Final report

March 2018

Innovating for Improvement

Developing a shared care digital platform for children and young people with ADHD and their families

Oxleas NHS Foundation Trust

The Health Foundation

About the project

Project title:

Developing a shared care digital platform for children and young people with ADHD and their families.

Lead organisation:

Oxleas NHS Foundation Trust

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Part 1: Abstract

This project aims to address the challenge of delivering high quality, effective care to a growing population of children and young people with Attention Deficit Hyperactivity Disorder (ADHD) in the London Borough of Greenwich.

The intervention developed is a web-based platform,“Headscape Focus”, that brings the ADHD care team, families, schools and other professionals in to a secure, shared online environment. This was developed alongside the “Healthlocker” platform being developed by South London and Maudsley Trust (SLAM), and builds upon the “Headscape” website previously developed by Oxleas. The significant innovation is that the platform has been developed for children with ADHD and has the additional functionality that enables schools and other professionals to communicate with the team about a child’s progress.

The platform launched in December 2017. We currently have 20 families and five schools signed up to the platform. The platform has enabled the team to communicate more effectively with families and schools to provide more effective support.

The team used the COM-B model and Behaviour Change Wheel (Mitchie et al 2011) to help them develop and implement the intervention. The main challenges in this project were managing human factors and finding time within our existing clinical demands to implement the platform. The main enablers were the teams shared vision for what it was aiming to achieve, the teams culture of fun, safety and openness to change and support from senior management. It is intended that the platform will become embedded into routine clinical practice within the team and beyond to other teams.

Part 2: Progress and outcomes

This project aims to address the challenge of how to deliver high quality and effective care to a growing population of children and young people with ADHD in the London Borough of Greenwich. The team has seen a rapid increase in demand for assessments and ongoing management of young people with ADHD. The caseload has grown by 25% in the past year but resources in the team have not increased to match this demand. This has presented challenges to delivering the clinical standards set out in NICE guidance for ADHD. The traditional model of face to face service delivery has led to episodic support for children and families and it can be challenging for families and schools to communicate and share information with the team in a timely way.

The team were aware that there is a growing body of research which demonstrates that digitally based interventions can be a cost effective, clinically effective and safe way to deliver interventions that are scalable. The team were therefore keen to explore whether a digitally based model of service delivery for children and young people with ADHD could address the challenge of delivering high quality and effective care to children and young people with ADHD.

The team developed a web based platform for children and young people with ADHD, and their families, that enables them to access self-help resources, share information with the team, monitor their progress and communicate with the team via instant messaging. This platform was developed alongside the “Healthlocker” platform for adults with mental health difficulties being developed by South London and Maudsley Trust (SLAM). What made this platform particularly innovative was that it was the first of its kind to be developed for children and young people with ADHD and it has additional functionality that enables schools and other professionals to communicate with the team about a child’s progress.

The platform was launched to families in December 2017. It was then launched to schools in March 2018. We have created accounts for twenty children and five schools. We have not made as much progression scaling up as we would have hoped to at this point due to unforeseen delays in developing and launching the platform. The development and implementation of the platform was undertaken through an iterative process of PDSA (Plan – Do – Study – Act) cycles. Screenshots of the platform can be seen in Appendix 1.

The intended outcomes of the platform are to improve self-management of ADHD, thereby reducing difficulties at school and home, and to improve collaboration and communication between the team, families, schools and other professionals thereby enabling the team to address difficulties sooner and more effectively.

The outcomes of the intervention on children and families will be measured using standardized clinical outcome measures. These measures will include the Conner’s questionnaire, the Parenting Stress Index (PSI) and the Patient Activation Measure (PAM). These measures have well established validity and reliability and are used routinely in clinical practice.

Families were asked to complete these measures when they began using the platform and they will be asked to repeat these six months later to explore if there has been any change in their scores. We hypothesize that parent's report lower levels of stress, as reflected in the PSI; improved management of ADHD, as reflected in the Conner's and an increased sense of feeling more able to manage their child's condition, as reflected in the PAM. Baseline measures have been completed but it is too early to repeat the measures and we do not have sufficient numbers using the platform to make meaningful comparisons due to the unforeseen delays in launching.

Process outcomes for the team will include wait time figures, number of face to face appointments per family and number of phone calls to the team each week. It is anticipated that all these will reduce. The team have been collecting baseline data but we need to scale up to more families in the service before the impact of the intervention can be seen in these areas. At a PDSA level we have seen a positive impact with families communicating with the team via the messaging function rather than telephoning.

The team have obtained qualitative feedback from families and schools about the platform and made iterative changes to the platform content and implementation as a result. The team have successfully used the platform to support a family to implement a sleep programme to address their son's sleep difficulties. The family were able to use the sleep tracker and diary function to record their child's progress, which the team monitored and we used the instant messaging function to discuss progress and given advise. The family reported that their son was making great progress both at home and school. Prior to the platform the team would not have been able to support the family as effectively to bring about a change as the family would not have been seen regularly in clinic. The family gave us the following feedback :

*"The platform has been really helpful to me as I am able to write down how I feel and I also get a response from your team quickly. Keeping a track on ******'s sleep is helpful to as i am able to look back on the weeks. I would definitely like to keep going with the platform"*

"Being able to have chats on here is a massive help…. I would definitely recommend the platform to others."

Another family fed back that they liked being able to message us when a situation or problem arose and that they got a response quickly. They said that previously when they had to wait for a telephone call or face to face appointment they often forgot what they wanted to discuss.

Given the positive impact of the platform so far we intend to continue with its implementation and scale up within the team over the next twelve months.

Part 3: Cost impact

The ADHD team is funded by the Greenwich CCG and a business case would need to be made to them for any additional funding that is required to continue with the project. Without additional funding the platform can be used in its current format but we would not be able to develop additional functionality. We would also be limited to how many users we could have.

There will be ongoing new costs for the hosting of the platform and any further development of the platform. The costs of ongoing hosting are £200 per month, £2,400 annually on current platform. This will need to be monitored as the project evolves and users are adopted.

We will continue to collaborate with SLAM in the ongoing development of the platform. Another NHS Trust has also expressed an interest in developing the platform. As the platform is open source developments will be shared which will reduce costs associated with future development.

There is £10,000 of funding available within the Trust to support hosting and further development of the platform. The team will be exploring further opportunities for funding from grant applications to assist with scale up.

It is expected that any ongoing costs of the platform will be offset by savings made in postage and printing of clinic letters to communicate with schools and families as communication will happen via the platform instead. It is also expected that there will be cost savings associated with clinical outcome measures. The team spent approximately £6000.00 in 2016-17 on routine screening tools. The team plan to develop free screening measures that can be available on the platform thus saving on postage costs.

There has not been a formal financial evaluation of this intervention yet so it is unclear what the cost impact of the project will be.

Part 4: Learning from your project

The team has completed two development sprints on the platform and has now launched to families and schools. We had initially planned to have more families and schools using the platform at this stage but this has not been possible due to unforeseen delays in developing and launching the platform. Despite this the team are pleased with what it has achieved in the past fifteen months and feel that we have met our aims and objectives in that families have given positive feedback about the platform and are using it to communicate with the team.

Throughout the project the team have found the COM-B model to be a very helpful framework to think about barriers and enablers to the project. The COM-B model is at the heart of the behaviour change wheel (Mitchie et al 2011) and describes how it is necessary to address capability (C), opportunity (O) and motivation (M) in order to bring about behaviour change. This project involved implementing a new model of

service delivery and therefore required a change in clinical practice and shift in culture for both the team and families.

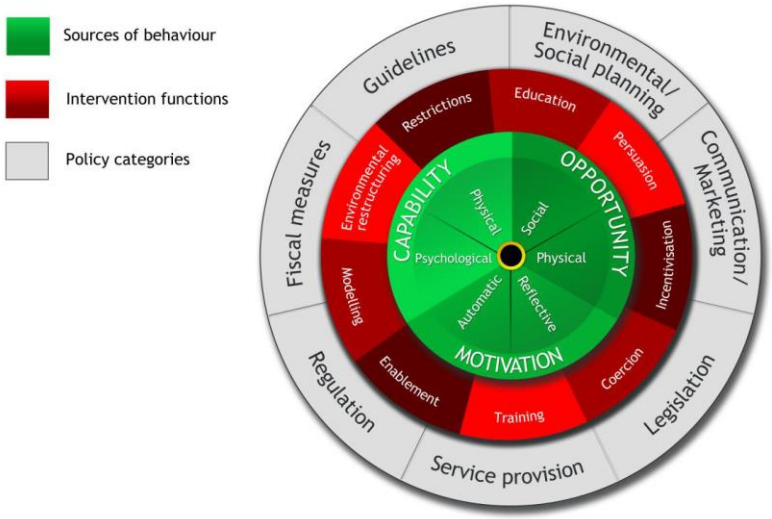


Figure 1 : The behavior change wheel.

Within the team there was a great deal of capability to develop and implement this intervention as a majority of team members had a background in research. One team member is seconded to NHS England as a senior fellow in mental health technology and innovation and therefore had extensive knowledge about technology enabled interventions and the current digital landscape within the NHS. Another team member had experience of web site design and development. These team members were therefore able to support others who felt less confident using technology. Some team members expressed anxiety about using the platform and required more time to learn how to use it and feel comfortable. One team member described having a “mental block” about using the platform initially. The team were able to overcome this by using team meetings to practice using the platform and simulating using the platform in clinic with families. Additional 1:1 training was provided to team members where needed and team members could also use their supervision time to practice using the platform if they wished to. The team addressed the young people’s capability to use the platform, and their families, during the co-design process. All families reported being confident in using technology and regularly used social media platforms.

The team were given the opportunity to attend training events and meetings related to the project. Senior management allowed the team to take time away from their normal clinical duties when needed to complete project tasks. The support of senior management was vital to the success of the project. A barrier to intervention was lack of opportunity to sign families up to the platform due to clinical demands. Team

members reported feeling overwhelmed by the thought of trying to introduce a new intervention into clinical practice when they already had so many demands on their time. This did cause feelings of anxiety and stress amongst staff members. As the chief investigator and team manager it was important to foster a culture of safety where team members felt able to express these feelings openly. Team members were supported to express their fears and worries in team meetings and supervision. As a team we developed a quicker process for signing families up to the platform through a number of PDSA cycles. When team members tried this method and found it to be less time intensive they were less anxious about how they would find the opportunity to embed it into clinical practice. The team also thought about how to support busy families to access the platform during persona work. The team showed families how to save the link to the platform to the home screen on their phone so that it looked like an App and enabled them to log on more quickly without having to type in the web site address each time.

There has been great enthusiasm and motivation in the team for the project. The team had a clear goal and shared vision so there was buy in from staff. At times enthusiasm and motivation waned, particularly in the face of delays and frustrations, but when this happened the team reminded themselves of the intended outcomes and potential benefits. The team addressed the families and young people's motivation during the co-design process. All families and schools expressed enthusiasm for the platform when the idea was introduced. During the sign up process families have spontaneously commented on how they feel the platform will be beneficial to them.

The team have learnt a great deal from this project, both about quality improvement methodology and quality improvement process. Prior to this project many of the team had very good knowledge of research but limited knowledge about quality improvement. This was a big shift in thinking for the team and our methodology changed dramatically from the one outlined in the original bid. We learnt how important it is to have a clearly defined goal and shared vision so that there is buy in from all those involved in the quality improvement. Co-design is an important part of this process. The support of senior managers is particularly important as they can help to unblock barriers, aid communication and gain wider stakeholder engagement. The team have also learnt how important it is to consider human factors, and the nature of behaviour change, when implementing an intervention as the most well defined and planned intervention could fail if attention is not given to these. We have learnt that quality improvement takes time. Most things took longer than anticipated throughout the project. Feeling safe to take risks, whilst also having fun, is really important for innovation.

Part 5: Sustainability and spread

The intervention developed in this project will be sustained beyond the funding period and we are exploring further funding opportunities. Senior management have shown an interest in this intervention throughout and are keen to support its scale up and spread. The team recently had the opportunity to present the project to the Chief Executive and Chair of the Trust. We were thrilled that they both shared the project

via Twitter and gave positive feedback about it. The team recently won the Oxleas NHS Trust recognition award for the quality improvement work it has done.

The project has also attracted external interest. The team have presented a poster at the British Psychological Society - Children and Young People Faculty annual conference in September 2017 and they also presented at the Royal College of Psychiatrists - Faculty of Child and Adolescent Psychiatry annual conference. A highlight for the team was presenting a poster at the ISRII (International society for research on internet interventions) conference in Berlin in October 2017.

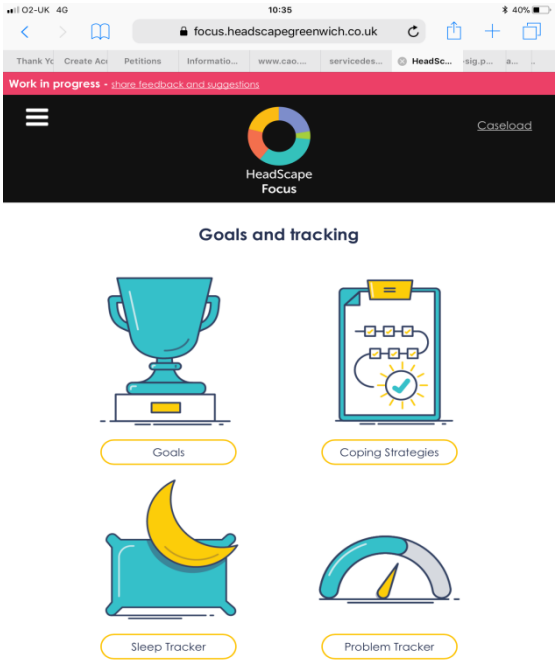
The team have raised awareness of the project on Twitter and discussed the project at cabinet office advisory meetings in relation to the recent government green paper for transforming child and adolescent mental health services. The government green paper emphasizes the role of schools in supporting children and young people with mental health problems. The team provided a written description of the platform for the green paper and how this can be used to improve support to schools. At recent cabinet office advisory meetings we have discussed how the platform can be used to provide support to families and reduce wait times.

The team plan to scale up within their team initially so that every child in the team is using the platform and all schools in the borough. We then intend to spread our intervention to other teams in the Trusts children and young people directorate who are working with young people with ADHD. This will require ongoing funding and we will be exploring funding opportunities with colleagues. In the next few years our ambition is to continue collaborating with colleagues in SLAM to spread the platform and develop a South East London innovative ADHD pathway. Other Trusts have expressed an interest in developing a platform and it is likely that we will establish a governance board with colleagues in other Trusts in order to work together to further develop the platform and assist with spread.

The team are currently organising a conference for the Trusts children and young people’s directorate on quality improvement which they will host in July 2018. The aims of the conference are to share our learning about quality improvement, disseminate our platform and encourage teams to identify further opportunities for quality improvement in the directorate.

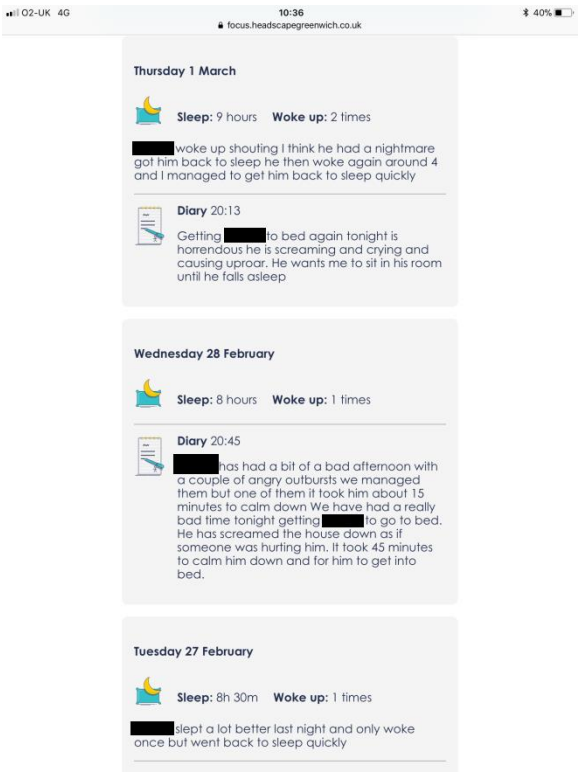
Appendix 1: Resources and appendices

Screenshots from the ADHD platform

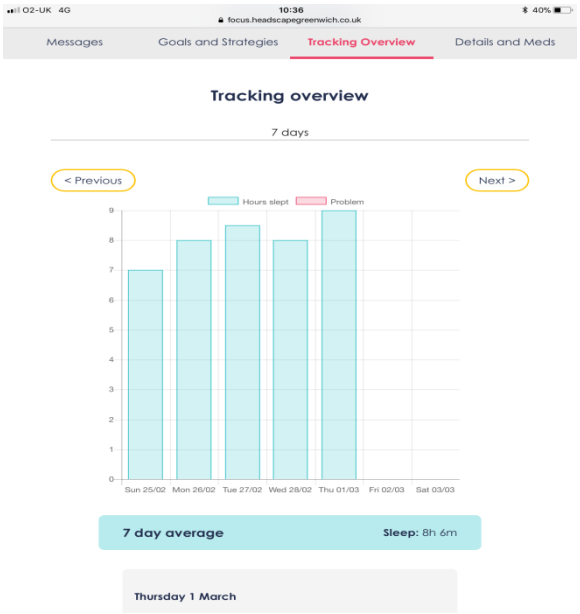


The landing page for families enables them to access various functions such as recording goals, track their sleep and progress.

The family can also access information about their child's medication, see reports from their child's school and share information about their child.

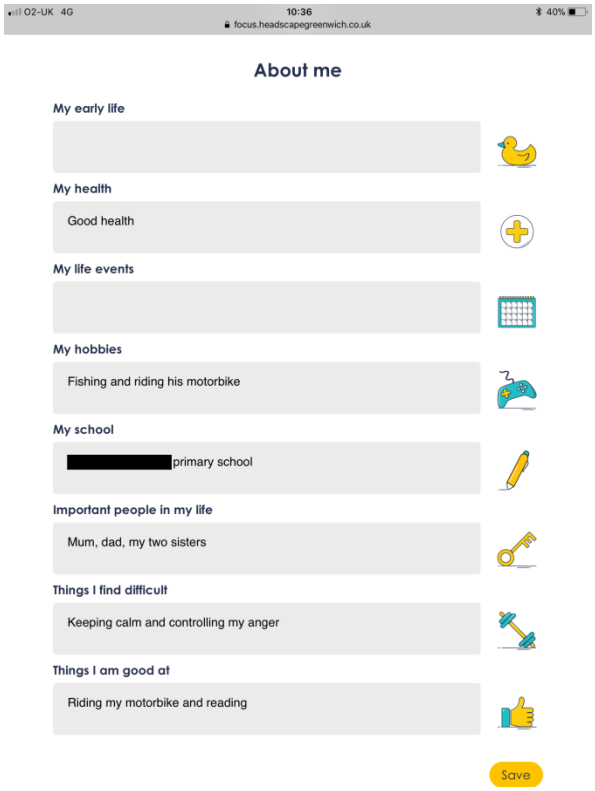


Families can use the diary to record their progress and the team can view this.



Families and the team can obtain an overview of progress on a weekly basis.

Schools can give feedback about a young person which the team and families can see.



Families can share information about their child.

Families and schools can talk to the team via messaging. Only the team can see these messages.