their personal wellbeing and nearly a fifth had used the App to track their physical activity.



Figure 2: Use of App features (n = 523)



3.3 What users thought of the App

Overall, feedback from users about the App was positive. People with Down's syndrome seemed to like the activities section as they had found this helpful in tracking the activities they undertook:



What we were finding with the other Fitbit and stuff like that was that a lot of the time he never remembered to wear the Fitbit when he went to the activity so it never recorded it, whereas with this App, he could come back after yoga and he'd say, "Mum, I can now add it to my App". The time lapse ... didn't matter because it still counts that activity.

If Lisa has been out with her support worker, we'll sit and compare notes on both our Apps to see who's done what. She quite likes it ... she

Awesome!

likes to see she's done more exercise than me.

Parents and carers also felt the badges and points were particularly appealing:

It's great to see progress and earn points.

Most people had also found it easy to download the App, although some parents had wanted to supervise this so that they knew what they were downloading:

She knows how to download things so she could have done it on her own, but ... I always tell her to let me know, and I'll have a look before she does it.



However, one person had not found it easy to locate the App online:

I went into the App store to download it onto my iPhone ... when you put it in the search engine on the App store, it didn't come up on the list.

The majority of people also felt that the App was easy to use and had found it clear and accessible:

It is clearly understandable.

He is fairly good at using technology already, but the easy symbols and colours make it easy to use.

It's easy to use for those with big fingers!

Most people had also found the App visually appealing which they felt was particularly important for people with Down's syndrome:

Marie and a lot of her friends are very visual learners and if you get something it's like, "Oh wow! I did this and I got that! I'll do it again tomorrow". So, it's really good.

The language [other Apps] use just didn't click with him whereas with this App ... because it was quite pictorial and it connected a few different things ... it gave him little rewards...for him, that was quite important.

One person with Down's syndrome described how looking at the pictures made it easier to decide what to eat. Some parents liked the way that the App was specifically designed for people with Down's syndrome and felt that this made it particularly easy to use:

So many of the other Apps ... we tried using those but they weren't so simple. He'd had the Google Fit App on his phone ... but he was never enthused by any of them.

It's something that he could get on and use independently.

They had also liked the fact that the App did not include any advertising or tracking cookies. However, one person felt that the App was not visual enough for those with literacy problems and that it had been difficult to edit information once it had been submitted:

Mary set herself up on there but she had herself as being 350 centimetres tall ... she tried to sort it out [but couldn't] so we've just gone through and done that again. And when we were trying to change the amount she weighs, [the button] is very sensitive ... it jumped from 47 to 62. It's a bit too sensitive for them to use.



3.4 Suggestions for improvements

Key suggestions for improving the App included:

Adding more recipes

Some people suggested that more recipes need to be added as they felt there were not enough options to maintain its value over the longer-term:

At the moment, we have to double up on a few because we use it quite a lot.

The vegetarian options were quite narrow and after about a month, we sort of ran out of things to choose from.

One carer also felt that there were not enough recipes for people on a limited budget and felt that it would be helpful for the App to provide an idea of the cost of meals:

[For someone who] has a learning disability, if they had been looking at the App to find something that they could have for the next week that's healthy but on a very low income, there's not the information on there.

Another parent commented that the meals were orientated towards a traditional English diet and did not include meals from other cultures:

We are vegetarian and Indian but the meal plans are English.

The project manager also felt it was important to keep adding new recipes to the App and suggested that people with Down's syndrome could be asked to contribute ideas, in order to support user-generated content that is relevant and appropriate.

More information on dietary requirements

In addition, a few people felt that the App should use prompts to encourage users to choose balanced meals:

Lisa doesn't have any protein at all on her shopping list. So, there's nothing here to say, "You need to think about protein and vitamins etc..."

In addition, one parent had found it difficult to know whether recipes were appropriate for people with particular food allergies:

If she had a dairy allergy, for example, would [the App] only show you dairy-free recipes?

Another parent felt that, compared to others, the App did not have enough simple information about the nutritional value of foods:

We still keep going back to how much sugar does this item have because he's slightly overweight and we found that [the Health Swap] App didn't have any of



those functionalities. The NHS sugar app that is online is very simple. It gives you a picture of how much sugar a soft drink has ... and we used that quite often when we were planning a meal.

Activities section

One person suggested that the App should provide more information on the benefits of the different activities in order to encourage users to do more exercise:

You've got "activities" ... so you [record that you] did swimming yesterday but then it doesn't say, "Really good activity, it'll help with movement, or muscle tone". It's just, "Yes, you've done swimming, you've got 22 points for it" but what's the point in that?

They also felt that the App needed to be developed further to include a mechanism, other than the badges and points system, to encourage users to continue using the App:

After he got that reward and he got that badge, that's where it stopped. There's nothing after that whereas if you do a certain amount on your Fitbit and your Google, it allows you to reach another level.

Another person felt that logging into the App as a carer should give them access to additional information that could help them support people with Down's syndrome:

Signing in as a carer doesn't give me anything extra. It's not helping me to help Mary to use it better or to use it to look up, for example, if you've got the choice of three different activities, like swimming or running or gym, which is the most useful activity for her? It could be swimming three times a week is better for her than going to the gym twice a week. I don't think it needs to be massively detailed, but there needs to be more information there for support staff and carers.

A few people we interviewed also felt that it would be helpful to be able to add additional activities:

Lisa does walking-netball quite a lot and there isn't a netball icon so she always has to click on basketball.

We went wall climbing and he couldn't add that on so he added a bit to yoga instead. He was recording it that way, just to feel that he was recording it.

One parent also suggested including other activities such as mindfulness in order to maintain the interest of some of its users:

The way that this generation is, if they're not continuously or differently stimulated, then I think they're just not going to bother. It is why [my son] stopped using the App.



Regular updating

Finally, one parent felt that the App needed to be updated regularly as otherwise users would stop using it:

The fact that it wasn't being updated, he got bored with it.

This was reflected in the feedback from the project manager who recommended that the DSA should setup a maintenance contract with the developers of the App so that the App could be regularly updated as technology moves on. He suggested that this could be done by seeking financial support for the App:

What I'd like to see is more backing in the App, whether that be a commercial sponsor or the DSA opening their mind to another way to help commercialise the project from here on out ... we're still working on [how to] keep this project going ... because all the software needs updating and maintaining.



4. PROFILE OF USERS

This section describes the profile of the people who used the App in terms of their gender, age and their needs/abilities relating to cooking and engaging in physical activity.

Over two-thirds (68%) of the people who used the App (n = 523) indicated they were the parent or carer of someone with Down's syndrome, while nearly a third (32%) were people with Down's syndrome. In addition, of the 85 people (16% of users) who completed the 'About Me' section (which asked for information on age, gender, dietary issues/food intolerances, height, weight, cooking ability and engagement in physical activity), the majority were female (74%) and aged under 30 (see Figure 3). In addition, over two-thirds (67%) were individuals with Down's syndrome, suggesting that this section particularly appealed to them or was easy for them to complete.

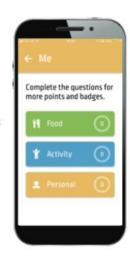
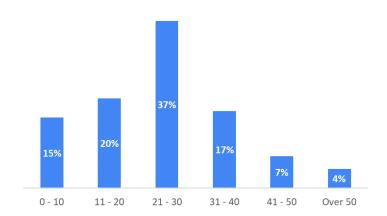
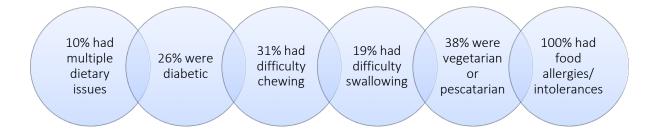


Figure 3: Age of users (n = 71)



As Figure 4 shows, 42 people provided information on dietary issues indicating that meal planning for people with Down's syndrome could be complicated.

Figure 4: Dietary issues among App users (n = 42)





In addition, 45 people provided information on the cooking ability of the person with Down's syndrome (based on whether or not they could make a sandwich, bake a cake, cook pasta and sauce and/or make a shepherd's pie). Of these:

- over half (53%) could only make one or two items (generally a sandwich and/or a cake)
- less than a fifth (16%) could make three items
- nearly a third (31%) could make all four.

Figure 5: Physical activity ability among App users (n = 55)

Furthermore, 55 people provided information on the ability of the person with Down's syndrome to engage in physical activities (e.g. whether they could run, swim, kick a ball, use a racquet etc). As Figure 5 shows, this revealed that nearly half were able to do more than six different kinds of physical activity.

Finally, 44 people provided information on how often the person with Down's syndrome took part in physical activities. Of these (again, excluding information on infants), the majority (66%) were taking part in physical activities more than once a week.

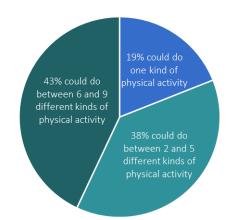
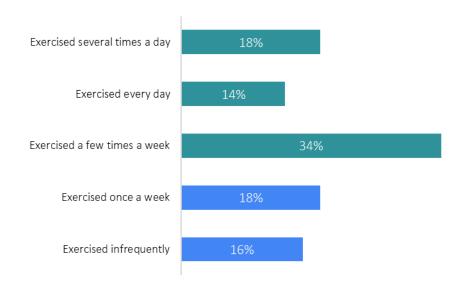


Figure 6: Frequency of physical activity among App users (n = 44)



Generally, this suggests that users had complex dietary issues and limited culinary skills but a relatively high level of engagement and ability in terms of physical activity.



5. THE DIFFERENCE THE APP HAS MADE

This section summarises the difference that the Health Swap App has made to people with Down's syndrome in terms of enabling them to have a healthier lifestyle and improving their physical and mental wellbeing. It is based on our interviews with seven people with Down's syndrome and three parents/carers, and a feedback survey completed by seven parents/carers.

5.1 Enabling people with Down's syndrome to make healthy lifestyle choices

One of the key aims of the App was to enable people with Down's syndrome to make health lifestyle choices through supporting them to choose and cook healthy foods, either with support from their parents/carers or independently.

People with Down's syndrome make healthy food choices

A third of users (174 people) had used the App to earn badges and/or points related to healthier food choices.

Some of the people we interviewed said that they had used the App to plan their meals. For example, one person told us that the App had made it easier to make a shopping list for the meals they had planned to make while another described how they had cooked some of the recipes from the App with the help of their support worker:

We get the ingredients, cook it and eat it.

Another person told us that they had made so many of the recipes, they couldn't remember which ones they had made, while another had made use of recipes they had not tried before:

I've been making lasagnes and I'm making jacket potatoes.

As a result, some people said that the App had helped them choose healthier options and eat more healthily. This was reflected in an email sent in by a parent:

Her mum wrote in and said that she's now on YouTube significantly less, and is absolutely glued to the app. She's really dived into it and we have photos of her shopping with the app, prepping and cooking food. (Project Manager)









People with Down's syndrome are more able to be independent in their food choices

One parent described how the App had helped her daughter become more independent in terms of planning and preparing her meals:

She doesn't tend to rely on me to write the list and choose the meal for a week. So now, she'll use the App, she'll choose what she wants and she'll maybe take a screen shot of it and then she'll save it, and then she'll put down that she's having that on Tuesday and then something else on Wednesday.

She also felt that it had helped her daughter to understand more about the process of preparing a meal which, in turn, helped manage her anxiety about food:

When she has a few meals in advance she tends not to worry about food, because it's always ... "what are we having next, and when is it going to be ready". It's given her more of an idea that it's not just about choosing a meal and it's there. It's made her realise that you have to go to the shops, pay for it, then you have to take it home, put it away, prepare it. So it's not quite as cut and dried as finding a meal on the table.

People caring for those with Down's syndrome are more able to support people with Down's syndrome to make healthier lifestyle choices

One mother explained how the App had helped her to support her daughter when planning meals:

We used to do [lists] on pieces of paper and tick it off ... but now, I can just refer her to back to the app and say "go and have a look, see what you think, and do your shopping list", so it's actually saved me a job, if you like.

She had also found that it had enabled her to discuss meal options with her daughter:

She cooks once a week with her support worker and they will look through the App and then she'll message me and say, "Have a look at so and so, what do you think? Do you like that? Shall I cook that one?" So then I'll look on my phone and say "oh yes, I like the sound of that." It's opened up more of a dialogue.

People with Down's syndrome live more active lives

Nearly a fifth of users (98 people) had used the App to earn points and badges related to physical activity.

A few of the people we interviewed said that they had used the App for recording their physical activities and that this had helped them keep track of what exercise they had done. Some had also found it helpful in reminding them of what exercise they should be doing. This was reflected in the comments of one carer who described how the App could act as a



reminder for their clients of their exercise schedule. She also described how she had used the App with one of her clients to choose what exercise they do:

Depending on who's supporting her, if they suggest something other than the gym, or cycling, Laura will go with whatever...she's not particularly assertive. But if she's looking at the app, she might say "look at my app, this is what I could do" without actually saying that's what she wants to do. Then the member of staff will say "ok, we'll go to the gym, or swim, or whatever". So, it's useful for her in that respect.

One person with Down's syndrome also said that they had liked earning the badges as it encourages them to do more exercise.

5.2 Improving the physical and mental wellbeing of people with Down's syndrome

In addition, it was envisaged that using the App to make healthy food choices and live more active lives would help improve the physical and mental wellbeing of people with Down's syndrome.

Of the people we interviewed, only one person with Down's syndrome told us that using the App had helped them exercise more and improve their physical wellbeing:

It really helps me quite a lot ... to lose weight. It helps me to move about.

A few parents also felt that the App had helped their relatives to increase their physical activity while another found that the App had helped their son to become more independent in recording the exercise he was doing:

He could select activities in there that he was doing. So, he does yoga, and after whatever activity, he puts [it on the App] and he could do that himself.

One parent also felt that using the App had helped boost their son's confidence:

With his Fitbit app he used to go to his sister [for help] but with the Down's syndrome one he could quite happily look at the badges he's earned and say to his dad, "Look, I did that today." So the independence was there, so that was useful. The really good thing about the App was that it was his App ... it was tailored to him.



5.3 Improving digital skills among people with Down's syndrome

While our interviews did not reveal any evidence of changes in digital skills among the people we interviewed, the feedback survey revealed that:

- six parents felt that using the App had increased their relative's confidence in using technology
- five parents felt that their relative was better at using technology as a result of using the App.

Furthermore, using the App may have helped increase other digital skills through enabling users to become more confident in:^{ix}

- turning on a device (including entering and updating any account information safely, such as password)
- using the available controls on a device
- interacting with the home screen on a device
- connecting to the internet safely and securely
- opening and accessing the App on their phone/tablet.



6. CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Despite the short timescale and limited budget for developing the App and the challenges of creating an App that meets varying levels of ability, the Health Swap App has reached over a 500 people with Down's syndrome and/or their parents/carers. Feedback from a small sample of people with Down's syndrome and their parents/carers has indicated that the App is easy to download and use, as well as being visually appealing.

Nonetheless, the evaluation has shown that only a very small proportion of those who had downloaded the App went on to use it, suggesting that the App, in its current form, may be limited in its ability to engage a wide range of people with Down's syndrome. However, the positive feedback from some users shows that the App is relevant and appealing to some people and suggests there is value in further research, testing and development to enable the App to engage a wider range of people. In addition, sustaining the interest of current App users will require ongoing investment in order to keep the App up-to-date and relevant.

This evaluation has also revealed the challenges of designing an App for a group of people with varied abilities and needs that is both user-friendly and effective. Moreover, the time and budget constraints on the App development process limited the opportunities for researching the content for the App and testing it with users. However, carrying out the initial literature review and baseline research as well as having a project team with a good combination of skills and experience helped mitigate some of the challenges.

While the data from the App provides some evidence of people with Down's syndrome using the App to support healthy choices around food and physical activity, our interviews and surveys provided limited evidence of the difference the App is making to users. This could be because, as our baseline research suggested, many people with Down's syndrome are eating healthily and exercising regularly. However, the limited evidence of the App's outcomes may also be due to the small-scale nature of this evaluation which did not engage enough people for the evaluation to report on these more comprehensively. Furthermore, while the evaluation only found limited evidence of the App helping to improve users' confidence and skills using technology, use of the App may have helped to increase users' basic digital skills. Nonetheless, it is important to note that the positive feedback from some users highlights the potential of the App to support some people with Down's syndrome to live healthy lives and points to the value of carrying out further research and development to increase uptake and use of the App.



6.2 Recommendations

In order to support the continued use and update of the App in its current format, the DSA may wish to seek further funding for maintenance and development costs and set up a maintenance contract with the developers of the App. The DSA could also consider ways to develop the App further by:

- Expanding the recipe section by setting up a group of volunteers to create new content or inviting users to submit ideas for healthy meals.
- Adding recipes that reflect different cultures.
- Providing simple information on the nutritional value and cost of foods so that people can choose healthy meals more easily.
- Providing information on the benefits of different activities.
- Exploring other ways to encourage/motivate users to do more exercise (in addition to the badges).
- Adding a mechanism to enable users to enter additional activities into the exercise section.
- Offering a different log in for carers which enables them to access information that helps them support people with Down's syndrome to lead healthy, active lives.
- Developing new features to promote mental wellbeing among people with Down's syndrome.
- Adding a feedback mechanism into the App to capture more information on how the App benefits users.
- Carrying out further research to assess the App's relevance for people with varying levels of ability and tailoring the App functionality to meet a range of needs.



APPENDICES

Appendix 1: Evaluation data

| Baseline face-to-face interviews with people with Down's syndrome | 7 |
|---|-----|
| Baseline survey to parents/carers of people with Down's syndrome | 230 |
| Questionnaire for App testers | 7 |
| Interviews with project manager | 2 |
| Telephone interviews with Down's syndrome | 7 |
| Telephone interviews with parents/carers of people with Down's syndrome | 3 |
| Feedback survey to parents/carers of people with Down's syndrome | 7 |

Appendix 2: App data

| App usage | No. |
|--|-------|
| No. who used the App | 523 |
| No. who downloaded but did not use the App | 750 |
| Total no. who downloaded the App | 1,273 |

| Frequency of use | No. of | % of all |
|--|--------|----------|
| | users | users |
| No. who used the app between 2 and 5 times | 454 | 87% |
| No. who used the app between 6 and 10 times | 51 | 10% |
| No. who used the app between 11 and 20 times | 12 | 2% |
| No. who used the app over 20 times | 6 | 1% |
| Total | 523 | 100% |

| Profile of those who used the app more than 10 times | No. of users | No. of frequent users |
|--|-----------------|-----------------------------|
| Person with Down's syndrome | 12 | 67% |
| Parent/carer | 6 | 33% |
| Total | 18 | 100% |

| App features used | No. of | % of all |
|---|--------|----------|
| | users | users |
| Used the App to earn badges and/or points related to healthier food choices | 174 | 33% |
| Used the App to earn points and badges related to physical activity | 98 | 19% |
| 'About me' section | 85 | 16% |

25



Profile of App users

| | No. | % |
|-----------------------------|-----|------|
| Person with Down's syndrome | 165 | 32% |
| Parent/carer | 358 | 68% |
| Total | 523 | 100% |

| Age | No. | % |
|---------|-----|-----|
| 0 - 10 | 11 | 15 |
| 11 - 20 | 14 | 20 |
| 21 - 30 | 26 | 37 |
| 31 - 40 | 12 | 17 |
| 41 - 50 | 5 | 7 |
| Over 50 | 3 | 4 |
| Total | 71 | 100 |

| Dietary issues (n = 42) | No. | % |
|------------------------------|-----|------|
| Diabetic | 11 | 26% |
| Difficulty chewing | 13 | 31% |
| Difficulty swallowing | 8 | 19% |
| Vegetarian or pescatarian | 16 | 38% |
| Food allergies/ intolerances | 42 | 100% |
| Multiple dietary issues | 4 | 10% |

| Physical ability | No. | % |
|--|-----|------|
| Able to do one kind of physical activity | 10 | 19% |
| Able to do between two and five kinds of physical activity | 21 | 38% |
| Able to do between six and nine kinds of physical activity | 24 | 43% |
| Total | 55 | 100% |

| Engagement in physical activities | No. | % |
|-----------------------------------|-----|------|
| Exercising several times a day | 8 | 18% |
| Exercising every day | 6 | 14% |
| Exercising a few times a week | 15 | 34% |
| Exercising once a week | 8 | 18% |
| Exercising infrequently | 7 | 16% |
| Total | 44 | 100% |



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