

# Medication Adherence in Paediatric Epilepsy (MAPE): Summary report

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# Contents

Introduction.....	2
Rapid evidence review.....	3
Consultation with children and young people and their families .....	4
Evidence synthesis and innovation identification .....	6
Next steps .....	8
Appendix 1 – Planned publications.....	9
Appendix 2 – Horizon scan questions .....	10
Appendix 3 – Digital Health Passport case study.....	13
Appendix 4 – Heba: Child Health Tracker case study.....	16
References .....	18



# Introduction

Epilepsy is a long-term condition that affects approximately 112,000 children and young people in the United Kingdom (1). It has been identified as one of the five conditions in the Children and Young People Core20PLUS5 document (2), highlighting its prevalence and need to focus on healthcare in this area.

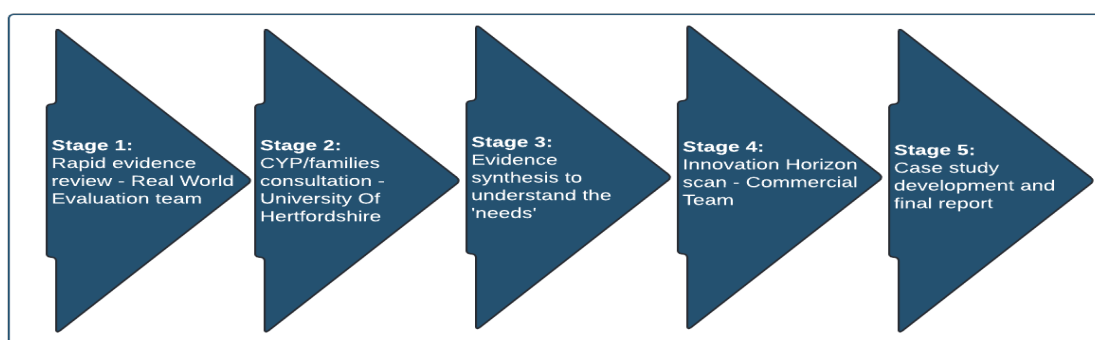
Adhering to medication regimes is crucial for children and young people with epilepsy to both maximise their overall health and wellbeing and fulfil their potential. However, evidence tells us that adherence can be poor (3).

The NHS East of England Children and Young People (CYP) Transformation Programme team was interested in understanding children and young people's adherence to epilepsy medication, including factors that influence adherence, variation, and best practice in supporting patients, parents and carers. To support this understanding, the NHS East of England CYP Programme team commissioned Health Innovation East to identify enablers and barriers relating to medication adherence and find solutions to support better adherence.

The project encompassed a rapid review of the academic literature, qualitative research exploring the views of CYP with an epilepsy diagnosis and their parents and carers and a horizon scan identifying appropriate innovations to improve adherence.

Health Innovation East led a programme of work titled '**M**edication **A**dherence in **P**aediatric **E**pilepsy' (MAPE), that included:

1. **Stage 1** - A review of the evidence (grey and published literature) to understand the factors that influence medication adherence.
2. **Stage 2** - Consultation with children, young people, parents and carers to understand perceptions and beliefs about epilepsy medication, and what would help adherence.
3. **Stage 3** - An innovation horizon scan focused on enablers of medication adherence such as digital reminders, behaviour change tools, and engaging information for self-management.
4. **Stage 4** - Develop a set of case studies with real-world examples of successful approaches to children and young people with epilepsy, medication adherence.
5. **Stage 5** - A summary report (this document) bringing together each element of the project.



Health Innovation East is also continuing to support dissemination activities, including publication of the evidence review and consultation report, to share the findings with regions across England.

This report provides a summary of each of the stages, including links to the produced outputs.

# Rapid evidence review

A rapid evidence review ([Medication Adherence in Paediatric Epilepsy \(MAPE\); Rapid Evidence Review](#)) of the literature, pertaining to factors influencing medication adherence and best practice (MAPE stage One) was conducted by the Real World Evaluation team at Health Innovation East.

The primary outcomes of the rapid evidence review were to:

1. Describe the factors which influence medication adherence for young people with paediatric epilepsy.
2. Describe any factors influencing variation relating to young people's adherence to epilepsy medication.
3. Report on best practice in supporting patients, parents and carers with young people's adherence to epilepsy medication.

The rapid evidence review was also designed to inform qualitative interview topic guides to be used within MAPE stage two.

After screening 2,639 studies, 20 were considered eligible studies for the review. The rapid evidence review identified positive and negative influences on modifiable and non-modifiable determinants of medication adherence, along with a list of recommendations for improving medication adherence in young people.

The following recommendations for best practice could be broadly classified into the following themes:

- **Patient level:** Improve patient knowledge and empowerment about the condition, importance of adherence, and ways they can help to self-manage (maybe supported by remote monitoring).
- **Familial level:** Increase early and ongoing family centred/tailored care and support from HCPs for families and carers, improve parent/caregiver knowledge and empowerment, family-focussed support on family functioning, problem-solving and communication, and encourage parents/carers to remind patients to take medication.
- **Clinical level:** Improve knowledge of, and early identification of factors of adherence, patient-centred prevention, and intervention by HCPs, assessments of children throughout the disease course, support patient-centred care, telephone reminders for appointments, simplified complex treatment regimens where possible, psychosocial input for young people.
- **Health and Care system level:** Improve accessibility/equity of medications for patients and their carers and integrate hospital and community services with a linkage system.

The full report can be found [HERE](#)

# Consultation with children and young people and their families

On behalf of Health Innovation East, the University of Hertfordshire used the review findings and engagement with the University's [Young Peoples Advisory Group](#) to design the interview question schedule to deliver 22 semi-structured interviews with children and young people and their caregivers.

Qualitative research that had specifically sought the views of children and young people (who have an epilepsy diagnosis), as well as their parents/carers, about medication adherence had not previously been undertaken within a UK context.

The aims of the research were to gain insight and understanding of:

- The facilitators and barriers to epilepsy medication adherence in children and young people (aged 0-16 years).
- How the barrier(s) to epilepsy medication adherence in this age group could be addressed.
- The changes required to facilitate good epilepsy medication adherence.

The report uses data from semi-structured interviews with:

- Children and young people (aged 5-16 years) who had a diagnosis of epilepsy (n = 5)
- The parents of children/young people (aged 0-16 years) who had a diagnosis of epilepsy (n = 16)

Interviews with children and young people provided an invaluable insight into their experiences of taking epilepsy medication. Most had limited understanding of how their medication worked, and disruptions to their daily routines often affected their ability to take it consistently. Parental support was crucial in helping them adhere to their prescribed regimen. However, their involvement in medical consultations varied significantly, suggesting inconsistency in how healthcare professionals engage them. Additionally, none of the participants reported any involvement with epilepsy-related organisations or charities, despite being asked directly about this.

Interviews with parents highlighted the significant emotional and practical impact that an epilepsy diagnosis and ongoing medication management had on both the child and their family. Parents described the need for constant vigilance and forward planning to ensure adherence to medication schedules, often structuring daily routines around this responsibility. While they were committed to helping their children lead as normal a life as possible, they also expressed a strong desire for more accessible and reliable information about epilepsy and its treatments. Many turned to online sources such as charity websites and social media for support, though they acknowledged that their understanding of how the medication worked was often limited. This lack of knowledge sometimes affected their ability to manage missed doses or understand the flexibility of medication timing.

Parents valued responsive communication with healthcare professionals, particularly consultants and epilepsy nurses, and felt reassured when advice was readily available. Most took full responsibility for managing their child's medication, including ordering and administering it, and used various reminder strategies like alarms and dosette boxes to stay on track. While many children took their medication without issue, others faced challenges related to taste, form, or their child's stage of development. Parents were also concerned about side

effects, but generally trusted their healthcare teams to manage these proactively. As children grew older, parents attempted to shift responsibility toward them, though this transition often increased anxiety. Notably, parents' understanding of adherence was sometimes incomplete, and they were not always asked about it during appointments, suggesting a need for clearer guidance and more consistent support.

The report's findings led to several key recommendations aimed at improving medication adherence in children and young people with epilepsy:

- Families understand the importance of medication adherence and try hard to follow prescribed regimens. However, timely access to professional advice—especially in situations like a child vomiting medication—was seen as essential. The report also suggested establishing a clear point of contact, such as an on-call epilepsy nurse, to provide occasional but prompt support was important.
- Building strong, trusting relationships with healthcare professionals, particularly consultants and epilepsy nurses, was also emphasised as vital for shared decision-making and sustained adherence.
- The report highlighted the impact of routine disruptions on adherence and recommended promoting the use of dosette boxes, appropriate to the child's developmental stage.
- It was noted that adherence and side effects were not consistently discussed during hospital appointments, so incorporating these topics into all consultations was advised.
- Parents also expressed a need for better access to reliable information and support networks, including age-appropriate resources for children. The report also highlighted the importance of clearly explaining to parents and children and young people what adherence means, including acceptable timing flexibility, and encouraging families to report any challenges with medication administration so that appropriate support can be provided.

The full report can be found [HERE](#)

# Evidence synthesis and innovation identification

Following review and approval of the two reports (MAPE stage one and two), evidence from the two reports were synthesized/consolidated into a set of 'needs' by Health Innovation East, loosely based on the [Stanford Biodesign principles](#).

A face-to-face workshop with the MAPE steering group members (consisted of key stakeholders and experts from various relevant fields) was held at Health Innovation East office on Tuesday 4<sup>th</sup> February 2025. The purpose of the workshop was to:

1. Review the results of the evidence synthesis and collaboratively refine needs statements for each evidence theme.
2. Focus on 1 to 2 themes and associated needs statements and develop appropriate needs criteria.
3. Develop clear horizon scan parameters so appropriate innovations can be identified that are meeting a clear, evidenced need

Following review and refinement, the following need statements were agreed:

Area	Draft needs statements
Parent/carer anxiety	A way to reduce parent/carer anxiety for parents of children with epilepsy in order to improve quality of life and medication adherence.
Information and resources	A way to address unmet information needs for CYP and their families in order to provide tailored and responsive advice to support medication adherence.
Parent/carer resourcefulness	A way to improve parent/carer health literacy, problem-solving and communication for parents of children with epilepsy in order to improve medication adherence and decision-making.
Parent/carer involvement	A way to increase parent/carers involvement in their CYP epilepsy care to increase shared decision making.
Acquiring medication	A way to improve access to medication (as well as shared decision-making and communication) for CYP with epilepsy and their families in order to ensure doses are not missed.
Administering medication	A way to improve the administration of medication for CYP with epilepsy in order to ensure that doses are not missed and to reduce any CYP anxiety around medication taking.
Side-effects	A way to help CYP with epilepsy and their families with joint decision making and communication around medication-taking to improve adherence.
Forgetting medication doses	A way to help CYP and their families to remember all medication doses in order to support medication adherence.

These two statements were chosen for further investigation during the horizon scan:

	Need	Must have criteria	Nice to have Criteria
1	A way to help CYP and their families to remember all medication doses in order to support medication adherence	<ul style="list-style-type: none"> <li>• Service availability across all geographies</li> <li>• Tailored to all families e.g. literacy/language, dexterity etc</li> <li>• Monitoring feedback</li> <li>• Cost neutral or better</li> </ul>	<ul style="list-style-type: none"> <li>• Digitally available</li> </ul>
2	A way to address unmet information needs for CYP and their families in order to provide tailored and responsive advice to support medication adherence	<ul style="list-style-type: none"> <li>• Seven days a week advice</li> <li>• Timely response from clinicians to general requests</li> <li>• Rapid response from clinicians to very urgent requests</li> <li>• Address health inequalities e.g. Language barriers</li> <li>• Regularly updated</li> <li>• Help/information decision making tools for families</li> </ul>	<ul style="list-style-type: none"> <li>• Low time commitment for clinical teams</li> <li>• Feels modern</li> <li>• Both expert and co-produced with CYP/families</li> <li>• Cost neutral or better</li> <li>• Low environmental impact</li> </ul>

To inform the innovation horizon scan, a questionnaire (see Appendix 2) was completed for each of the two needs and submitted to the Health Innovation East commercial team. The identified innovations were:

A way to help CYP and their families to remember all medication doses in order to support medication adherence'	A way to address unmet information needs for CYP and their families in order to provide tailored and responsive advice to support medication adherence
<a href="#">Albert Voice Assistant</a>	<a href="#">Tiny Medical Apps - Digital Health Passport</a>
<a href="#">Tiny medical app - Digital Health Passport</a>	<a href="#">Heba: Child Health Tracker</a>
<a href="#">Heba: Child Health Tracker</a>	<a href="#">Global ePRO ecosystem</a>
<a href="#">Wave Health ePRO</a>	<a href="#">Share2Care</a>
<a href="#">Medisafe Digital Drug Companion</a>	<a href="#">Nile AI</a>
<a href="#">Nile AI</a>	<a href="#">My Epilepsy App</a>
<a href="#">Mango Health App</a>	

Consultation with the MAPE steering group helped to develop a selection criterion to identify the two innovations to conduct a case study:

- Review 1 - assessed the innovations, focussing on those that achieve the main review criteria, choosing the three highest scoring innovations for each need.
- Review 2 - Taking each of the two identified needs individually, assessed the three highest scoring innovations against the 'must have search criteria'.
- Review 3 - Based on review 1 and 2, it was recommended to conduct a case study on the two innovations that rank among the top three for each of the two identified needs.

Following this process and further consultation with the MAPE steering group, a case study was developed for [Tiny medical app - Digital Health Passport](#) (Appendix 3) and [Heba: Child Health Tracker](#) (Appendix 4).

# Next steps

The MAPE project approach (a five stage process), including a comprehensive review and qualitative research have resulted in evidence-based recommendations that can be used to inform best practices in healthcare provision.

Establishing what the 'healthcare need' is before having a developed solution ensures that innovations are identified/tailored to address specific challenges effectively, facilitating a "pull" into the NHS where demand drives adoption rather than a "push" where solutions are imposed without sufficient due diligence. As a result, we have also identified two innovations meeting two important needs which may be implemented to better support CYP and their families.

It is hoped that the insights gained from the MAPE project will both inform policies aimed at improving medication adherence among children and young people with epilepsy and enable healthcare providers/commissioners to develop implementation strategies to address identified barriers and enablers for more effective medication management.

This report (and associated resources) will be shared with the NHS East of England CYP Transformation Programme team, with an aim of increasing understanding children and young people's adherence to epilepsy medication and the factors that influence adherence.

A knowledge mobilisation plan will be developed to ensure the findings are shared with regions across England in a way that is accessible, relevant and tailored to all key stakeholder groups, including a presentation at the OPEN UK network (Organisation of Paediatric Epilepsy Networks in the UK) conference in September 2025.

# Appendix 1 – Planned publications

The following reports will be submitted for open access publication in the Archives of Disease in Childhood by the end of 2025:

1. [Medication Adherence in Paediatric Epilepsy \(MAPE\); Rapid Evidence Review commissioned by NHS East of England and undertaken by the Real World Evaluation Team at Health Innovation East](#)
2. [Medicine Adherence in Paediatric Epilepsy \[MAPE\]; A qualitative study commissioned by Health Innovation East and undertaken by the University of Hertfordshire](#)

## Appendix 2 – Horizon scan questions

No.	Question	Response
Q1.	Name:	Ben Jackson
Q2.	Health Innovation East Contact (If not the requester):	As above
Q3.	Email Address of requester:	<a href="mailto:Ben.jackson@healthinnovationeast.co.uk">Ben.jackson@healthinnovationeast.co.uk</a>
Q4.	General context of what sort of innovations you are searching for, please give as much detail as you can: The more information you provide at this stage, the better we can scan for suitable innovations. Feel free to include what you are NOT looking for, if easier.	We are searching for innovations that will <b>help CYP with epilepsy and their families to remember all medication doses in order to support medication adherence.</b>
Q5.	What is this Horizon Scan going to be used for (e.g. to inform an external report; to use as part of internal discussion)?	<p>Following assessment of the horizon scan, the identified innovations will be submitted to the MAPE steering group for review/recommendations</p> <p>A set of use case studies with real-world examples of successful approaches to children and young people’s medication adherence will be identified and developed.</p> <p>A summary report will be completed bringing together all elements of the MAPE project, including the case studies and horizon scan recommendations.</p> <p>An appropriate knowledge mobilisation approach will be developed in partnership with NHS England East to advocate the testing of the innovation, including a real world evaluation to assess impact. Findings will be shared with other regions in England as appropriate.</p>
Q6.	Time scales: Please indicate the desired completion date and the depth of information required, bearing in mind turnaround times for horizon scan workstreams.	End of March (up to six weeks)
Q7.	What stage of innovation maturity are you looking at?	Pilot Ready; Implemented in a single site; Implemented in more than one site; Market Ready; Adoption and Spread Ready
Q8.	As part of our universal offer, we can provide 3 levels of Horizon Scan, tick as appropriate you would like us to search:	Level 3 plus levels 1 and 2: Widespread scoping of tools in particular space

No.	Question	Response
Q9.	Does your horizon scan need to scope innovations outside of the Health Innovation Network databases? Please note if yes, then this falls under our enhanced paid for services and will need to be discussed first directly with the commercial team for capacity, pricing and resourcing purposes.	Yes
Q10.	We can use the following search terms in our databases, please tick as appropriate the search terms you would like us to use:	Patient Monitoring; Treatment; Self management; Patient education; Children
Q11.	Any other key words you would like us to include in the search?	CYP; Medication adherence; Digital; Epilepsy; Medication tracking; Medication reminders; Paediatric medication management; Medication tracking apps; Smart pill dispensers; Medication schedules

No.	Question	Response
Q1.	Name:	Ben Jackson
Q2.	Health Innovation East Contact (If not the requester):	As above
Q3.	Email Address of requester:	<a href="mailto:Ben.jackson@healthinnovationeast.co.uk">Ben.jackson@healthinnovationeast.co.uk</a>
Q4.	General context of what sort of innovations you are searching for, please give as much detail as you can: The more information you provide at this stage, the better we can scan for suitable innovations. Feel free to include what you are NOT looking for, if easier.	We are searching for innovations that will address the <b>unmet information needs for CYP with epilepsy and their families</b> in order to provide tailored and responsive advice to support medication adherence.
Q5.	What is this Horizon Scan going to be used for (e.g. to inform an external report; to use as part of internal discussion)?	Following assessment of the horizon scan, the identified innovations will be submitted to the MAPE steering group for review/recommendations A set of use case studies with real-world examples of successful approaches to children and young people's medication adherence will be identified and developed. A summary report will be completed bringing together all elements of the MAPE project, including the case studies and horizon scan recommendations. An appropriate knowledge mobilisation approach will be developed in partnership with NHS England East to advocate the testing of the innovation, including a real world evaluation to assess impact. Findings will be shared with other regions in England as appropriate.

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Q9.	Does your horizon scan need to scope innovations outside of the Health Innovation Network databases? Please note if yes, then this falls under our enhanced paid for services and will need to be discussed first directly with the commercial team for capacity, pricing and resourcing purposes.	Yes
Q10.	We can use the following search terms in our databases, please tick as appropriate the search terms you would like us to use:	Prevention; Patient Monitoring; Treatment; Management; Remote Consultation; Self management; Patient education; Children; Data Analytics Decision Support; Education & Learning;
Q11.	Any other key words you would like us to include in the search?	CYP; Advice and guidance; Clinical support; Medication adherence; Education; Epilepsy; Medication schedules; Paediatric health information; Personalised health advice; Health literacy; Tailored health communication; Responsive healthcare solutions

## Appendix 3 – Digital Health Passport case study

<b>Innovation</b>	Digital Health Passport	<b>Innovator</b>	Tiny Medical Apps.	<b>Innovation readiness</b>	Pilot ready (Adoption and scale for asthma)
<b>Certification</b>	DHP for Epilepsy is built upon the existing DHP platform which has achieved several key milestones including DTAC (Digital Technology Assessment Criteria) approval, ISO 27001 certification, Cyber Essentials + certification, ORCHA approval with a score of 88%, Listing on G-Cloud and NHS procurement frameworks, Integration with NHS login (Summer 2025), Medical Device Class 1 certification (Summer 2025)				
<b>Introduction</b>					
<p>Tiny Medical Apps (TMA), in collaboration with Young Epilepsy, is developing a digital epilepsy service aimed at transforming care for children, young people (CYP), and their families.</p> <p>Initially designed for asthma management, the Digital Health Passport (DHP) platform is now being expanded to support epilepsy care. It combines clinical management tools with educational content, focusing particularly on CYP aged 13-25 living with epilepsy, including those with mild to moderate learning disabilities. Secondary users include parents and carers of younger children.</p> <p>The aim of the DHP platform is to improve self-management, enhance communication between patients and clinicians, reduce emergency admissions, and potentially lower mortality rates. Once fully developed the platform will include a wide range of features such as personalised care plans, emergency first aid support, seizure tracking, medication management with NHS prescription reordering, stress reduction tools including guided meditation and a sleep player, and high quality gamified educational resources.</p>					
<b>Evidence to date</b>					
<p>The evidence for the DHP for epilepsy is limited due to the early stage of development, however the individual features incorporated within the platform have a strong evidence base and align to <a href="#">NICE NG217</a> guidelines including 10.2.2 'Support people with epilepsy to take their medications as prescribed'. The underlying behaviour change techniques within the DHP platform have demonstrated effectiveness in asthma management, including significant positive impacts on Asthma Control Test scores (ACT) and patient activation. Notably, patients with the lowest baseline ACT scores (indicating poor asthma control) experienced the greatest gains. This pattern highlights the potential of DHP to improve outcomes in high-risk groups, where poor control is associated with higher healthcare costs. These surrogate markers – improved ACT and patient activation scores – are linked to reduced urgent and emergency care use. While the company acknowledges that a more robust evaluation (with a comparator control group and longer follow-up) is needed, the current evidence has been well received by NHS commissioners. The economic model developed alongside this work predicts a return on investment of £9.78 for every £1 spent over three years..</p> <p><a href="https://uclpartners.com/project/using-a-digital-health-passport-to-improve-asthma-care/">https://uclpartners.com/project/using-a-digital-health-passport-to-improve-asthma-care/</a></p>					

Innovation	Digital Health Passport	Innovator	Tiny Medical Apps.	Innovation readiness	Pilot ready (Adoption and scale for asthma)
<p>As part of the DPH Epilepsy platform development (SBRI Phase 1) the project conducted 12 workshops with 88 participants, including 49 young people (aged 13-25), 34 parents, and five care workers. 16 of the young participants had learning disabilities. These workshops, led by Young Epilepsy in partnership with the Caribbean and African Health Network, NIHR HRC in Paediatrics and Child Health, and St Piers College, provided valuable insights demonstrating the need and desirability of the main features.</p> <p>TMA secured SBRI Phase 2 funding of £800,000 and are working with UCLPartners as evaluation partners. This evaluation aims to engage with approximately 500 users across five NHS Integrated Care Boards, with focus areas including cost-effectiveness, implementation barriers and facilitators.</p>					
<b>Implementation</b>					
<p>Building on the success of the Asthma version of the DHP, which has demonstrated impact with target populations across 10 NHS ICBs, the epilepsy service is poised for rapid development, implementation, and potential adoption across the NHS.</p> <p>Based on the DPH for Asthma, TMA indicate that they are planning expansion to full NHS systems integration with low implementation and maintenance costs based on an annual recurring revenue model with clear pricing structure.</p> <p>DHP currently supports NHS login integration with primary care records to deliver medication reordering and prescribing, with further phased plans developed for enabling a fully integrated digital care pathway.</p> <p>Evaluation of implementing the Asthma support (UCLPartners) shows that strategic staff time allocation is required. This includes Information Governance, Senior Management, Clinical Leads, and Nurse/GP/Pharmacy Practitioners. Estimated 100 hours approximately in Year 1 approx., with subsequent years set at approx. 70 staff hours (to be validated in phase 2). <a href="#">TMA-Digital-Health-Passport-FINAL-REPORT</a>.</p> <p>Key barriers included clinician resistance, funding concerns, interoperability, and initial user adoption. Mitigation strategies involve engaging local clinical champions within ICBs, providing clinical training through CPD-accredited programmes, and communications support. The DHP service also works directly with patient groups through social media campaigns and community outreach programmes in order to ensure uptake in traditionally underserved populations. The MYPASS evaluation showed that this was a cost-effective way of reaching high risk population groups</p>					
<b>Next steps</b>					
<p>TMA, as part of their 2025 development plan, aim to launch a Minimum Viable Product (MVP) in the first quarter 2025. Following initial release, TMA will adopt a quarterly release schedule throughout 2025, allowing continuous improvement and expansion in platforms capabilities. This could include epilepsy management, voice-activated UI development and enhanced NHS systems integration.</p>					
<b>Conclusion</b>					

<b>Innovation</b>	Digital Health Passport	<b>Innovator</b>	Tiny Medical Apps.	<b>Innovation readiness</b>	Pilot ready (Adoption and scale for asthma)
<p>The Digital Health Passport has already demonstrated effectiveness in asthma management, and its expansion into epilepsy care holds strong potential to meet the two key needs: helping children and young people and their families remember medication doses, and providing tailored, responsive advice to support medication adherence.</p> <p>Although the current stage of development does not yet support full scale adoption, a pilot programme within the East of England could provide a valuable opportunity to test and evaluate the platform's effectiveness in this new context.</p>					

# Appendix 4 – Heba: Child Health Tracker case study

<b>Innovation</b>	Heba: Child Health Tracker	<b>Innovator</b>	Heba Care (formerly Hibi)	<b>Innovation readiness</b>	Adoption and spread (product is available on the app stores)
<b>Certification</b>	Heba is not classified as a medical device, it functions as a care coordination platform, rather than a clinical tool. The platform complies with NHS Digital Technology Assessment Criteria (DTAC), General Data Protection Regulation (GDPR) and is Information Commissioner's Office (ICO) and Cyber Essentials certified. Data is stored and backed up on secure AWS cloud servers located in the UK.				
<b>Introduction</b>					
<p>The Heba Care platform has been developed to support caregivers of children with additional needs and long-term conditions by providing tools for effective care coordination. It addresses the frequent fragmentation across health, education, and social care systems by offering a centralised space for information sharing, care tracking, and navigation support.</p> <p>The platform is designed for primary use by caregivers—most often parents or family members—while also enabling collaborative use by wider care teams, such as physiotherapists, care assistants, teachers, and social workers.</p> <p>To support coordination, Heba provides two core functions:</p> <ol style="list-style-type: none"> <li><b>Smart Care Management Tools</b> - These allow users to log medications (with reminders), securely store documentation, and record symptoms or behaviours using text, images, and videos. The app visualises trends and patterns to help caregivers and professionals monitor progress. Care teams can log in with multi-user access, and information can be securely exported, including through a digital care passport usable in emergencies. The app can also support with appointment notes and tracking, with some users using the app to keep track of the various meetings/outcomes they have with professionals.</li> <li><b>Personalised Care Navigation</b> - Heba includes a context aware conversational AI tool which provides tailored responses based on the users profile and location (overseen by human navigators), which can help families understand the care system, access relevant benefits, and explore care pathways.</li> </ol>					
<b>Evidence to date</b>					
<p>Initial evaluation results, conducted in partnership with <a href="#">Prova Health</a> and <a href="#">Differing Minds</a> and funded by UK Research and Innovation (UKRI), reveal positive outcomes among families using the platform. The evaluation suggest that care coordination saw a 37% improvement, with caregiver-reported ability to manage care increasing from 65% to 89%. Additionally, care navigation improved by 80%, as confidence in accessing resources rose from 40% to 72%. Communication with care teams also saw a 30% enhancement, with confidence levels increasing from 60% to 78%. Moreover, caregiver stress levels were notably reduced by 38%, decreasing from 45% to 28%. (<a href="#">Our Study Results: How Heba is Making a Difference for Families - Heba - Heba.care</a>)</p>					

<b>Innovation</b>	Heba: Child Health Tracker	<b>Innovator</b>	Heba Care (formerly Hibi)	<b>Innovation readiness</b>	Adoption and spread (product is available on the app stores)
<b>Implementation</b>					
<p>Since its public release in early 2024, Heba has been adopted by <b>over 10,000 families</b> and is now used globally in partnership with various care organisations. Families can download a free version of the app directly via app stores, as well as a premium version (<a href="#">Heba+</a>) available at for a monthly fee, while organisations can license Heba+ at a discounted rate to offer it free to families via access codes. Organisations can also customise the app with branded content and localised guidance.</p> <p><b>Implementation considerations</b> include:</p> <ul style="list-style-type: none"> <li>• <b>Technical requirements:</b> The platform runs on both iOS and Android and requires stable internet access for real-time syncing and AI navigation support. It is compatible with mobile phones and tablets commonly used in home and community settings.</li> <li>• <b>Staff and system integration:</b> While primarily designed for caregiver use, Heba is built to complement professional workflows. Staff interacting with the platform—such as SEND leads, community nurses, or allied health professionals are supported intuitively to understand how to access shared records, interpret symptom tracking data, and contribute to care coordination. Although Heba is used by some NHS patients and recommended by some NHS staff, it is not currently interoperable with NHS systems.</li> <li>• <b>Training and support:</b> Heba offers onboarding guides and online training modules. Further implementation at scale may benefit from structured CPD-accredited sessions for professionals involved in children’s care pathways.</li> </ul>					
<b>Next steps</b>					
<p>Heba aims to develop into a wider care platform, facilitating care coordination. This includes expansion across children’s care to support not just the one in six children with a developmental disorder, but more broadly across paediatrics for conditions requiring ongoing management, ranging from diabetes to anxiety. Heba will continue to scale access to care organisations involved in the support of children with developmental and health conditions, by providing access to Heba at critical points in their journey – in particular pre &amp; post diagnosis, in order to support families at home managing their child’s care. These organisations in the NHS include children’s services at acute &amp; community trusts, and SEND leads at Integrated Care Systems.</p>					
<b>Conclusion</b>					
<p>Heba is a well-developed digital health platform initially designed to support medication compliance which can be used by individuals with autism and other additional needs. Its features could prove useful in managing epilepsy, particularly in promoting adherence to treatment plans. Over 10,000 users are currently registered with the app and it holds an average rating of 5/5 on the App Store. It is also licensed for use by several private healthcare providers, including Bupa, which highlights its credibility and acceptance in clinical settings. While Heba offers helpful information on epilepsy and supports day-to-day management, it has some limitations. One key drawback is that users can't directly contact healthcare professionals through the app to ask questions or seek medical advice. Additionally, because it isn't integrated with NHS systems, its usefulness within standard public healthcare services in the UK may be limited.</p>					

## References

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