

Insights

The unified journey: Building a well-connected childhood

Protecting children, preventing gaps in care and creating better experiences through design and data

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Why this matters now

A digital safety net for every child

In my time working at the intersection of technology and public health, I have been involved in many projects where responsibility has been felt massively. Designing modern digital services that centre the patient and the front-line healthcare worker, making these systems better for all. But when it comes to children's health, we face an even bigger challenge.

The paradox that we need to address is this: in our era of unprecedented data, the systems for protecting and nurturing the next generation are still stuck in the previous generation. We need to transmute these analogue systems into the digital era.

These analogue systems are present within every milestone as our children grow up. From birth, the paper-based Personal Child Health Record (or 'red book') can be a burdensome document for any parent; the sole record of your child's health that can cause great headaches should you misplace it. Proxy access for a child's health record is not given by default and involves another paper-based process at your local GP surgery, which you then need to re-do if you move to a new one. Parents are sometimes forced to navigate the 'Wild West' of unverified health advice and guidance, because aged-based guidance and reminders for meeting critical milestones are not yet available at their fingertips in the NHS App.

Not to mention the analogue burden that this places on many front-line healthcare workers who spend their valuable time and resources supporting parents to navigate these processes and manually updating their own internal systems with the latest data. Wouldn't their time be better spent on delivering patient care?

This white paper is born from our belief that technology, when designed with empathy and always with the end-user in mind, acts as a safety net. It explores how we can establish a golden thread of data that follows a child from birth to adulthood. Our goal is to show that by connecting disparate systems of a child's journey, we create more than just efficiency. We create digitally-connected childhoods that set children up for the best start in life.



Adam Lewis

Adam Lewis,
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Section 1: Executive Summary

As healthcare leaders work to deliver the NHS 10 Year Health Plan, the transformation of digital child health services is an opportunity that sits right within the three key pillars of the Plan (From Hospital to Community; From Sickness to Prevention; From Analogue to Digital).

This white paper explores how NHS leaders can consider a shift from a reactive, fragmented system of records and processes into a streamlined, smooth journey that protects children and empowers families and healthcare professionals. By moving away from the current reliance on analogue tools such as the paper-based 'red book', we can begin to reduce the admin tax that currently forces our most skilled clinicians into hours of manual 'data detective' work.

NHS leaders should consider how to address the unstandardised approach to digital proxy access and create a national standard, which ensures a parent's ability to securely manage their child's healthcare requirements regardless of where they live. Simultaneously, we have the chance to bridge the visibility gap that often leaves vulnerable children at risk of being unseen by multiple safeguarding partners and MASH teams through enhancing interoperability and connecting disconnected datasets.

Ultimately, these ideas are about using design and data to create a digital system that is robust and resilient, being a complex user journey with multiple touch points. By prioritising user-centred design, we return valuable clinical time to the healthcare teams who need it most and ensure that every family has the connected, secure start to life that they deserve. We put forward a roadmap for a digital safety net that follows a child as they grow up, ensuring no milestone is missed and that no child falls through the cracks.





Setting the foundations: Pregnancy, birth and the first eight weeks

A child's journey with the healthcare system doesn't start with birth. It starts when their mother's antenatal care begins, at around week ten of pregnancy with their first midwifery appointment to assess the mother's health, care plan and approximate due date. From there, routine developmental scans and appointments follow throughout pregnancy, often interacting with different stages of the health system. This disparate, unconnected series of touchpoints often means that families are having to repeat their medical history to different professionals across various NHS and community settings.

Once a child is born, the intensity of data generation increases significantly. The National Neonatal Data Set alone extracts a vast list of data items from electronic clinical records covering demographics, clinical interventions, and diagnoses. In the first 72 hours, babies undergo a Newborn Physical Examination (NIPE), followed by a repeat check between six and eight weeks to look for developmental issues in the eyes, heart, and hips. Concurrent with these are the Newborn Blood Spot (NBS) screenings — which test for nine rare but serious conditions — and Newborn Hearing (NHSP) screenings.

While the immediate notification burden does not fall directly on the parents, it creates a significant data challenge for healthcare professionals. NHS England has identified nursing and midwifery documentation as a 'wicked' problem[1] that significantly impacts not only productivity and efficiency but also the morale of an already over-burdered workforce. Scoping research found that the sheer volume of required documentation can take several hours to complete, often driving a "task-focused" culture where clinicians feel compelled to complete assessments rather than focus on care.

These challenges show how the current systems are not fit for purpose when aiming to create smooth and easy experiences for both expectant families and healthcare workers alike. A through-line of records, accessible by different teams within the health ecosystem, is required to ensure parents do not have to continually repeat their medical history throughout pregnancy. And a digital-firs

[1]NHS England, Towards a unified vision of nursing and midwifery documentation, September 2023

Prevention by default: Ages one to five

Statistics paint a concerning picture of young children's health in the UK. Currently, tooth decay is the most common reason for hospital admission in children aged between five and nine years old.[2] Vaccination rates are also on the decline in the UK, with 2023/2024 data revealed that no routine immunisations met the World Health Organisation (WHO) 95% target by age five.[3] The most prominent and important immunisations of which include the MMR vaccine (91.9% for the first dose at age 5), pre-school boosters (81.4%), and 6-in-1 vaccines.

These concerning statistics can be addressed and prevented from worsening in the future. The Neighbourhood Health Plan is a core pillar of the NHS 10 Year Health Plan and will play a vital role in delivering preventative care directly in the heart of the community. Best Start Family Hubs will serve as anchors for community needs, offering integrated services where midwifery, health visiting and digital registration seamlessly take place.

Ensuring that services and data are connected and accessible by those who need to view them most is imperative in combatting these figures. Moving away from disconnected, analogue records towards a digital, integrated service reflects the real-time status of a child's healthcare needs. Combining CHIS data and the 'My Children' feature within the NHS App provides a robust digital alternative to the traditional paper-based Red Book.

For parents and care-givers, this creates a single portal for appointments, reminders and health records, reducing the need to remember multiple logins. It offers an upfront checklist of required documents or vaccinations which allows parents to prepare for the appointment and self-service features that let families update contact details.

These changes support a fundamental shift in preventative care by making it easier for families to take action at the right time and ensuring their children meet all their important healthcare milestones.

[2]Department for Education, Giving every child the best start in life, July 2025

[3]UK Parliament, Childhood Immunisation Statistics, May 2025



Bridging the gap: Ages five to sixteen

Once a child starts school, the number of agencies involved in their care increases significantly as safeguarding comes under the combined care of health, education and local authority agencies. This has the potential to create high-risk 'visibility gaps' that can undermine clinical safety and safeguarding efforts.

As part of the Neighbourhood Health Plan, digital NHS leaders should consider how health services can work in partnership with nurseries, schools and colleges, and Multi-Agency Safeguarding Hubs (MASH) to ensure that support is accessible and visible within the local community. Joining up these disparate services — and therefore data services — is essential to making this vision a reality.

Historically, the lack of a shared identifier has hindered effective collaboration between health, education, and social care. While healthcare identifies individuals via the NHS Number, local authorities and safeguarding partners often rely on fragmented local IDs. This discrepancy is most dangerous if a child and their family move across regions or counties. Their local authority record often doesn't reflect their move and 'stops', while the new authority may have no immediate visibility of their history, vulnerability, or specific care needs.

Safeguarding must become a digital priority by establishing a unified data marker that stays with a child throughout childhood, much like a National Insurance number later in life. This means we can bridge these organisational divides by and create a golden thread of information that protects the most vulnerable of children.

A shared, live record gives a social worker in a MASH team or a school nurse an instant, entire view of a child's history, removing the need for manual record-checking and significantly reducing the data visibility gap. This shifts the burden off frontline workers with other duties to perform, moving from a reactive system of manual work to a proactive system that follows a child wherever in the country they and their family might go.

The transition: Ages sixteen and beyond

The current handover gap where children age out of childhood and move into young adulthood — especially those in care, in the justice system or other vulnerable situations — abruptly lose access to their health history. Reaching out proactively to these groups to bring them on the digital transformation journey is crucial to closing this gap and enabling the onward through-line of a child's healthcare record.

One such way is by providing true equity of access. A system that seamlessly transitions from the medical record from a parental proxy model to one that champions adolescent ownership and agency.

Protecting children starts by recognising that not everyone has the same access to education and growth in childhood and that children have their own levels of digital literary and technological confidence. 2025 research from RM Technology and the Digital Poverty Alliance highlights this reality: over half (57%) of families said their child struggles to access devices or reliable internet outside school and that most teachers (75%) warned that poor digital access is causing pupils to fall behind or disengage from learning. For young adults to take ownership of their healthcare for the first time, protecting them means designing systems that balance security with inclusion. Strong controls matter but they need to be navigable by people with differing ranges of ability and digital competency.

Identity systems should support safer journeys without making them harder to complete. By offering strong but flexible authentication journeys, including a hybrid mix of passwordless methods and secure traditional fallbacks, we can ensure that these transitioning young adults are not locked out of their own health data.

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How do we get there?

The mechanics underpinning the idea

To achieve this overarching vision of a digitally connected childhood requires the transition from analogue to digital ways of working. We need to:

1. Move from outdated architectures and processes that rely on manual notifications and paper-based documentation toward an event-driven model that supports real-time updates.
2. Modernise legacy CHIS databases into cloud-native systems that support the critical infrastructure of tracking a child's 'in-spells' and 'out-spells' when moving between new homes and schools.
3. Ensure that the NHS App can serve as the digital single-source-of-truth for families by fully integrating screening reminders, NIPE checks and My Children records through Proxy access.

Delivering this will be no easy feat. It hinges on fragmented data standards being replaced by national schemas, open APIs to support consistent data exchange and reinforcing data-sharing protocols within Multi-Agency Safeguarding Hubs (MASHs). We must build an interoperable foundation that connects healthcare teams, local authorities, schools and Family Hubs in a seamless and smooth way.

[4]RM Technology and the Digital Poverty Alliance, Half of low-income families warn children face digital exclusion this summer as holidays expose inequality, 2025

Why UCD derisks digital health innovation

Technology itself is rarely the problem. Instead, we find that the implementation gap stems from the controlled environments in which the system was made does not match the real-world, high-pressure contexts in which it is used. Services are inevitably not as effective when they are built around decisions made by back-end system logic rather than human behaviour.

Complex interfaces and processes increase cognitive burden and mental effort for both clinical staff and parents. A UCD approach underpinning the engineering of a digital system is a critical component in building services that are robustly stress-tested, future-proofed and explicitly designed to perform during the moments that matter most. Whether it's for a busy parent booking a vaccination appointment, a young adulthood gaining ownership of their own data or a healthcare worker trying to reconcile an outdated paper record, these tasks become vastly more manageable with the end-user always at the forefront of key design decisions.

How do these design principles impact real-world digital systems?

Design principle	Operational example	Outcome
Event-driven workflows	Moving away from static forms to systems that trigger actions based on real-world events (e.g. a birth registration).	**Reduces cognitive load:** Clinicians no longer need to manually track milestones, the system prompts the next action, thereby reducing the risk of missed care.
Automatic, secure accessibility	Ensuring data captured by a midwife is accessible to the health visitor and GP without manual re-entry.	**Eliminates administrative latency:** Directly addresses healthcare workers spending valuable time hunting down critical data, reducing hours of clinical time to face-to-face patient care.
Frictionless onboarding	Designing simple, digital-first identity and relationship verification processes (e.g. NHS Proxy Access service).	**Increasing digital uptake:** By removing the need for in-person GP visits for access, digital engagement rates rise and free up phone lines for higher-priority enquiries
Information hierarchy	Prioritising the most critical data (vaccination status, safeguarding alerts) so it is visible at first glance, not after a scroll.	**Enhancing clinical safety:** Reducing search time during consultation, making key information easy to access and find.
Inclusive, accessible design	Designing for all end-users but particularly those with low digital literacy or accessibility requirements	**Mitigates digital exclusion:** Inclusive-by-default design means the Neighbourhood Health Service remains equitable, reaching the most vulnerable families who are often the hardest to engage.

Conclusion: Making the next generation of children happier and healthier

Every child in England deserves to grow up meeting every milestone that represents a happy, healthy childhood. The goals set out in the NHS 10-Year Plan, supported by the Best Start in Life strategy, present a genuine and unprecedented opportunity to achieve this.

However, this clear mandate to shift to a digital-first approach will only be successful if the systems built to support it are designed with the exact same rigour, empathy, and attention to detail as the policies that commissioned them. If healthcare organisations put their users' needs at the heart of their services, and build the right technology and data solutions, they can create more seamless and secure experiences while fulfilling their regulatory obligations.

Modernising legacy CHIS databases into real-time Population Registers, streamlining complex onboarding processes, and securely connecting disparate public services should be front-of-mind considerations for NHS digital leaders. By treating such systems as dynamic tools that adapt to context, this allows for confidently managing risk without slowing clinical work down. Ultimately, aligning our design, technology, and mindset will ensure that no child ever falls through the cracks when it comes to their health, providing them with the connected, secure start to life they deserve.

We invite NHS Digital leaders, ICS partners and others to consider what comes next with regards to digital children's health. With successful pilot phases already underway for key projects in this space, the foundations have been set to move these pilots into real-world implementation. And the thinking behind these projects can be applied to many others that require the same depth of knowledge, context and technical expertise in the children's health space. We'd be happy to start a conversation about how we can turn these strategic considerations into a frontline reality for your workforce and the nation's families.

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