



National Information Board

NHS
England



**Healthy Children:
Transforming Child Health
Information**

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1. Foreword

High quality care for all, now and in the future

We are delighted to introduce *Healthy Children: A Forward View for Child Health Information*, which sets out an exciting new vision for how child health information can support both parents and professionals in providing the highest quality care for children and young people and would like to thank everyone who has taken time to contribute to its development.

The *NHS Five Year Forward View* outlined three gaps: the care & quality gap, the health & wellbeing gap, and the finance & efficiency gap. None of these gaps can be closed without better use of technology and information, and this strategy will revolutionise the way that information is used to support development of new care models, as well as promoting health & wellbeing and evaluating preventative programmes.

NHS England has led the development of this bold strategy in collaboration with stakeholders in health, social care and education, and voluntary organisations, as well as with parents and young people and the information technology supplier market. All agreed that the existing configuration of child health information services, based on organisational care records and paper-based information flows, can constrain what can be achieved in modernising service delivery and improving the health outcomes and experience of those children and young people accessing care services.

Our vision is to create a step change in the way information and technology are used to provide new opportunities for collaboration between health and care and education professionals and the families, children and young people receiving care. We will use the capability of modern systems to exchange important events and information rapidly and securely between professionals and parents and young people as a means of joining up care across organisational boundaries and promoting active participation in care. This work supports the findings of the recent national maternity review which recommends more personalized care, centred on women, their babies and their families and facilitating continuity through use of digital technology.

Every child deserves the best start in life and the highest quality care throughout childhood and their transition to adulthood. Using information and technology more effectively is crucial to delivering this, and I hope you will support us in working together to achieve this aim.



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2. Executive Summary

Providing a good start in life and enabling children to achieve their full potential and be physically and emotionally healthy provides the cornerstone for a healthy, productive adulthood¹.

Public Health England and the NHS Outcomes Framework 2015/16² stress that a focus on children's health is essential and that we should be striving to provide the best start in life possible for our children. The recent National Maternity Review³ has highlighted that this begins not just with the newborn child but with the mother's experiences in pregnancy and the birth itself.

The importance of ensuring this good start for the future health of children for the sustainability of the NHS and the economic prosperity of Britain is one of the key themes of the Five Year Forward View⁴.

Across health and social care and education there is now a determined focus on improving outcomes for children's health and wellbeing. Emphasis is on the importance of early interventions and preventive measures in improving health, more coordinated approaches to health and wellbeing and giving greater weight to the voices of children, young people, parents and families to develop effective care strategies.

Access to information and effective information services have a strong role to play in supporting this agenda.

This forward view outlines a new vision for how child health information can support parents and professionals in their direct care for children and young people and how the same information can be used to promote their health and wellbeing.

We set out the case for restructuring our information services and systems for children, young people, parents and families so they can contribute fully to improving their health and wellbeing and collaborate easily with professionals across the spectrum of care.

¹ [From evidence into action: opportunities to protect and improve the nation's health, PHE October 2014](#)

² [NHS Outcomes Framework 2015/16, Department of Health, December 2014](#)

³ [Better Births: Improving outcomes of maternity services in England](#)

⁴ [Five Year Forward View, December, 2014](#)

3. Shaping the Future: Our Vision

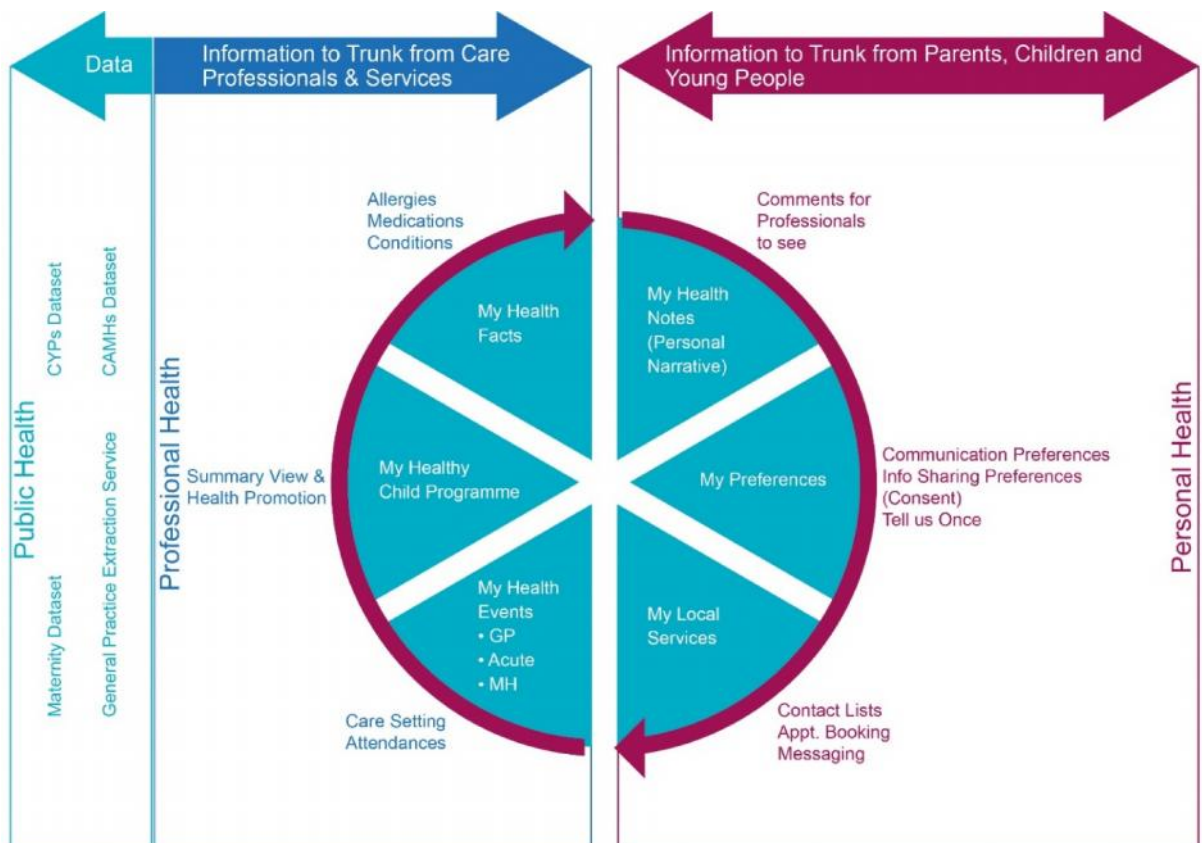
Our vision is for transformed child health information services which achieve two objectives:

- **Knowing where every child is and how healthy they are**
- **Appropriate access to information for all involved in the care of children**

Redesigned information services will support personalised care, promote the offer and uptake of preventative programmes of care and provide the foundation for integration across the domains of health, social care and education.

The vision is not one of a single centralised information service or system for children’s health but of various information services exchanging data in a standardised format via a central hub. Information will flow to where it is needed, improving the experience of care and health outcomes for children, young people and their families and supporting the professionals providing that care.

Figure 1: Business Operating Model - Digital Child Health Hub



This is a new business operating model for child health information services, a Digital Child Health Hub, describing a service where professional health information drawn from existing organisational systems meets personal health and care information provided by parents and families and young people through use of online personal health records.

Information can be thought of as a series of 'events' exchanged electronically in real time within a consent framework so that all involved in the care of children have the information they need. Not all information recorded about children will need to be an exchangeable event. Careful thought needs to be given to identifying which events are 'key' and who needs to see them and for what purpose.

This dynamic events driven model of information exchange is what will replace the current configuration of child health information services for children. That configuration is based on organisational health systems which for the most part do not speak to each other and consequently rely on exchange of information by paper notification. This constrains the pace at which more integrated services can develop and the timeliness of information being provided to professionals and parents to support care of children and young people.

Moving to an events driven model is an incremental journey, with more information becoming available for exchange year on year. We will start this journey by creating events which are applicable to the whole children's population and are already designated as being important markers for public health. As experience of working with this type of interoperability grows and starts to show benefit, we can use that experience to move into more complex areas of children's health information and create further events for exchange. As the events available for exchange increase new digital services can be provided to the key audiences for that information:

New information services for parents, families, carers and young people

'I want to be in control of decisions to share my information'

'I want personalised care from professionals who know about my history'



Parents, Carers, Children & Young People

1. Parents, families and carers will have an online record of their child's health and development.

2. Young people will have an online record of their own health and care issues.
3. Parents, families, carers, young people and professionals will share a common (core) view of the health information recorded about children and young people to better support their care.
4. Parents, families, carers, children and young people can set their own preferences for information sharing and can see who subscribes to their information.
5. Parents, families, carers, children and young people can publish their own goals for health and wellbeing and share these with professionals, empowering them to manage their care in a collaborative partnership.

New information services for professionals

'I want to have accurate, up to date information when I need it'

'I want to be alerted if there is a significant issue with a child under my care'



6. Professionals will have access to a core view of child health information at the point of care to improve decision making.
7. Professionals will have up to date child health events available in their own organisational record systems: they will not need to access other systems for key events.
8. Professionals with a responsibility for a child will have real time access to key events occurring for that child in other organisations, where it is appropriate to do so.
9. Professionals will only have to record information about a child/young person once as that information can then be published automatically to those in the extended network of care.
10. Professionals will be able to identify when a child has fallen outside the care of the usual responsible agencies, such as a GP or Health Visitor, assisted by alerts from a failsafe management service.
11. Professionals delivering preventative programmes of care will be alerted by a failsafe management service when an intervention is due or has been missed.

New information services for public health

'I want to have high quality, relevant, reliable information to assess the health of the population'

'I want to be able to reach individuals in a population easily in the event of public health concerns'



12. Public health professionals will have access to more comprehensive, more up to date datasets as interoperability of events gradually replaces the re-keying of information from paper notifications.
13. Administration of public health programmes and call and recall can be standardised to a high degree through applying immunisation rules and schedules nationally as a series of events rather than locally.
14. Public health professionals will have access to real time population data for analysis as interoperability of events becomes routine.
15. It becomes possible to deliver personalized health promotion materials to people and enter into dialogue with them. As parents, families, carers and young people begin to use personal health records routinely.

Our vision of an events driven model of child health, when implemented, will finally allow information to follow the child/young person, whatever their journey through different health and care and education services and organisations.

4. The Case for Change

It has been twenty years since the current configuration of child health information services was introduced. In that time the organisational structure of the NHS has changed several times, policy for children's health and wellbeing has evolved and new technologies to support health and care have become available. The existing configuration of services based on organisational health care systems exchanging information between care settings on paper can no longer support the direction of travel. In summary the current challenges in child health information services are;

- There is no current view of a core set of data for a child outside of the Personal Child Health Record (PCHR)
- There is no capability to manage the care of children who are unregistered to child health information systems or GP systems
- Currently professionals don't have access to relevant child health information
- Services still very paper driven and manually intensive

The case for change can be summarised into three priority themes; the need for prevention, for personalisation and for integration. The recommendations of the National Maternity Review, which forefronts these same themes, provides an additional impetus for change.

Prevention

The first position put forward in the Five Year Forward View is that the future health of millions of children, the sustainability of the NHS, and the economic prosperity of Britain all now depend on a radical upgrade in prevention and public health.

This argument follows the findings of the *Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays (October 2013)*⁵ which provided a new assessment of the state of children's health in England and concluded that children and young people in England are not doing as well as they could and recommended a new emphasis on the importance of early interventions and preventive measures in improving health.

Preventative interventions should locate children within the broader context of the family, recognising the huge impact families and parenting has on child health and wellbeing. So although this review deals with digital services for children's health this must also be seen to include the crucial linkages to other members of the family, particularly the mother during pregnancy.

Consideration needs to be given to information services which provide

⁵ [Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays](#)

continuity of care for both mother and baby throughout the antenatal and postnatal period.

Personalisation

The second position put forward in the Five Year Forward View is that when people do need health services, they should be given far greater control over their own care, including the option of shared budgets combining health and social care. This will result in a 'personalisation' of care.

Personalisation requires a new collaborative partnership between patients and clinicians to improve outcomes that are important and meaningful for the child and their parents or carers. There is therefore a strong shift in the direction of co- production of health between families and the providers of services and emphasis on greater participation of children, young people and families in decision-making at all levels within health and care. For this to happen there must be greatly improved access to information for children, young people, parents / carers and clinicians to enable the making of timely, informed decisions.

Integration

The third position put forward in the Five Year Forward View is that the NHS will take decisive steps to break down the barriers in how care is provided, that is, it will aim to integrate and coordinate care more effectively across organisational boundaries.

Integration is essential in children's health services in the wake of the Health and Social Care Act (April 2012) which moved the commissioning of some public health services for children out of the NHS and over to local authorities. This has increased the number of commissioners and the number of providers of care for children and created further users of and audiences for child health information. It makes it imperative that information move beyond organisational silos to join up care pathways and assist in improving health outcomes.

Making the Future

The Forward View outlines five foundations for the future of child health information services:

Interoperability

The events model we outline in our vision is predicated on interoperability: systems currently collecting child health information will be able to publish elements of that information as events and will be able to subscribe to events originating from other systems and display these events and act on the information they provide. This will replace the use of paper notifications between different care settings and professionals.

Failsafe Management (Knowing where every child is)

If child health information services are to know where every child is, population management for public health must be delivered within the framework of a national population of children to provide the failsafe that no child is denied the services offered via the Healthy Child Programme.

Programmes of care aimed at prevention and early detection of health issues must be capable of inviting all children and young people in a local population to receive those services and monitoring whether the offer has been taken up, when the treatment or review took place and what the outcome was.

A failsafe management service for children and young people and population-based programmes of care would provide a series of prompts and alerts to ensure these services are offered and delivered to families and children.

Core Record Dataset (Knowing how healthy a child is)

A core record dataset is required so that all involved in a child's care can know with certainty what the health status of that child is. This would ensure that baseline information for a child is available prior to treatment.

The idea of a core shared view is not new. The Summary Care Record (SCR) of primary care information provides such a view and the current record available in child health information systems provides such a view. But the drawback of both these views is that they are only partial.

The new service required is a core record dataset for children and young people which is shared by parents and professionals. In line with the events driven model being proposed, the core record dataset would be described as a set of discrete child health events, an events catalogue, which existing systems can publish and subscribe to.

Access (Appropriate access to all involved in the care of children)

In introducing health events and the capability to publish and subscribe to events, the forward view suggests a major way in which the problem of access can be addressed. In suggesting use of a core dataset, it also provides a way in which important summary information can be made available to professionals and to parents and young people too.

Access to such information needs to be 'appropriate' and there needs to be transparency as to who has access to information and why. Compliance with the Data Protection Act 1998 is also required.

To facilitate appropriate access to child health information for all involved in the care of children, consent frameworks, role based access and authentication standards will need to be implemented so that parents and young people and professionals have confidence that data is held securely and shared in alignment with the parents' and young person's wishes.

Personal Health Records

Personal Health Records for children have been in use in England for over 20 years. The Personal Child Health Record (PCHR or 'red book') is usually given to parents shortly before or after the birth of a child.

The PCHR has functioned as a summary child health record within England's health economy and been an essential adjunct to organisational records precisely because it provides a holistic overview of a child's health and development which is often not present in organisational records.

The consideration for the forward view is to ensure that the ethos of this original personal health record (PHR) can be taken forward and transferred to a digital platform to provide improvements in service to parents, families, carers, children and young people and the professionals who provide the care.

As the PCHR is a cross-professionally agreed summary record with a core record dataset agreed nationally, PCHR content will form the basis of the core child dataset and the initial events catalogue. This will ensure that systems used to provide care to children can subscribe to the summary of events and have a baseline overview of a child or young person's health prior to beginning treatment.

The same foundations we are implementing for children's information service can also be used to support the recommendations of the National Maternity Review.

Implementation of the Forward View

To realise our full vision of personalised and collaborative care for children and young people work will be ongoing from now until 2021. The priorities for 2016/17 are to:

- establish a programme of collaboration and engagement,
- start 'discovery' work to define the information, interoperability and architectural models in consultation with collaboration partners, plan proofs of concept for these models and begin the approach to transformation of services by modelling current and future processes to understand the impact and benefit of change.

The information models and approaches defined in the discovery phase are an input to the proof of concept projects and the intention is that these will establish the viability of the vision within 2016/17 allowing much more detailed plans and costings for delivery of the full vision to be available going into

2017/18. Detailed plans for implementation will be released in a roadmap later in 2016/17.

5. INTRODUCTION

Terms of reference

Issues of children's and young people's health and wellbeing are now a major priority within health, social care and education.

Public Health England, the NHS Outcomes Framework 2015/16 and the Five Year Forward View have all stressed that a focus on children's health is essential and that we should be striving to provide the best start in life possible for our children.

The recent National Maternity Review report, *'Better Births: Improving outcomes for maternity services in England'*⁶ has highlighted that this best start begins not just with the newborn child but with the mother's experiences in pregnancy and the birth itself, making it essential that we join up our thinking and our information services to provide better experiences for families.

Healthy Children: A Forward View for Child Health Information is a response to these new drivers for change and also a response to a National Incident Team finding that the effectiveness of child information services could be improved with regard to identifying children for preventative programmes of care.

The team responsible for the forward view was established with a brief to consult colleagues across the care spectrum to determine what improvements were needed to provide effective child health information services.

Redesigned services should support the new emphasis on the importance of early interventions and preventive measures, integration across different care settings and the need to enfranchise children, young people and parents as equal partners in their care. It should also reduce the operational risks which have been reported throughout the period of consultation.

Terminology

We are aware that care professionals and technology and management specialists are all prone at times to using 'jargon' which can be off-putting to readers. We have tried not to do this and where acronyms and technical terms are used we have provided a glossary at the end of the document to assist understanding.

The subject of this document is the information gathered and shared to support the health and wellbeing of children and young people, recognising that sometimes this information is held by their parents, carers or other family members. It can be cumbersome to repeat the phrase 'children, young people, parents, families and carers' throughout the document, so sometimes we will use just 'children' and 'families' instead. This is done purely for the sake of brevity and we wish to emphasise that we recognise the complexity of

⁶ [Better Births: Improving outcomes of maternity services in England](#)

family constellations and the independence and maturity of many young people who would not self-identify as 'children'.

We use the term 'professional' or 'care professional' to denote anyone who is providing direct care to children and young people, whether in the NHS, in social services, local authorities, educational establishments, voluntary organisations or in other organisational settings.

When we talk about 'children's information' or 'child health information' we have in mind information gathered by professionals in support of direct care but also information recorded by families and young people that they want professionals to be aware of.

The vision we set out in the following pages is predicated upon the move away from regarding information as being organisationally 'owned' and instead seeing it as an important asset which should be put to work on behalf of the subject it is about, children and young people, to improve their experience of care and their health outcomes.

Scope of child health information

Child health information services have not generally been well understood outside of the professional circles who work day to day with children and rely on those services to provide information about children's health.

For the last 20 years, these services have comprised:

IT systems: the child health information system (CHIS) used to record some clinical activities and public health interventions with children. These systems can vary considerably in scope and function but as a minimum will track the population within a particular Clinical Commissioning Group (CCG) or local authority geographical boundary and schedule routine interventions such as immunisations and developmental checks. In some cases Child Health is a module of a much larger Community Health Information System (also CHIS).

Information services departments: the child health record departments (CHRDs) who support the information systems and any associated paper records and manage queries about the health status of children in the local population. These departments are responsible for maintaining active and accurate child health records for a given local population.

The personal child health record (PCHR): a national standard health and development record given to parents/carers at a child's birth, often referred to as the 'red book'. The PCHR is the main summary record of a child's health and development. The parents/carers retain the PCHR and health professionals should update the record each time the child is seen in a healthcare setting so that a full record of results, observations and interventions is maintained.

These three components can be thought of as comprising an information hub in each locality from which various categories of child health information, both

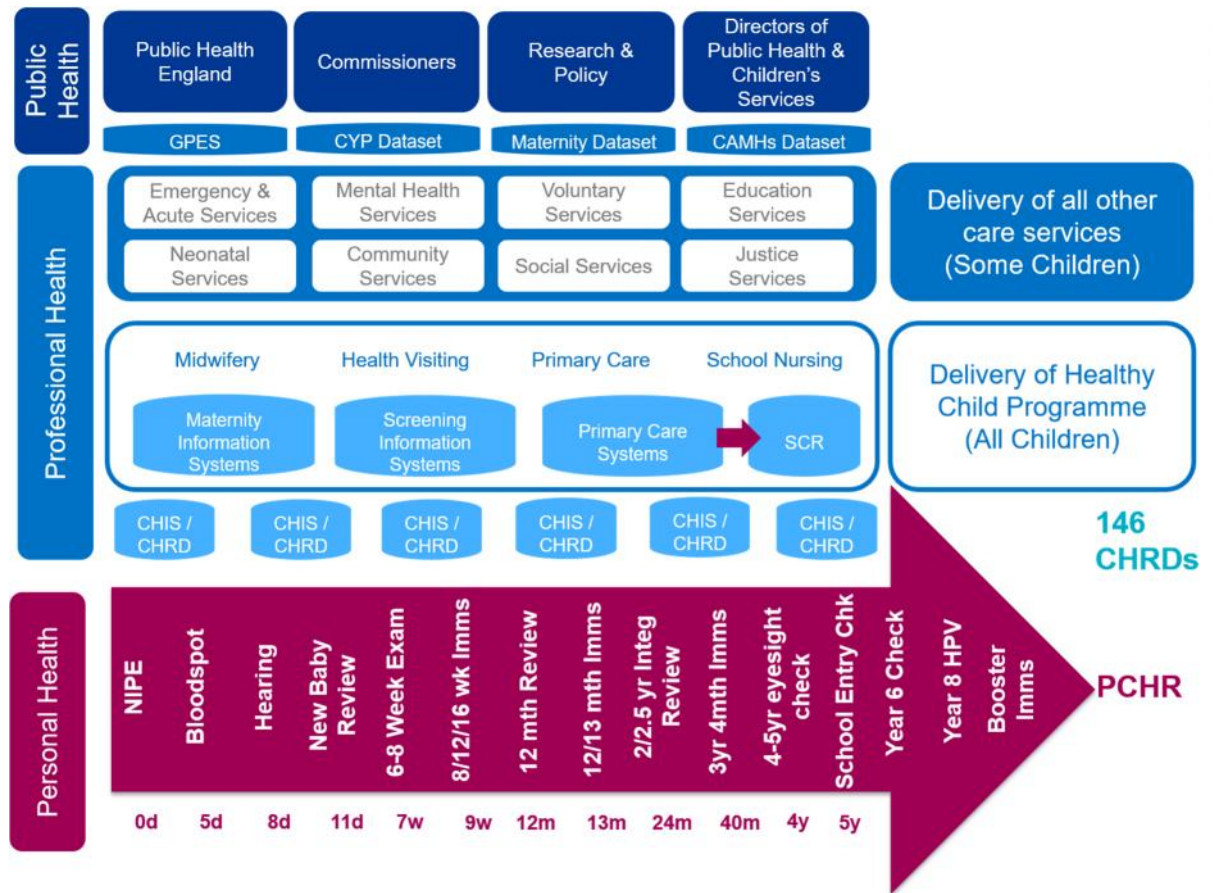
personal and anonymised, have been directed to the professionals who need to use that information.

The hub sustains an extensive network of connections in health and social care who co-operate to deliver the Healthy Child Programme; a series of reviews, tests and immunisations to which every child in England is entitled and which is free at the point of care.

Child health information services liaise across care settings and agencies and regions to ensure that children and young people in their local population are offered the Healthy Child Programme and that key information on children's health is available to parents and professionals and for public health purposes.

Child health information, however, is much, much wider than that generated by the Healthy Child Programme and collated into the Personal Child Health Record and the diagram below shows where delivery of this programme sits in relation to the wider model.

Figure 2: Map of Child Health Information



Further information on this model can be found in Annex A, which describes how child health information services currently operate.

The consequences of the Health and Social Care Act 2012 and the Children and Families Act 2014 are that health information must be available to inform decisions in social care and education and vice versa extending how many organisations now need to co-operate to improve the health and wellbeing of children and young people.

For this reason the scope of the Forward View includes looking at how all children's health information can be shared effectively, not just the elements of the Healthy Child Programme which are captured by CHIS.

Audience for child health information

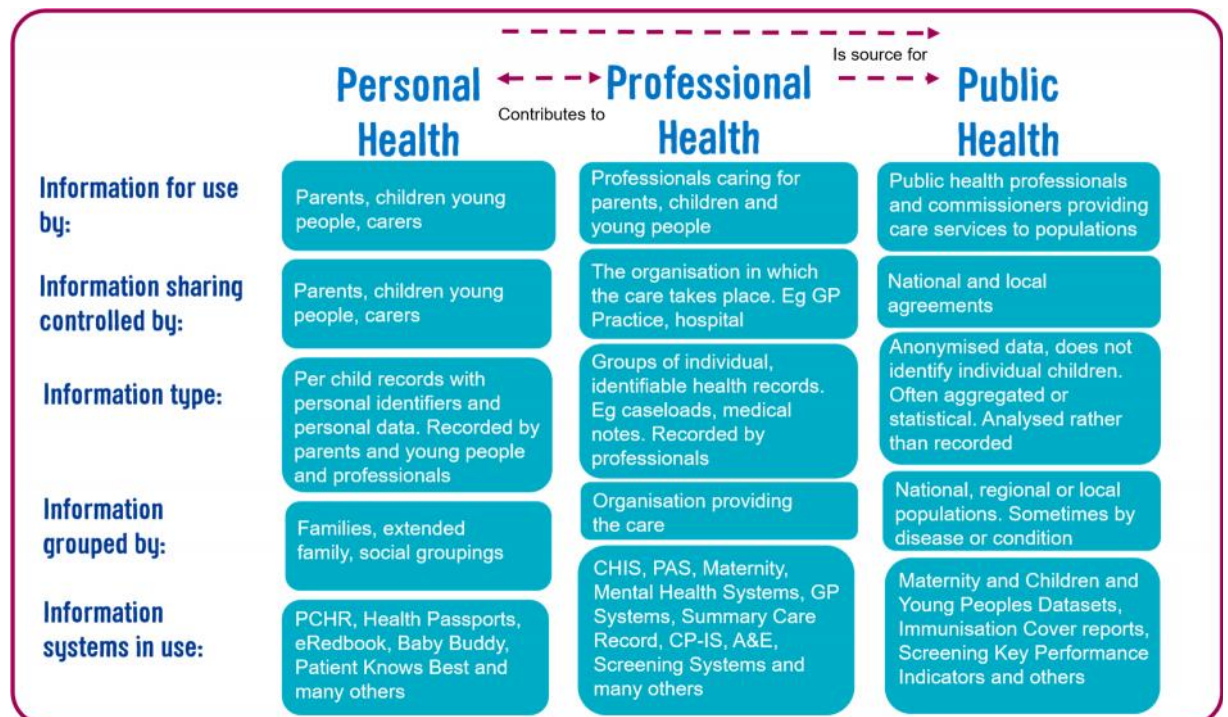
To understand how child health information services function now and who they serve it is easiest to think of them as three overlapping sets of information, each providing different types and depth of information to different audiences:

Personal Health: parents, families, children, young people and carers who hold the PCHR and need information for the purposes of self-care/self-management.

Professional Health: professionals across health and care and education services who record and use information about the children they see for the purposes of direct care.

Public Health: professionals who look at local population health and the effectiveness of the healthcare given to the population, whether that population is geographically defined or defined by an illness type: these include public health professionals, medical researchers and commissioners.

Figure 3: Who needs child health information?



In the current configuration of services these information sets are interlinked:

- Some health records of children kept by health and care professionals are summarised and entered into the Personal Child Health Record (PCHR) retained by parents. The PCHR is therefore a collaborative health record containing information entered by both parents and health professionals.
- Professional health records are also the source for public (population) health. Here information is abstracted and anonymised using datasets

and then analysed to evaluate how healthy a population is and whether the treatments delivered to that population are effective. Individual children cannot be identified in the data used for this aspect of public health.

The principle that needs to be adhered to when information is collected and used by different audiences is that it should be collected only once yet used many times. Due to the current lack of interoperability between the services/systems used by the different audiences this is largely not the case, although it remains the guiding principle for this and other digital strategies.

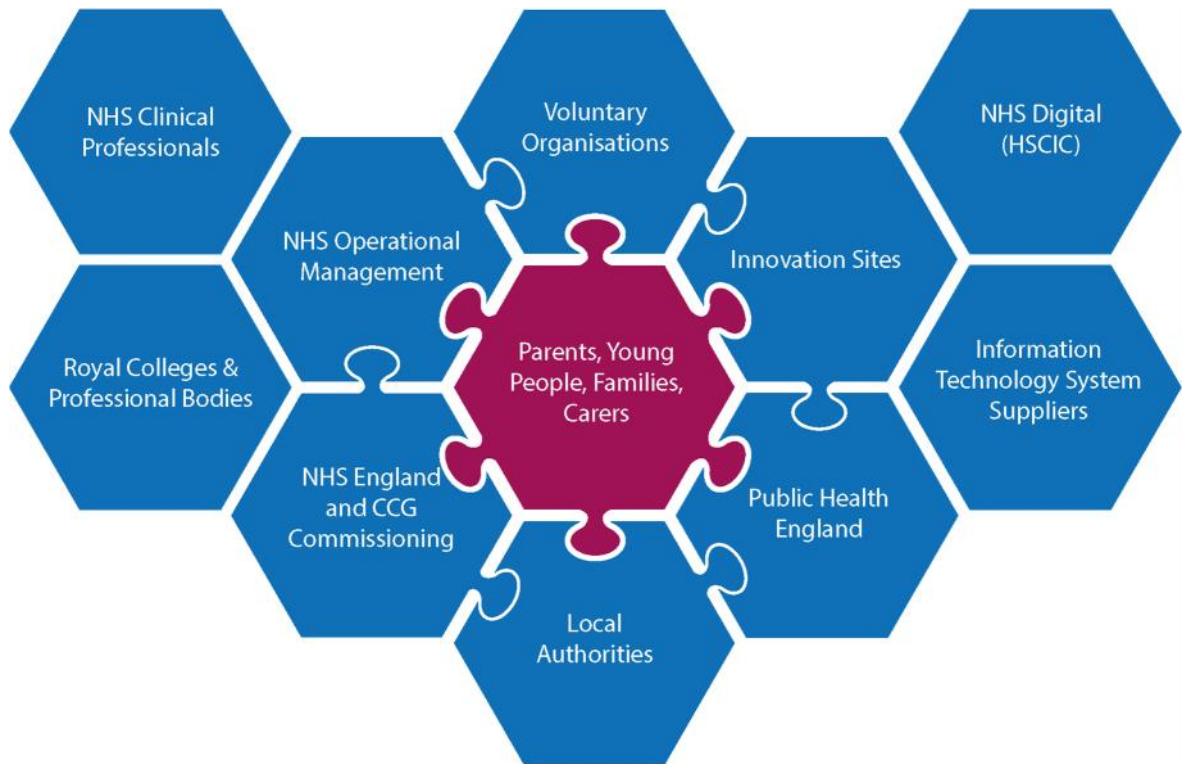
The key to re-designing effective information services for children and young people is to ensure that each of these domains has the information it needs in the format most suited to those needs and that the way this information is shared between organisations is transparent and is in accordance with the preferences set by families and young people themselves.

The forward view assigns a central place to personal health records as a means of enfranchising parents, families and young people as equal partners in their care and providing a means of collaborative care.

Engagement

The team working on the Forward View carried out a focused engagement over a six month period consulting with stakeholders in health, social care, education, voluntary organisations, as well as with parents and young people and the information technology supplier market. The consultation covered all the following stakeholder groups:

Figure 4: Stakeholders



This activity explained the scope of current child health information services and sought discussion of and contribution to what future information services should do and what needs should meet. As ideas about the future of information services emerged these were actively shared with stakeholders at events, individual meetings and via online forums. Each new iteration of the forward view was shared and stakeholders were actively encouraged to comment and/or contribute to the evolution of ideas.

The programme of engagement included:

3	National stakeholder events including discussion with and contribution from 133 stakeholders	2	National supplier engagement events, discussions with 137 supplier representatives
50	Individual interviews with key stakeholders and experts	26	Group consultations / interviews with stakeholders and experts
31	Contributions to an online consultation survey which ran from November 2015 to March 2016	131	Online Forum members, sharing versions of the Forward View and other relevant material and with a question and answer stream
7,059	SlideShare downloads		Direct consultation with parents and young people run by the Association for Young People's Health and the Royal College of Paediatrics and Child Health
1,590	Blog views		
179	Web page hits		

6. THE CASE FOR CHANGE

It has been twenty years since the current configuration of child health information services was introduced. In that time the organisational structure of the NHS has changed several times, policy for children's health and wellbeing has evolved and new technologies to support health and care have become available. The existing configuration of services based on organisational health care systems exchanging information between different care settings on paper can no longer support the direction of travel.

The case for change can be summarised into three priority themes, the need for prevention, for personalisation and for integration. The recommendations of the National Maternity Review, which forefronts these same themes, provides an additional impetus for change.

Prevention

The first position put forward in the Five Year Forward View is that the future health of millions of children, the sustainability of the NHS, and the economic prosperity of Britain all now depend on a radical upgrade in prevention and public health.

This argument follows the findings of the *Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays* (October 2013) which provided a new assessment of the state of children's health in England and concluded that children and young people in England are not doing as well as they could, citing high mortality, morbidity and inequality when compared with other countries. Also the nature of childhood morbidity and mortality has changed, moving away from acute illness and injury, particularly in the under-fives, and seeing increases in suicide and long terms conditions in adolescence, particularly related to lifestyle factors.

The report recommended children's services should provide:

- Emphasis on the importance of early interventions and preventive measures in improving health
- Proportionate universalism: improving the lives of all, with proportionately greater resources targeted at the more disadvantaged groups
- More coordinated approaches to child health and wellbeing if outcomes are to be improved
- Investment in the current and future health of children and young people rather than focusing purely on spend
- Greater weight to the voices of children and young people and families if effective strategies are to be developed

Since that report was published efforts have been made to develop and evaluate effective models of care for children and young people. The Children and Young People's Health Outcome Forum reports of 2013 and 2015

showcase this work and emerging new models of care have been reviewed very recently by the Nuffield Trust in the report *The Future of Child Health Services: New Models of Care*, (February 2016)⁷

This Nuffield review brought together frontline clinicians, senior health researchers, service users, commissioners and others to examine new models of care for children and young people. In doing so they identified four underpinning principles of an ideal system for health services provided to children and young people which would result in improvement to health outcomes.

These principles are:

- Understanding children, young people and their families' specific needs
- Enabling access to high quality paediatric/child health expertise in the community
- Linking up information, data and communication and care
- Health literacy and education.

These principles call for a dismantling of the traditional boundaries between users and providers of care, organisational settings, information systems and domains in order to provide more effective care integrated around the needs of children, young people and families. A move away from single institution/silo based care to networks of care distributed across providers, enfranchising users as equal partners in that care.

Preventative interventions should locate children within the broader context of the family, recognising the huge impact families and parenting has on child health and wellbeing. So although this forward view deals with digital services for children's health this must also be seen to include the crucial linkages to other members of the family.

The health of the mother during pregnancy and maternal risk factors are particularly important here and consideration needs to be given to information services which provide continuity of care for both mother and baby throughout the antenatal and postnatal period, as recommended in the National Maternity Review report, *Better Births: Improving outcomes of maternity services in England*.

These are changes that an effective digital strategy for children - one based on interoperable systems exchanging information in support of personalised pathways of care - can enable. Annex B provides a list of suggested actions to support the principles on which new models of care for children are based.

⁷ [The Future of Child Health Services: New Models of Care, 2016, Nuffield Trust, Kossarova, L. Devakumar, D. and Edwards, E.](#)

Personalisation

The second position put forward in the Five Year Forward View is that when people do need health services, they should be given far greater control over their own care, including the option of shared budgets combining health and social care. This will result in a ‘personalisation’ of care.

The Children and Families Act 2014 introduced improvements to children’s rights and further measures to assist children and families in accessing the care and support they need. The act is specific about improving the co-ordination of care for children with special educational needs or disability. Both these things support the personalisation agenda.

The Act also gives children, young people and their parents more say about the care they get and requires that schools provide much more help to children with medical problems and not just those with special education needs or disability.

Personalisation requires a new collaborative partnership between patients and clinicians to improve outcomes that are important and meaningful for the child and their parents or carers. This will include the provision of personal budgets.

These principles and recommendations indicate a strong shift in the direction of co-production of health between families and the providers of services and emphasis on greater participation of children, young people and families in decision-making at all levels within health and care.

For this to happen there must be greatly improved access to information for children, young people, parents/carers and clinicians to enable informed decisions to be made.

The recent ‘Children’s Commissioner Takeover Challenge’ run by the Children’s Health and Wellbeing Partnership and focusing on young people with long term conditions, stressed how important access to information and information services are to achieving co-created, personalised services:

Figure 19: Themes and goals for an improved experience of healthcare as agreed by young people with long term conditions, December 2015, Children’s Health and Wellbeing Partnership.

Theme	Goals
<p>Integration</p> <p>Care is coordinated for young people with long term conditions so young people don’t have to repeat their story and care better meets their needs.</p>	<p>To have a health passport or record for young people with long terms conditions which is transferable to different settings and means young people don’t have to repeat their story.</p> <p>There is national access to data about children and young people’s health to assist in the management of long term conditions and transitions between services</p>

Theme	Goals
	Children and young people have the flexibility to use technology to access services and information etc. (e-mail, Skype and Telephone)
<p>Consistency</p> <p>Care is consistent for young people with long terms conditions and we remove unnecessary variation in care.</p>	<p>Children and young people have safe ways to share their experiences and it makes a difference to how services are provided.</p> <p>Information travels with the young person or child but the professional can share across the health care network.</p> <p>Data about children and young people’s health is collected regularly, consistently published and learnt from to implement change.</p>
<p>Engagement</p> <p>The voices of young people with long-term conditions are listened to and inform the development, delivery & commissioning of services nationally & locally.</p>	<p>Use social media to engage with young people.</p> <p>Ensure engagement activities themselves are accessible and that engagement enables transparent discussions that improve information and services for young people</p> <p>Developmentally appropriate engagement for age and stage of children and young people.</p>

The vision set out in the recent national maternity review is also one of personalised care. The review recognises that every woman, every pregnancy and every family is different and therefore quality services must be personalised.

The review recommends that unbiased information should be made available to all women to help them make decisions and develop their care plan and that this should be provided through their own digital maternity tool enabling them access to their own health records.

The drive towards personalisation provides a tremendous opportunity to deliver an information service which recognises the continuity of the journey from expectant mother through childbirth, caring for the newborn child and on through childhood and transition to adulthood.

Integration

The third position put forward in the Five Year Forward View is that the NHS will take decisive steps to break down the barriers in how care is provided, that is, it will aim to integrate and coordinate care more effectively across organisational boundaries.

Integration is essential in children's health services in the wake of the Health and Social Care Act (April 2012) which moved the commissioning of some public health services for children out of the NHS and over to local authorities. This move provides opportunities to integrate health and care in a holistic way, joining up healthcare provision with access to non-clinical services such as housing, schooling, employment and leisure which can have a profound effect on health and wellbeing.

However this also produces new complexity in the provision of services for children and young people as it proliferates the number of commissioners and the number of providers of care, creating further users of and audiences for child health information. It makes it imperative that information move beyond organisational silos to join up care pathways and assist in improving health outcomes.

The Children and Families Act 2014 furthers the need for integration as it requires that health, social care and education services work together to provide a single assessment of the needs of children with special educational needs or disability and a single plan to meet their education, health and social care needs which can run from birth to age twenty five.

These changes in how care is commissioned and delivered makes it essential that child health information be available not just to professionals within health services but to those in social care and education, as well as to families, children and young people themselves.

In such a distributed model of care delivery and commissioning it becomes impossible to bring together information on what has happened with a particular child if information services remain organisationally bound and tethered.

Information has to be available across the whole network of care provision and has to be capable of being consolidated to provide a meaningful overview for professionals, parents and young people. This is essential for improving interventions at the point of care but also for monitoring the quality of care in a distributed system.

National Maternity Review

In our introduction we highlighted that the best start to life for children begins not just with the care of the newborn child but with the care of the mother in pregnancy and her experiences during delivery of the baby. This makes it essential that we join up our thinking and our information across antenatal and postnatal services delivered in different care settings by different professionals to provide better continuity of care for women and their families.

The National Maternity Review report, *'Better Births: Improving outcomes for maternity services in England'* published in February 2016 recommended that NHS England and the National Information Board should support the national roll out of interoperable maternity records for professional use combined with support for a digital tool (or personal health record) for woman as an urgent priority.

This recommendation is made on the basis that in order to improve quality of care, learning and productivity, the NHS needs to make it much easier for health professionals to collect and share data with each other and with those for whom they care. This echoes our findings in children's health.

The first requirement is that investment should be made in electronic, interoperable maternity records to reduce the administrative burden of information recording and sharing and that the systems providing those records should have simple, intuitive interfaces to minimise data entry time and allow health professionals to spend more time with women and their babies.

The second requirement is to ensure that all women have access to comprehensive digital sources of information via a digital tool or personal health record. The purpose of providing this is to help women and their families:

- Find the best information and advice during pregnancy
- Understand the choices available and find the best service to meet their needs
- Connect with peers online to share and learn from the experiences of others
- Manage their own care and book and access services
- Feedback on their experiences of using NHS services.

The review further recommends that the digital tool or personal health record must be able to interface with professionally held electronic maternity records so that the woman can access her own records and receive personalised information.

The technological solutions invested must be accessible to women, families and professionals, particularly outside of the hospital setting and they must be clinically supported and assured.

Maternity services face many of the same challenges as children's services in terms of the need for sharing and integration of information and ensuring that women are not missed for vital preventative (screening) services in pregnancy. The vision and new digital services we set out for child health information are equally applicable to maternity services.

Risk reduction

One of the key reasons we need to transform child health information services is to reduce the risks arising from the current configuration of services.

During the consultation process, a great many issues were raised with us describing the ways in which child health information services are less than optimal. Sometimes these are limitations and constraints within the systems themselves, sometimes they are to do with organisational practices and some highlight a lack of national guidance on key issues.

We identified what capabilities and services were missing that caused these many issues to surface and we found four root causes:

- Lack of effective population management; how can we know with certainty where a child is?
- Lack of up to date, accurate and consolidated records; how can we know how healthy a child is?
- Lack of access to information; how can we ensure appropriate access to information for all involved in the care of a child?
- Lack of guidance and collaboration; no roadmap for how to develop child health information services, no national forum for promoting development ideas or for sharing remedies for operational issues , no central framework for information sharing for children.
- These deficits in our current information services for children mean the health of children may be jeopardised in two major ways:
 - Children may be missing from the population registered with CHRDs/CHIS and are consequently not offered preventative services
 - Professionals seeing the child do not have a full history in front of them to inform treatment and cannot get access to the information they need easily in the absence of such a summary.

Our proposals for transforming children's information services address both these key risks. The detail of the operational issues raised with us during the consultation period are set out in Annex C.

7. WHAT WE HEARD

Consultation about the kind of change needed in children's information services has been ongoing for some time, not only in the six month engagement programme for the forward view but in initiatives aiming to improve the patient's experience of healthcare and in improving the way that care is delivered.

As a result of our programme of engagement with the different groups of stakeholders, support was given to two vision statements:

- An information service which knows where every child is and how healthy they are.
- Appropriate access to child health information for all involved in the care of children

This chapter summarises the key messages we heard from each of the following groups:

Personal Health: what young people want

As part of our consultation with young people we liaised with children's and young people's advocacy groups, who attended our workshops, and we asked for feedback on this forward view from their networks. We directly commissioned the Association for Young People's Health to produce a report on young people's (and parent's) views and colleagues in the Department of Health fed back the results and actions from the Children's Health and Wellbeing Partnership Children's Commissioner Takeover Challenge which took place in December 2015.

Here is what they want:

- I want to be listened to
- I don't want to repeat health information about myself to multiple professionals or fill out multiple forms
- I want to be in control of decisions to share my information
- I want to be able to find help and access services quickly and easily
- I want to be considered an equal partner in my care
- I want personalised care from professionals who know about my history
- I want that history to be accurate and up to date
- I want to learn about my condition, its treatment and possible outcomes
- I want to be able to make appointments that suit my lifestyle
- I don't want to be issued appointments that I can't make
- I want to see the information in a format that I understand
- I want to know my information is secure

- I want to see health and care information in a way that is easy for me to take in, not just text but film and video



- I want to learn about how I can be more healthy

We asked young people how they thought information services and information sharing currently worked:

7% of respondents thought nothing was shared

10% said that when they see a health professional 'they know all about my health condition'

37% said 'they know nothing about my health condition and I have to repeat my story'

When asked about the entire concept of accessible digital health records, one young person said 'I thought it was already accessible'

We asked them whether they thought personal health records were a good idea:

Almost **87%** of respondents thought having access to their own digital health record would be a good thing for them.

The number of positive responses decreased to **50%** when asked about parents accessing this same information.

Amongst the **50%**, one respondent wrote, 'They would be armed with all the information and facts, as I would be, and could support me in the best, most effective and safest way possible.'

Of the **39%** who responded it would be bad, one wrote, 'Some things are private and I don't want them knowing, such as things to do with gynae issues. I'd want to be selective so they only could see what's relevant with my permission'

We asked young people what they thought a personal health record app should do, including things like booking appointments, getting test results, controlling what information gets shared, writing their own notes and finding out about local services.

Young people responded positively to all the suggestions on the survey.

They also suggested that being able to give feedback about services should be easier and should be incorporated into it.

One focus group participant was hopeful that this could be a useful tool for young people who are transitioning into adult services, making it possible to take more control of their own treatment/condition and work alongside parents to do this.

Freedom from having to repeat their personal story was another positive benefit.

Several respondents wrote about how they feel unable to take everything in or remember everything that is said to them at an appointment and thought this could help.

One respondent wrote that it would be good to be able to share the information with voluntary sector organisations that support on specific conditions.

And finally we asked what their concerns about online records were:

There was widespread concern amongst respondents about a lack of security, information being leaked or hacked.

There was also a general concern about who this information would be shared with and who would be deciding who has access.

There were more specific concerns about the information being shared (or leaked) where young people don't want it going, such as schools, insurance companies and even journalists.

There was also concern about which medical professionals have access.

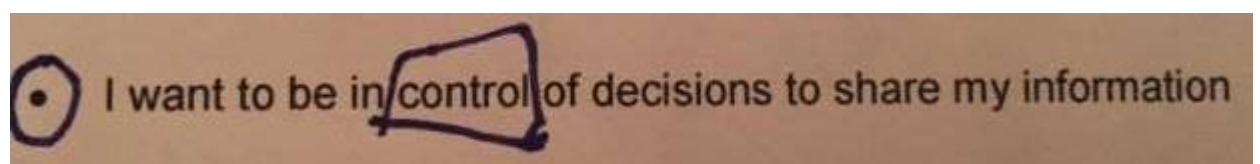
A young person in one focus group expressed concern that some young people are unaware about how much they already share online i.e. giving their Facebook password to friends. There is a general lack of awareness/attention paid to privacy settings on the internet.

What kind of language will this be written in? Medical terminology and jargon? Will it be young people friendly?

Who decides when a young person is ready to take control?

The importance of having control is a clear emerging theme as illustrated by the box drawn round this survey result:

Figure 22: Real survey result



Personal Health: what parents want

These views are taken from many of our workshop attendees who are parents. Additional material is from the report from the Association for Young People's Health, as before:

- I don't want to repeat health information about myself to multiple professionals or fill out multiple forms
- I want personalised care from professionals who know about my history
- I want that history to be accurate and up to date
- I want to know my information is secure
- I want health and care services to be joined up around my pregnancy and the birth and health of my baby (one episode of care)
- I want to be listened to
- I want to be in control of decisions to share my information
- I want to be able to make appointments that suit my lifestyle
- I want to learn about my condition, its treatment and possible outcomes
- I want health professionals to work with me not against me (collaborative care)
- I want to see the same information as professionals see
- I want to be considered an equal partner in my care
- I want to see the information in a format that I understand
- I want to see health and care information in a way that is easy for me to take in, not just text but film and video
- I want access to trustworthy information on health and lifestyle
- I want to be able to find help and services quickly and easily
- I don't want to be given appointments that I can't make



We asked parents how they thought information services and information sharing currently worked:

76% thought their child's GP records were shared between medical professionals and **73%** thought hospital records were shared

51% thought medication and allergy information for their child were routinely shared

35% said professionals they consulted know something about their child's condition

62% said the professional knows nothing about their child's health condition and they have to repeat the story

We asked them whether they thought personal health records for children and young people were a good idea:

89% thought they were

94% thought that it would be useful if health professionals could see all the information in one place too.

We asked parents what they thought the young person in their family might use a personal health record app for:

86% thought they would use it to find out about local services

85% thought they would book appointments

75% thought they would get their test results this way

69% said they would control what information gets shared about them

Other suggestions they made for how a personal health app could be used were:

Being able to email a health professional

Have access to their list of prescription medications, allergies, inoculations.

Information leaflets and even chat support groups etc., information about healthy lifestyles, contraception, relationships, managing stress.

Emergency button for help in a mental health crisis

Have some appointments online i.e. over Skype

Status of referrals and reports

And finally we asked what their concerns about online records were:

33% said 'None'.

37% cited security as a concern, including hacking and data protection, and the safety of data on mobile devices which are easily lost.

10% said information sharing was a concern, including who the information is shared with (which professionals, what information might be shared, and 3rd parties e.g. government /insurance companies having access to the data.

Professional Health: What care professionals want

Care professionals were invited to a series of workshops in 2015 and 2016 and the following statements reflect what they want from information services for children and young people. They also contributed information via an online survey.

- I want to have accurate, up to date information when I need it
- I want to know which other services and professionals are seeing a child
- I want to be alerted if there is a significant issue with a child under my care
- I want to record information once, in one place, never to have to duplicate that
- I want to have a framework/guidance for information sharing for children so I don't get it wrong.
- I want to be able to access information quickly when I need it
- I want to have better communication between agencies and professions
- I want to be able to access or record information when I am on the move and to have remote access for agile working

- I want to have an accessible summary of a child's care available at the first consultation
- I don't want to have to log in and out of multiple systems all the time
- I want information systems to be intuitive and require minimal training



Public Health: what public health professionals and commissioners want

Public health professionals were also invited to the series of workshops in 2015 and 2016 and the following statements reflect the feedback they gave us:

- I want to have high quality, relevant, reliable information to assess the health of the population
- I want to be able to reach individuals in a population easily in the event of health scares.
- I want information to support different cohort markers – Postcode, GP, School, Condition - so that it can be analysed in different ways
- I want information to be up to date, timely and accurate
- I want to be sure that all parents and young people are aware of and understand the services available to them.
- I want to ensure all parents and young people are offered the services available to them
- I want information to have standard definitions so that care can be compared nationally regardless of originating systems or regions
- I want to provide personalised, relevant health promotion materials to parents and young people

I want to be able to link data, once anonymised, more easily to support effective commissioning and service design.

Providers: what those involved in procuring and managing information systems want

Some of those attending workshops in 2015/16 were responsible for buying or managing child health information systems and they provided the following statements:

- I want there to be a national standard operating procedure for population management in child health
- I want national interoperability messages and standards to be defined and mandated via ISN
- I want to have an interoperability roadmap, showing how children's information can be brought together
- I want to have a framework/guidance for information sharing for children
- I want systems to comply with mandated datasets
- I want to have a robust framework against which to assess systems for child health and to have expert help available to help with that assessment
- I want compliance with standards and timelines to be assessed and enforced, with removal from frameworks if needed
- I want to be able to send and receive messages without a substantial increase in licensing costs
- I want there to be a national training module/competency for child health records administration
- I want to have simpler, shorter, less costly procurement routes



I want integrated systems
that don't add
bureaucratic processes.

Suppliers: what those creating information systems want

A workshop for suppliers of information systems and services was held in February

2016 and the following views are taken from that event:

- I want to have a clear steer about national standards and requirements for interoperability
- I want earlier oversight of proposed changes to datasets, including immunisation changes
- I want to know early on if you're changing statutory reports that our systems are expected to compile
- I want accreditation for interoperability to be straightforward
- I want accreditation for framework agreements to be straightforward
- I want to know the strategic direction for the development of child health information
- I want regular consultation/updates
- I want to have simpler, shorter, less costly procurement routes

8. SHAPING THE FUTURE

The Vision

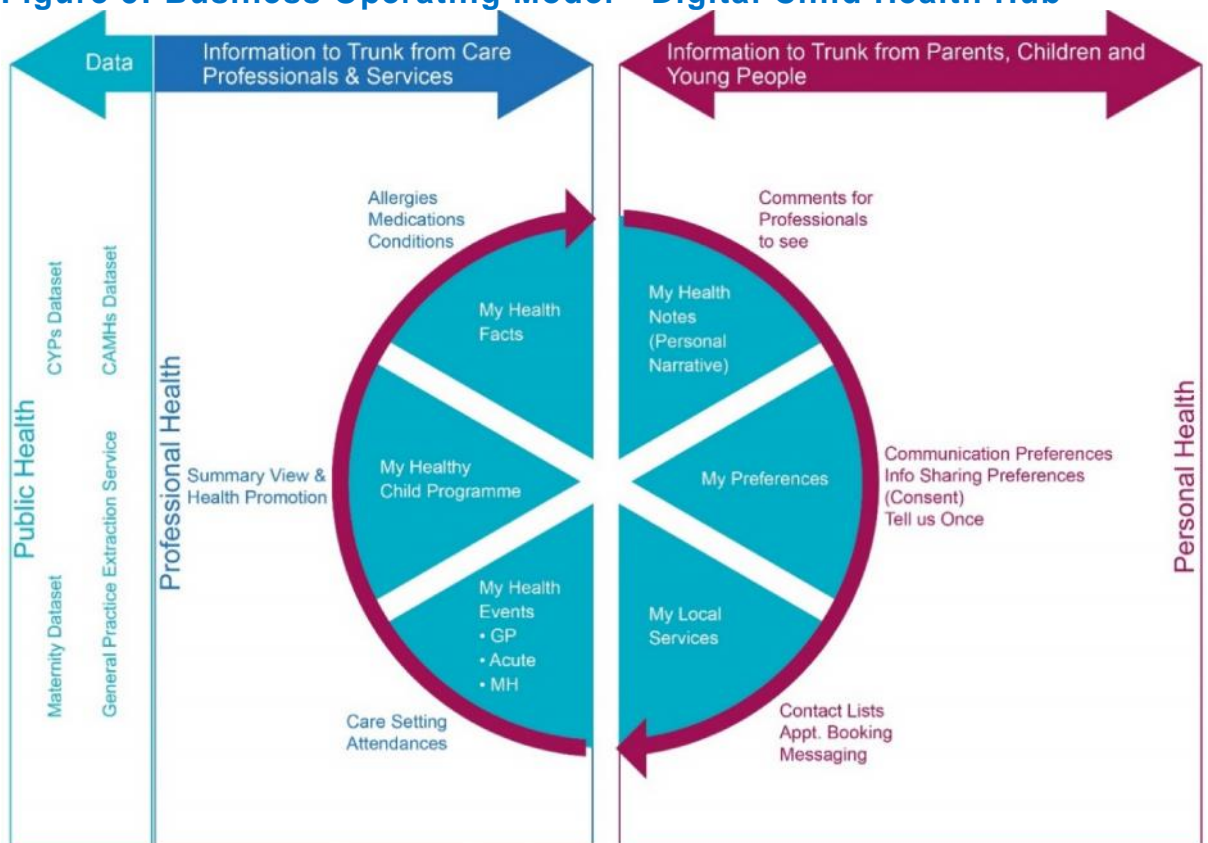
Our vision is for transformed child health information services which achieve two objectives:

- **Knowing where every child is and how healthy they are**
- **Appropriate access to information for all involved in the care of children**

Redesigned information services will support personalised care, promote the offer and uptake of preventative programmes of care and provide the foundation for integration across the domains of health, social care and education.

The vision is not one of a single centralised information service or system for children's health but of various information services exchanging data in a standardised format via a central hub. Information will flow to where it is needed, improving the experience of care and health outcomes for children, young people and their families and supporting the professionals providing that care.

Figure 5: Business Operating Model - Digital Child Health Hub



This is a new business operating model for child health information services, a Digital Child Health Hub, which describes an information service where professional health information drawn from existing organisational systems meets personal health and care information provided by parents and families and young people through use of online personal health records.

Events Driven Model

Information can be thought of as a series of 'events' which are exchanged electronically in real time within a consent framework so that all involved in the care of children have the information they need. Not all information recorded about children will need to be an exchangeable event. Careful thought needs to be given to identifying which events are 'key' and who needs to see them and for what purpose.

This dynamic events driven model of information exchange is what will replace the current configuration of child health information services for children. That configuration is based on organisational health systems which for the most part do not speak to each other and consequently rely on exchange of information by paper notification. This constrains the pace at which more integrated services can develop and the timeliness of information being provided to professionals and parents to support care of children and young people.

Exchange of events electronically is the only way an up to date overview of a child's health can be maintained when delivery and commissioning of care is distributed across many organisations. A system reliant on paper will inevitably fail due to the number of events needing to be distributed and the time and resources needed to distribute/ uptake the information manually.

Events are simple, structured messages containing information meaningful to those managing the personal health of themselves or their families, those professionals providing direct care to children and young people and those managing the health of populations.

An example would be the details of a child's birth which are already routinely transferred from the maternity setting in which they are recorded to GPs and health visitors who need the information for the onward care of both mother and baby. This 'event' is already recorded in the parent-held PCHR and in the Maternity Dataset information used to analyse and improve the health of mothers and babies.

This event data is shown below in both those formats, respectively:

Place of Birth:

Length of Pregnancy in weeks:

Type of Delivery:

Mother's NHS Number:

Problems in pregnancy, birth of neonatal period:

.....

.....

Admitted to Neonatal Intensive Care Unit?

17206080	BIRTH WEIGHT	BirthWeight	Weight of baby in grams at birth
17206120	GESTATION LENGTH (AT BIRTH)	GestationLengthBirth	Gestation at DATE TIME OF BIRTH (BABY) in days
17206160	DELIVERY METHOD (CURRENT BABY)	DeliveryMethodBaby	The method of delivering baby

This event data can be transferred easily into an agreed, lightweight message structure and information can then be exchanged rapidly by systems in support of different pathways of care.

There will be publishers of events, those who complete an action related to the health of a child and there will be subscribers to those events who need to know about that action to maintain an overview of the health of a child. A hub is the place that these events are exchanged. Annex D describes the hub and the events model in more detail.

How does the Model Work?

To appreciate how this model can work, it is important to understand that it does NOT necessitate building or procuring a large new child health information system nationally. Instead the model is based on retaining separate organisational information systems which continue to collect detailed information for the purposes of direct care but ensuring that those systems can publish key elements of that data as an event to be communicated to other systems/audiences and subscribe to events that are needed to maintain an overview of the health of a child or young person within that organisation.

Moving to an events driven model is an incremental journey, with more information becoming available for exchange year on year. We will start this journey by creating events which are applicable to the whole children's population and already designated as being important markers for public

health. As experience of working with this type of interoperability grows and starts to show benefit, we can use that experience to move into more complex areas of children's health information and create further events for exchange. As the events available for exchange increase new digital services can be provided to the key audiences for that information.

It is envisaged that parents and young people will have an online personal health record which allows them to subscribe to the information on their own health and care events published by multiple organisations across the spectrum of care, building a consolidated view of their health and wellbeing.

This same operating model is also applicable to maternity services and is capable of delivering the recommendations made in the National Maternity Review.

The new digital services which underpin the events model outlined above are discussed in the Chapter called Making the Future.

New Information Services

Below we outline the new information services that become available as the forward view is implemented.

New information services for parents, families, carers and young people

'I want to be in control of decisions to share my information'

'I want personalised care from professionals who know about my history'



Parents, Carers, Children & Young People

1. Parents, families and carers will have an online record of their child's health and development.
2. Young people will have an online record of their own health and care issues.
3. Parents, families, carers, young people and professionals will share a common (core) view of the health information recorded about children and young people to better support their care.
4. Parents, families, carers, children and young people can set their own preferences for information sharing and can see who subscribes to their information.
5. Parents, families, carers, children and young people can publish their own goals for health and wellbeing and share these with professionals, empowering them to manage their care in a collaborative partnership.

New information services for professionals

'I want to have accurate, up to date information when I need it'

'I want to be alerted if there is a significant issue with a child under my care'



Professionals

6. Professionals will have access to a core view of child health information at the point of care to improve decision making.
7. Organisational record systems: they will not need to access other systems for key events.
8. Professionals with a responsibility for a child will have real time access to key events occurring for that child in other organisations, where it is appropriate to do so.
9. Professionals will only have to record information about a child/young person once as that information can then be published automatically to those in the extended network of care.
10. Professionals will be able to identify when a child has fallen outside the care of the usual responsible agencies, such as a GP or Health Visitor, assisted by alerts from a failsafe management service.
11. Professionals delivering preventative programmes of care will be alerted by a failsafe management services when an intervention is due or has been missed.

New information services for public health

'I want to have high quality, relevant, reliable information to assess the health of the population'

'I want to be able to reach individuals in a population easily in the event of public health concerns'



Public Health

12. Public health professionals will have access to more comprehensive, more up to date datasets as interoperability of events gradually replaces the re-keying of information from paper notifications.
13. Administration of public health programmes and call and recall can be standardised to a high degree through applying immunisation rules and schedules nationally as a series of events rather than locally.
14. Public health professionals will have access to real time population data for analysis as interoperability of events becomes routine,
15. It becomes possible to deliver personalised health promotion materials to people and enter into dialogue with them. As parents, families, carers and young people begin to use personal health records routinely.

9. MAKING THE FUTURE

The preceding chapters outlined what the vision for child health information is and why we need to redesign our services. In this chapter we discuss how that change can be achieved. This is our outline planning approach for how we make the vision set out in this forward view a reality.

We stated when outlining the vision that implementing it does NOT necessitate building a child health information system nationally. Instead we will work to create a standardised data and interoperability model for children's health information which will be embedded in all existing and future health systems.

This model will evolve iteratively to encompass all the different events which need to be exchanged. We will document where child health information exists, what the different categories of child health events are and explain how they can be standardised and exchanged to provide improvements to direct care and drive productivity and financial efficiencies in service delivery.

How transformation of services can be achieved requires careful and detailed planning. It is not possible to know everything or design how everything will work at the outset. For this reason we will build elements which are foundation stones for the vision incrementally, test them in proof of concept work and then standardise them into readily deployable projects which can be taken up by local services as part of their Local Digital Roadmaps and Sustainability and Transformation Plans.

The five foundation stones for the forward view are:

- Interoperability
- Failsafe Management (Knowing where every child is)
- Core Record Dataset (Knowing how healthy they are)
- Access (Appropriate access to all involved in the care of children)
- Personal Health Records

It should be noted that the same foundations can be used to support the recommendations of the National Maternity Review.

Five Foundations for the Future

Interoperability

The events model is predicated on interoperability, that systems currently collecting child health information will be able to publish elements of that information as events and will be able to subscribe to events originating from other systems and display these events and act on the information they provide.

Standards for this interoperability will be agreed on and existing (or new) datasets can then be packaged into message events. Agreeing standards and

the content and phasing of message events will be a collaborative and iterative exercise.

An events management service will be required to manage the flow of events messages and securely archive them. This is envisaged as a national service ensuring that suppliers of systems recording or using child health information only have to make a single connection rather than developing multiple connections to multiple systems. This contains the cost of interoperability and drives national standardisation of events for children.

Reducing the cost of interoperability and standardising health events lowers the barriers to entry for new suppliers of health and care systems. This helps to fuel innovation and competition in the market so providers of healthcare have improved system functionality available, a wider choice of suppliers and more competitive pricing.

Creating a national platform and framework for interoperability for children's health – the enabling of the events stream - will ensure that the software market can deliver new applications which respond to the current needs for personalisation, preventative care and integration across health, social care and education.

The programme of interoperability can be phased to take advantage of messaging projects already in flight and to prioritise those that will deliver greatest benefits to health gain and/or reduction of administrative overhead and cost. For example, current messaging projects include electronic transfer of birth notification, newborn screening results and immunisation results. If these projects were to be fast tracked and planned nationally as a rollout, the administrative overhead for re-keying data in many CHRDs could be reduced substantially, leading to more efficient services.

Failsafe Management – Knowing where every child is

Each CHRD has a population 'footprint' that they manage, usually defined as all children registered with GPs in that area and those who are resident with a 'local' postcode but not registered with a GP. These population footprints are now being aligned to local authority boundaries, given that some population health services are now commissioned by local authorities rather than CCGS.

The issue with this local administration of population management is just that, it is local and does not refer back to the national population (the denominator population registered on the Personal Demographic Service). It is possible to lose track of children as they move between footprints and additionally to lose them in the gaps between footprints which are not necessarily seamlessly aligned in neighbouring areas.

This lack of ongoing checking against the denominator population creates difficulties in assessing whether an agency has missed out offering services to children born into or moved into the local area.

If child health information services are to know where every child is, population management for public health must be managed within the framework of a national population of children to provide the failsafe that no child is denied the services offered via the Healthy Child Programme.

Programmes of care aimed at prevention and early detection of health issues have to be capable of inviting all children and young people in a local population to receive those services and monitoring whether the offer has been taken up, when the treatment or review took place and what the outcome was.

Although these services are population based, ensuring they are offered and received requires a means of communicating directly with individual parents and families and monitoring who within that population has and hasn't received the service.

A full failsafe management service for children and young people and population-based programmes of care would comprise three different types of events:

- Location events which identify where the child lives, which local authority or CCG boundary they reside in and what school they attend.
- 'Responsible agency' events which identify which professionals have responsibility for a child, for example, the registered GP, the midwife or the health visitor.
- Healthy Child Programme events which provide a series of prompts to ensure the programme is offered to parents and their children and that those responsible for delivering the services know that action is due and a series of alerts when services are missed. The interventions themselves, such as immunisations or developmental checks, would also be events.

These events would be published and subscribed to as outlined in the events model. As the Healthy Child Programme is a nationally prescribed set of interventions the publisher could be a rules engine described and implemented nationally. Location events and responsible agency events could come from the Patient Demographic Service or from local systems. Parents could opt to receive these prompts and alerts through a Personal Health Record or via email or SMS rather than receive immunisation letters as currently.

Although managed centrally/nationally on a whole population basis, failsafe management would still require active administration at the local level. However because the local cohort would be a constantly updated subset of the national cohort rather than a local, finite, registered population, the effort required to manage and

coordinate between localities and regions would be substantially reduced leading to the possibility of re-configuring or re-combining of current local CHRD services.

The failsafe management service would be capable of flagging children or young people who appear to be outside the care of the usual agencies so

these cases could be followed up locally. This initiates a move to pro-active targeting of resources for early detection of health issues and interventions rather than relying on retrospective discovery of cases as health issues present in acute care settings. Similarly it could be used to flag special needs or disability requirements.

A failsafe management service working in tandem with a core record dataset (see below) would reduce the administrative burden for child health information services considerably as when a new CHR or other agency becomes responsible for a child instead of relying on physical transport of child health records to new locations they simply subscribe to the core events.

Core Record Dataset – Knowing how healthy a child is

A core record dataset is required so that all involved in a child's care can know with certainty what the health status of that child is. This would ensure that baseline information for a child is available prior to treatment.

The idea of a core shared view is not new. The Summary Care Record (SCR) of primary care information provides such a view and the current record available in child health information systems provides such a view. But the drawback of both these views is that they are only partial. The PCHR is a parent held summary view but it is only available in paper form and cannot be independently consulted.

The new service required is a core record dataset for children and young people which is shared by parents and professionals. In line with the events driven model being proposed, the core record dataset would be described as a set of discrete child health events, an events catalogue.

Contents and structuring for a core record are proposed in the *Output and Information Requirements Specifications for Child Health Information Services, published by Public Health England in March 2015*⁸. The PCHR is already an agreed format for a shared core view of a child's health status⁹. The datasets now agreed across Maternity, Children and Young People's services and Child and Adolescent Mental Health services (and built into child health, maternity and mental health systems) provide further possible content for the events catalogue, as does the structured data already in use in primary care systems.

Contents and structuring for a core record for disabled children are also now available: paediatricians in collaboration with parents and carers and therapists have created a disabilities terminology set to describe the multi-faceted health conditions, technology dependencies and family-reported issues of disabled children and their families.¹⁰

⁸ [Output and Information Requirements Specifications for Child Health Information Services, Public Health England, March 2015](#)

⁹ [PCHR format and contents](#)

¹⁰ [Prospective pilots of routine data capture by paediatricians in clinics and validation of the Disabilities Complexity Scale, June 2016, Developmental Medicine and Child Neurology.](#)

The core record/catalogue will be built in successive waves of events. The initial waves of events will cover the data items already agreed and validated as being essential for a shared understanding of the a child's health (the Personal Child Health Record) and those already identified as being needed to evidence population health (the Children and Young People's dataset).

The events catalogue will be expanded in iterative waves. It should be noted, however, that agreeing what information is considered essential to exchange takes time and consensus amongst professionals and parents and young people.

Agreeing the event package is only the first step of a process which includes describing the information in technical specifications, adding any new entities to the NHS data dictionary (a form of standardisation) and accrediting systems to publish or subscribe to the new event. This process ultimately results in personal health records and organisational health systems being able to exchange and present information in a readily understandable format to professionals or parents and young people.

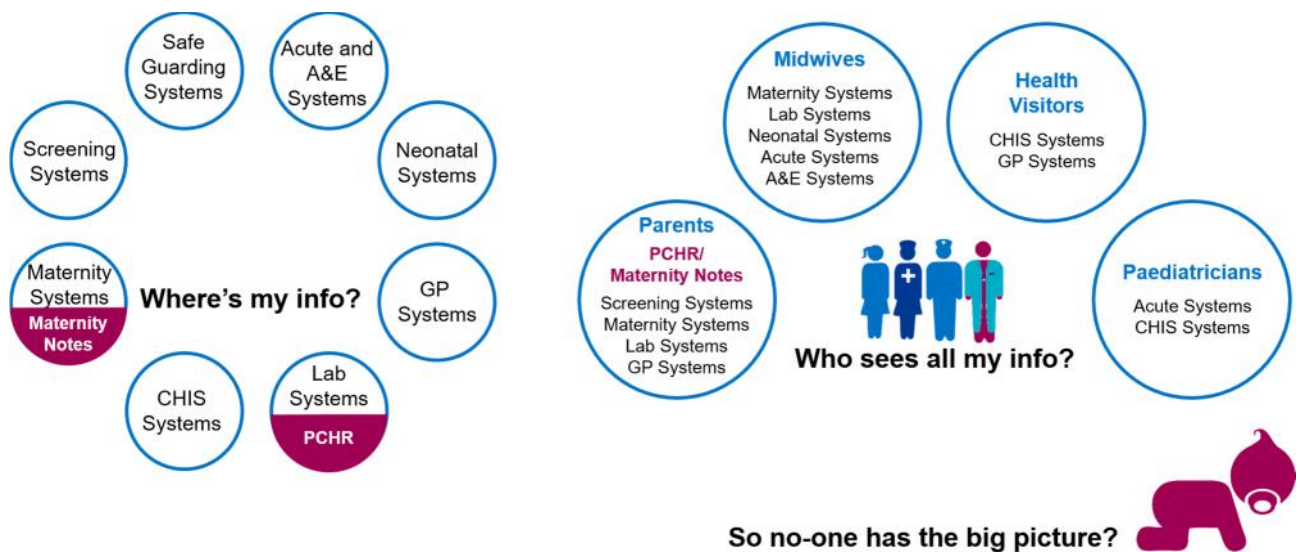
Access – Appropriate access to all involved in the care of children

Often important information on a child's health is held in organisational 'silos'. Information which could be important in the treatment of a child cannot be accessed by or has not reached other professionals involved in or about to be involved in the care of a child.

When a child moves unexpectedly to a different organisation or is taken to an Accident & Emergency service, professionals will not necessarily have an overview of that child's health and care available and so their ability to treat a child safely and effectively could be compromised by the lack of available information.

No one has the big picture and sometimes the biggest picture held may not be in professional hands but rather rests with the parent and the record of care transcribed in the PCHR or other notes held by them on behalf of their child.

Figure 8: Working and Thinking in Silos Creates Access Issues



In introducing health events and the capability to publish and subscribe to events, the forward view suggests a major way in which the problem of access can be addressed. In suggesting use of a core dataset, it also addresses a way by which important summary information can be made available to professionals and to parents and young people too.

Access needs to be 'appropriate' and there needs to be transparency as to who has access to information and why. Compliance with the Data Protection Act 1998 is also required.

In order to facilitate appropriate access to child health information for all involved in the care of children consent frameworks, role based access and authentication standards will need to be implemented so that parents and young people and professionals have confidence that data is held securely and shared in alignment with the parent's/young person's wishes.

- A consent framework details how parents and young people can set preferences for who their information is to be shared with. This framework would be built into how access to applications and/or systems is managed.
- Role based access describes the different categories of health and care professionals with whom parents and children and young people will come into contact and the subset of data they can access. This is appended to their log-in information when they access systems and forms an audit trail of who has viewed records. Role-based access interacts with the consent framework so that sharing permissions can be set by parents and young people and they can always see who has subscribed to their health information.

- Authentication refers to how we verify who the user of a system is and the subsequent assigning of a log-in and password to that user. For NHS professionals accessing national systems such as the Summary Care Record a smartcard is used (which stores the role-based information). The smartcard is only assigned once the professional's identify has been verified by a registration authority, usually on presentation of passport-type information and employment details.

These three components are all currently in use in various professional health information systems within the NHS. What remains is to define how they will be used for child health information services, paying particular attention to how those using personal health records will be authenticated and how the consent model will be implemented.

The forward view will await the publication of the new Caldicott review of consent in summer 2016 and will then produce an information governance framework specifically for children and young people's health information setting out how consent and information sharing works now and how it will be approached in the implementation work for the forward view.

Personal Health Records

Personal Health Records for children have been in use in England for over 20 years.

The Personal Child Health Record (or 'red book') is usually given to parents shortly before or after the birth of a child. A book is issued per child so a family with more than one child will have a collection of such books.

Figure 6: Red Book



(Image reproduced by kind permission of Harlow Printing Ltd).

The book provides detailed advice on health promotion issues such as feeding and prevention of injury and enables the parent to record the development of their child. It also provides a place that all reviews of the child, screening tests and immunisations offered and undertaken as part of the Healthy Child Programme can be recorded by health professionals. This ensures that parents are aware of the results and health professionals seeing the child for the first time can review the information prior to recommending or starting treatment. Free text areas are also included so that those seeing the child in other contexts, for example for a hospital admission, dental surgery, or an A&E attendance, can add to the record.

The PCHR has therefore functioned as a summary child health record within England's health economy, particularly since content was standardised to provide a national 'core' record.

The PCHR has been an essential adjunct to organisational records because it provides a holistic overview of a child's health and development which is often not present in organisational records.

It is often assumed that the primary care record is the default record for a child and whilst it can function in this way for many children and young people who have simple care needs, we need to exercise caution about seeing the primary care record or the Summary Care Record as the solution for the whole population as there are segments of this population for whom this will not work, as the diagram below shows:

Figure 7: Management of Care

Management	Super-Managed	Children and Young People with multi-agency care	10/20	Co-ordination of access and outcomes difficult. Need for a shared core record
	Managed	Children and Young People registered with a GP Practice	80/90	Access and information needs can be met by practice and SCR
	Unmanaged	Children and Young People NOT registered with a GP Practice	Up to 20	Potentially vulnerable population without access to services and information
	Population Type	Service Provision	Appx %	Status

The PCHR can be seen as a collaborative tool which encourages partnership between health professionals and parents and improves communication between health professionals and parents as well as between health professionals based in different organisations or care settings who do not share a common record or view of a child's care. It is particularly needed where there is no primary care record or where a child has complex needs and multi-agency care.

There is evidence that use of a personal health record increases parents' understanding of their child's health and development and that greater involvement of children and young people in the management of their own health or care givers in the management of their child's health may in turn lead to better health outcomes for children¹¹.

The consideration for the forward view is to ensure that the ethos of this original personal health record (PHR) can be taken forward and transferred to a digital platform to provide improvements in service to parents, families, carers, children and young people and the professionals who provide the care.

As the PCHR is a cross-professionally agreed summary record with a core record dataset agreed nationally, the PCHR content will form the basis of the core child dataset and the initial events catalogue. This will ensure that systems used to provide care to children can subscribe to the summary of events and have a baseline overview of a child or young person's health prior to beginning treatment.

Different models of online PHRs are beginning to emerge in England. Such models are not necessarily specific to the care of children and young people but do reflect the different types of approach that can be taken to improving health and wellbeing. Annex E describes these models.

The Royal College of Physicians recently collated a landscape review of use of personal electronic health and care records in the UK (May 2016¹²) and uses the following definition for PHRs, 'a digital tool that helps people to maintain their health and manage their care. It may do this by enabling them to capture their own health and care data, to communicate with health and care services, and/or to have access to their care record'.

There is some uncertainty as to how the use of online PHRs will improve health and wellbeing for children and young people, yet the ethos and purpose essentially remains the same as that provided by the current PCHR described above, it is a collaborative tool which:

- Encourages partnership between health professionals and parents, families and children and young people
- Improves communication between health professionals and parents
- Improves communication between health professionals based in different organisations or care settings who do not share a common record of a child's care
- Increases parents' understanding of their child's health and development

¹¹ [Use of personal child health records in the UK: findings from the millennium cohort study, February 2006, Walton, S., Bedford, H., Dezateux, C., BMJ 2006;332:269](#)

¹² [Personal Health Record \(PHR\) Landscape Review: Final Report, Royal College of Physicians, May 2016](#)

- Promotes greater engagement of children and young people in the management of their own health (or care givers in the management of their child's health) which may in turn lead to better health outcomes for children.

In making these type of health records available online the intention is to exploit the greater capability that digital formats have for personalisation, convenience, ease of access, 24/7 availability and rapid information sharing. Annex F describes the service improvements that can be made with regard to child health information through use of a PHR.

As use of online PHRs as an adjunct to professional health and care records is a new area, the forward view proposes an ongoing collaboration with PHR suppliers to establish how these tools can best support the need for personalisation of care as well as the need for collaboration across health, social care and education.

Digital Transformation

We have described at a high level how and why technologies should be used to better serve our three audiences:

- **Personal Health:** parents, families, children, young people and carers.
- **Professional Health:** professionals across health and care services who record and use information about the children they see for the purposes of direct care.
- **Public Health:** professionals who look at local population health and the effectiveness of the healthcare given to the population.

The real aim however is to begin a process of digital transformation by re-imagining how technology can improve:

- Consultations and conversations between people:
 - professionals to parents and children and young people
 - professional to professional
 - parents and young people with their peers
 - public health professionals to parents and young people
- The continuity and co-ordination of care for a child transferring between different care-settings and agencies. For example, the handover of responsibility for care of newborn children from maternity services to GPs and health visitors.
- Oversight of end to end care pathways and a holistic view of a child's health and wellbeing.
- Digital transformation is an intensive process and involves looking at established ways of doing things with fresh eyes and re-examining them not just from a technology perspective but also from a cultural and behavioural perspective.

- Transformation is aimed at liberating those in all three domains - Personal, Professional and Public Health - from the time swallowed up in needless administrative and bureaucratic tasks (tasks that may be better done by machines and applications) so that effort can be directed towards identifying the real changes needed and overcoming the barriers to those changes through collaboration, focused leadership and incentivisation.
- The key to delivering the forward view for child health information is collaboration. We will align national developments and services with local innovation initiatives and priorities to create real improvements in access to care and care pathways enabled by better information and technology support.

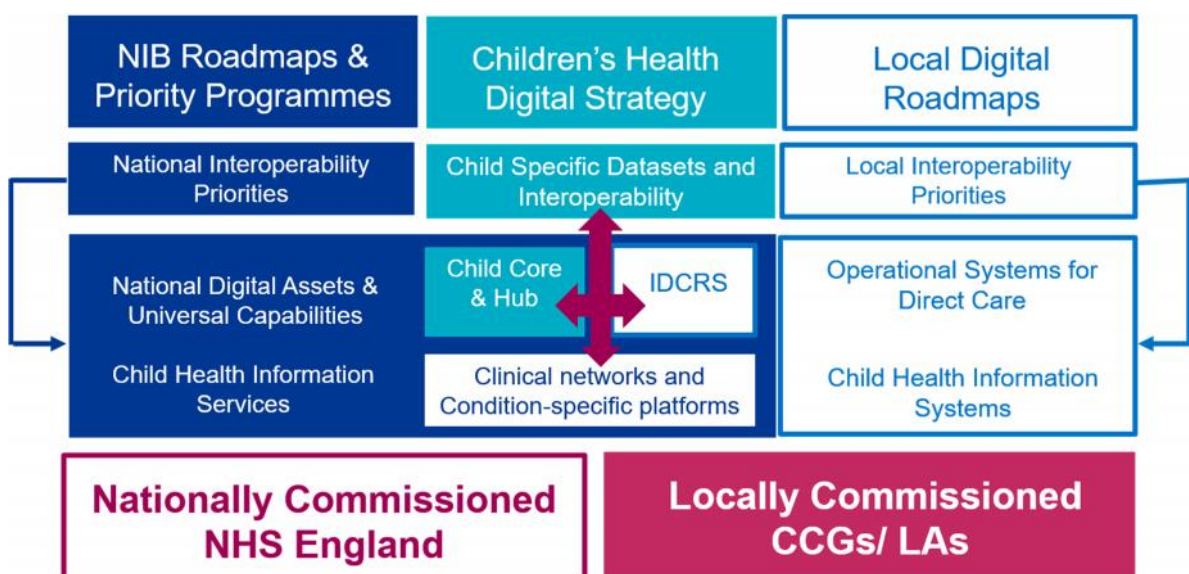
The focus for national action is threefold:

- Provide standards, definitions, frameworks and guidance where these are needed, particularly with regard to data, interoperability, information governance and consent.
- Ensure a sustainable platform is available for personalised and collaborative care.
- Act as broker for information exchange, enabling different parts of the health, care and education services to work together and to work with parents, children and young people.

At the local level, creation of digital roadmaps and the embedding of these within Sustainability and Transformation Plans provides a framework to help the financing and adoption of technology to support new models of care and greater efficiency.

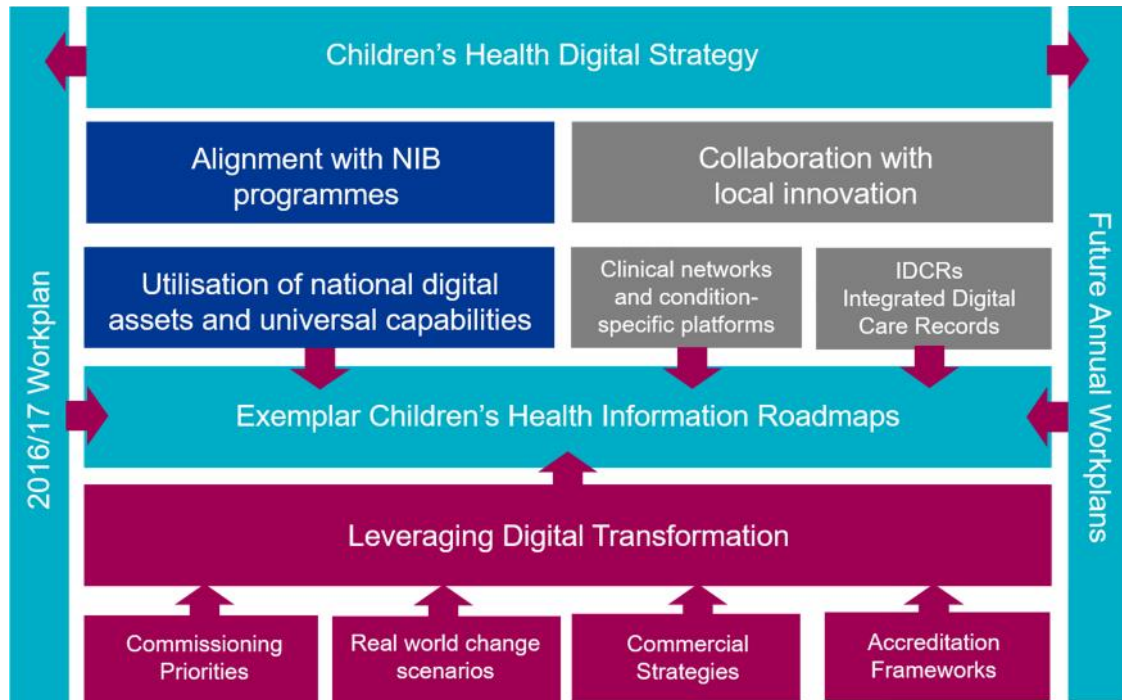
The diagram below shows how such collaboration can be coordinated when being commissioned from different parts of the health and care eco system.

Figure 9: Collaboration and Commissioning Structure



Getting such collaboration off the ground is firstly a matter of communication and engagement. The consultation for this forward view is the first major step in the collaborative process: we are announcing an intention to focus digital transformation in the area of children’s health information and will seek local partners to help make this a reality.

Figure 10: Collaboration Framework



Each year the programme will publish a roadmap for children’s health information describing the work undertaken in year and what the priorities and deliverables are for the coming year and when new digital services become available. These exemplar roadmaps will describe how and when services can be transformed either by the national solutions being developed or by adoption of innovative solutions already delivered in local/regional services. These exemplar roadmaps can then become component parts of local digital roadmaps, tailored to suit local circumstances and digital maturity.

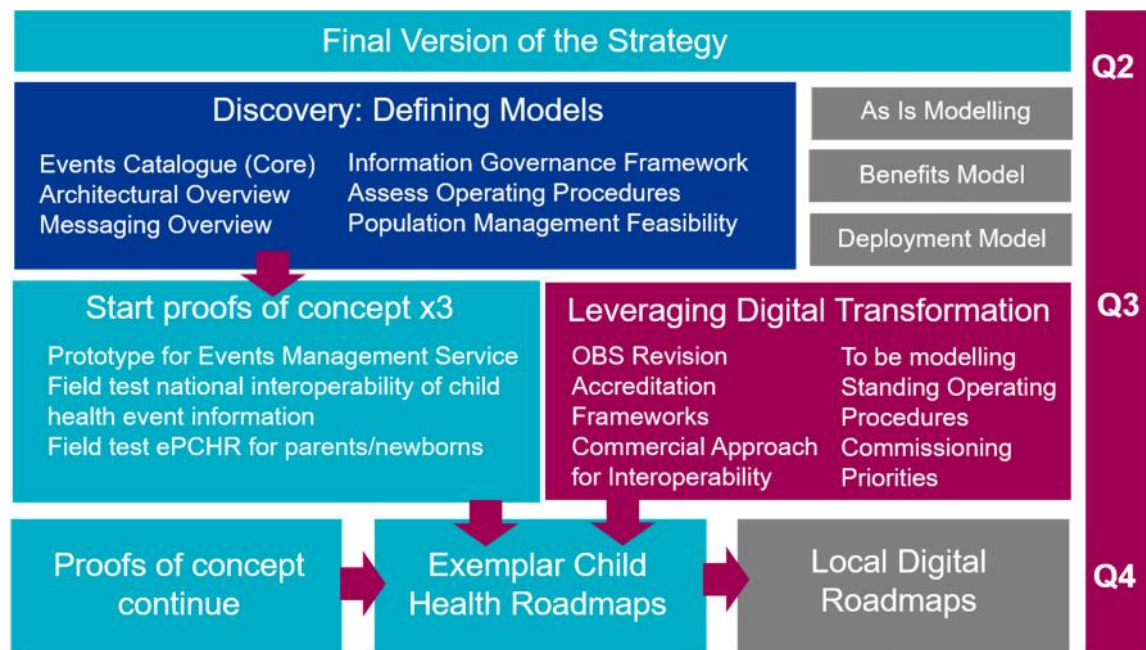
Starting Implementation

To realise our full vision of personalised and collaborative care for children and young people, work will be ongoing from now until 2021. The priorities for 2016/17 are to:

- establish a programme of collaboration and engagement
- start ‘discovery’ work to define the information, interoperability and architectural models in consultation with collaboration partners, plan proofs of concept for these models and begin the approach to transformation of services by modelling current and future processes to understand the impact and benefit of change.

The specific deliverables and the broad timelines are shown in the diagram below:

Figure 11: Deliverables



Discovery

On publication of the forward view we will begin a 4-5 month phase to elaborate on the information model which sits at the heart of the vision we set out. That information model will comprise:

- Describing the content of a first phase core record (events catalogue) for children and how subsequent expansion to that core will happen.
- An architectural overview of the events model proposed and how it can be built.
- A messaging overview describing the approach to interoperability and the standards to be used.
- An approach for failsafe population management for screening and carrying out the Healthy Child Programme.
- An information governance framework for parents, families, children and young people which can be started as soon as the Caldicott review concludes
- An approach for managing Privacy related requirements, for example, Privacy Impact Assessment
- The modelling phase is not an 'ivory tower' planning phase, it will actively use the collaboration model to ensure sharing of ideas, consideration of proposals and mechanisms for feedback.

- The discovery phase extends into planning and delivery for proofs of concept. Three proofs of concept are seen as essential to testing the viability of the forward view:
- Describing the core child health dataset as a set of events (events catalogue) and creating a working model of an events management service to begin testing.
- Field testing national interoperability of child health event information to establish how a consortia of publishers and subscribers can work together and how quickly message events can be subsumed into systems.
- Field testing a personal health record for newborn children for parents and establishing the interoperability and information governance requirements for this.

The information models and approaches defined in the discovery phase are an input to these projects and the intention is that the proofs of concept will establish the viability of the vision within 2016/17 allowing much more detailed plans and costings for delivery of the full vision to be available going into 2017/18. All three projects have strategic advantage in that they are building blocks for the full forward view and provide prototypes, messaging specifications and planning that will be reusable further downstream in implementation.

Although during 2016/17 much effort will be focused on starting delivery of these proofs of concept, we will remain open to offers to collaborate on other projects which contribute to the vision set out in this document as both national initiatives and local initiatives are required to transform children's health and care information.

Leveraging Digital Transformation

Although the technical discovery phase and the proofs of concept are very important steps in determining the viability of the vision for child health information services, equally important are the cultural, commercial and financial environments in which such solutions have to operate. In the same period that the proofs of concept get underway, we will therefore be taking a long look at precisely how these solutions can improve things on the ground and what it takes to drive adoption.

We will be looking at:

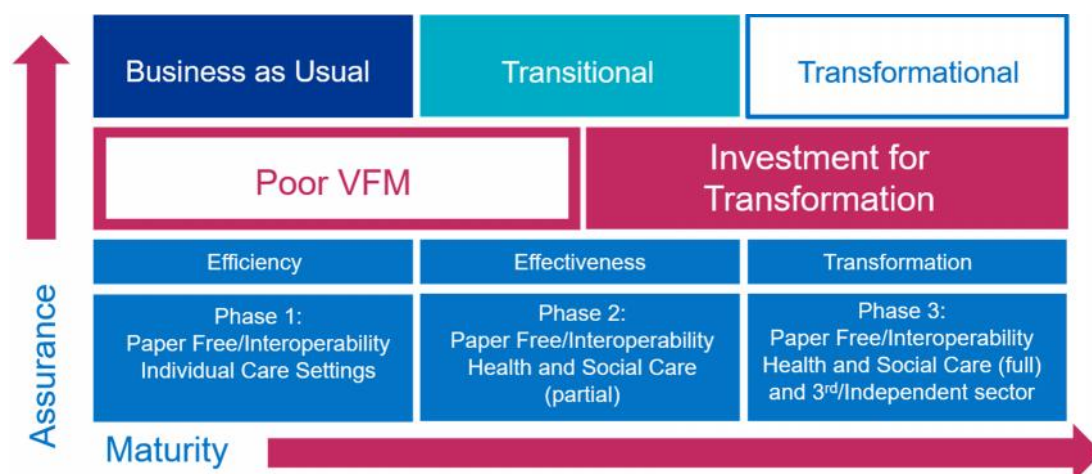
- What business processes will change ('to be' modelling) and what the impact and benefits of this will be and how this transition can be effectively managed.
- Effective commercial strategies for partnering with suppliers to get interoperability off the ground at scale and at pace.
- Setting commissioning priorities and incentivising adoption through the commissioning route.

- Setting out how systems are assessed and accredited for use and updating the Child Health Output-Based Specification so that it fits with new vision, incorporates new specifications and can act as a standard against which systems and applications can be accredited and procured.

Child Health Roadmaps and Local Digital Roadmaps

The results of the thinking, modelling and field testing in the preceding phases all get distilled into exemplar child health information roadmaps which describe the way in which digital transformation can happen in this area. These roadmaps will contain a digital maturity model which enables local areas to assess their progress against a three stage model: whether they are in business as usual with no change planned, whether they are beginning to transition and reform services with digital technology or whether they are already deeply into transforming services and starting to see system-wide benefits.

Figure 13: Maturity Model



So these exemplar information roadmaps describe the possible journey for transformation of child health information services and can then be tailored depending on a local community's current digital maturity and their priorities for the coming year. Exemplar roadmaps will be updated annually ahead of and in readiness for updates to local digital roadmaps and incorporation of these into sustainability and transformation plans.

10. GLOSSARY

Acronym where applicable	Term	Definition
API	Application Programming Interfaces	A set of routines, protocols and tools for building software applications, it specifies how components should work with other components
CH	Child Health	The overall wellbeing of a child
CHIS	Child Health Information Systems	Patient administration systems that provide a clinical record for individual children, showing all health related activities such as diagnoses and immunisations.
CHRD	Child Health Records Department	The umbrella term for the group of staff that maintains and updates child health records
CP-IS	Child Protection Information Sharing	A project set up to assist the NHS to provide better protection to children by being able to share information with other local authorities, such as anti-bullying charities
CAMHS	Children and Adolescent Mental Health Services	Specialist NHS services that offer assessment and treatment for young people with emotional, behavioural or mental health difficulties
Children and Young People		A term that covers all people under the age of 18
CCG	Clinical Commissioning Group	NHS Organisations set up by the Health and Social Care Act 2012, to organise the delivery of NHS services in England

	Digital Maturity Framework	A way of assessing the extent to which healthcare services in England are supported by the effective use of digital technology, identifying key strengths and gaps in healthcare providers' provision of digital services at the point of care
	Enabler	A technology or process or agreement which provides a foundation for transformation work
GPES	General Practice Extraction Service	The General Practice Extraction Service collects information from general practice (GP) clinical systems in England and forms part of NHS Digital's (HSCIC) GP Collections service
	Healthy Child Programme	The Healthy Child Programme is a universal preventative service, providing families with a programme of screening, immunization, health and development reviews, supplemented by advice around health, wellbeing and parenting
ISN	Information Standards Notices	Information Standards Notices are published by the Standardisation Committee for Care Information to announce new or changes to information standards and data collections, including those formerly licensed under the Review of Central Returns procedure
IDCR	Integrated Digital Care Record	Parent related information in a digital format, that can be viewed and used by an authorized user anywhere
LSP	Local Service Provider	Local Service Providers provided electronic care record systems and services to the healthcare system
LTC	Long Term Condition	A long term condition cannot be cured, but its symptoms and complications can usually be controlled with treatment

MH	Mental Health	Mental health is a level of psychological wellbeing
NSC	National Screening Committee	The National Screening Committee advises ministers and the NHS about all aspects of population screening and supports implementation of screening programmes
NIFE	Newborn and Infant Physical Examination	The NHS Newborn and Infant Physical Examination Programme offers parents of newborn babies the opportunity to have their child examined shortly after birth. The examination includes a general physical check as well as an examination of the baby's eyes, heart, hips and testes in boys
OBS	Output Based Specification	
PAS	Patient Administration System	The Patient Administration System records the patient's demographics e.g. name, home address, date of birth, and details all patient contact with the hospital, both outpatient and inpatient
PCHR	Personal Child Health Record	The personal child health record (also known as the red book) is a national standard health and development record given to parents/carers at a child's birth
PDS	Personal Demographics Service	The Personal Demographics Service is the national electronic database of NHS patient demographic details such as name, address, date of birth and NHS Number
PHR	Personal Health Record	A personal health record is an electronic application used by patients to maintain and manage their health information in a private, secure, and confidential environment

PRSB	Professional Records Standards Body	An organisation working with public and professionals providing care to define the standards needed for good care records and so improve the safety and quality of health and social care
	Roadmap	A high level plan for setting out what a programme or organisation will be doing, how they will be doing it and what the timeline and sequence of activities will be
SEN	Special Educational Needs	A child or young person has special educational needs if he or she has learning difficulties or disabilities that make it harder for him or her to learn than most other children and young people of about the same age
SCCI	Standardisation Committee for Care Information	The Standardisation Committee for Care Information is a subgroup of the NIB, responsible for delivering the information standards component of national informatics governance in health and social care in England
SCR	Summary Care Record	The Summary Care Record is a copy of key information from your GP record. It provides authorised care professionals with faster, secure access to essential information about you when you need care

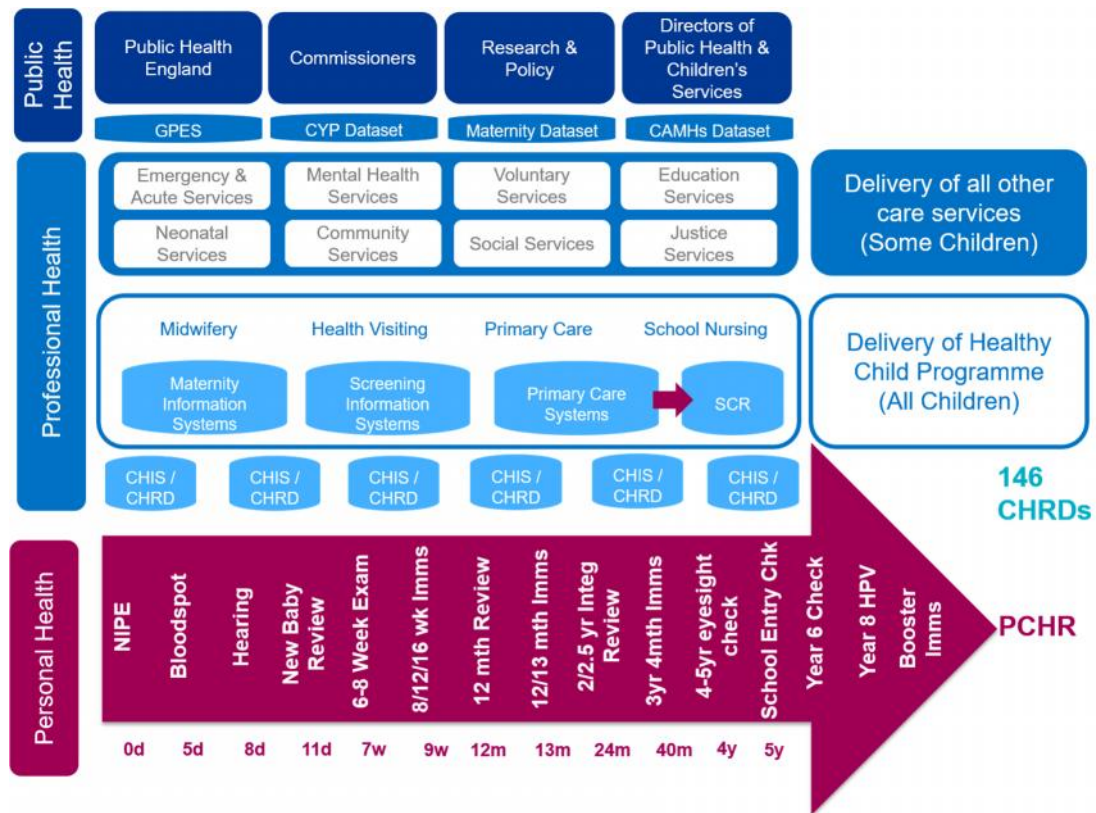
11. ANNEXES

Annex A: What are child health information services?

Child health information services liaise across care settings and agencies and regions to ensure that children and young people in their local population are offered the Healthy Child Programme and that key information on children’s health is available to parents and professionals and for public health purposes.

However child health information is much, much wider than that generated by the Healthy Child Programme and collated into the Personal Child Health Record. Health information must now be available to inform decisions in social care and education and vice versa extending how many organisations must now co-operate to improve the health and wellbeing of children and young people. The diagram below shows how and where the current model of child health information services relates to this wider model.

Figure 14: Map of Child Health Information



Map of Child Health Information Explained

The information structures in this model of health information are, from bottom to top of the diagram:

- A personal child health record (PCHR or 'red' book) given to all parents shortly before or after the birth of a child which contains a subset of health information about the child and enables the parents to record the development of their child and any questions or concerns they have.
- The 146 child health record departments (CHRDs) across England who register children as belonging to a geographical footprint, usually borough based and who enter subsets of health information about children into child health information systems (CHIS), often re-keying this information from paper notifications generated in other care settings.
- The key services delivering aspects of the Healthy Child Programme and the information systems in which data about those services is recorded. These services are Midwifery, Newborn Screening, Health Visiting, Primary Care and School Nursing. It is primarily the interventions from these services which are recorded, as a re-keyed duplicate in many instances, in the child health information systems.
- The next line represents all other health and care services who see children and hold information about them in their own organisational records, whether paper-based or electronic. The majority of this information is never shared with child health information services, although some may be shared with primary care services.
- The top lines represent the anonymised datasets which are derived from these operational and organisational record systems and are shared with professionals analysing population health.

Historic Structure of Child Health Information

The structure and format of the old operating model for sharing information about the health of children: CHIS, the CHRD, the PCHR, was justifiable between 1993 - 2013 when the NHS was organised into Community Care Trusts, then Primary Care Trusts, and before electronic health records became widespread and capable of exchanging information electronically. Primary Care Trusts delivered public health services for children: health visiting, school nursing and community pediatrics, to their local population, mostly registered with GP practices within the same area.

Primary Care Trusts were also directly responsible for commissioning (buying) primary, community and secondary health services for the local population, so it made sense for the assurance of health services being delivered to children to be managed from a central child health record department (CHRD) within these Trusts. At the time this service was created, most child health information was only available as paper records and the CHRDs functioned as a case records management service for community and public health services for children. They subsequently began to use locally provided electronic record systems – child health information systems (CHIS).

However in this old operating model of collecting information in child health information systems, the information collected was only ever a small summary subset of the total healthcare information available for a child. A similar, often more extensive, subset of information was handwritten into the PCHR and was 'owned' by the family of the child. The child would also have a primary care record detailing interactions with the GP and Practice Nurse, any medications prescribed and any referrals to/results from secondary care. Secondary and tertiary care services, those delivered in local hospitals, also kept (and still keep) their own health records for children, as do the extended primary care services: dentistry, optometry, pharmacy, podiatry.

A fully comprehensive care record for children has therefore never existed, only a summary of the Healthy Child Programme in CHIS and the PCHR and partial organisational records in other care settings. This lack of a set of summary information for a child, available to both parents and professionals, is one of the issues that the forward addresses.

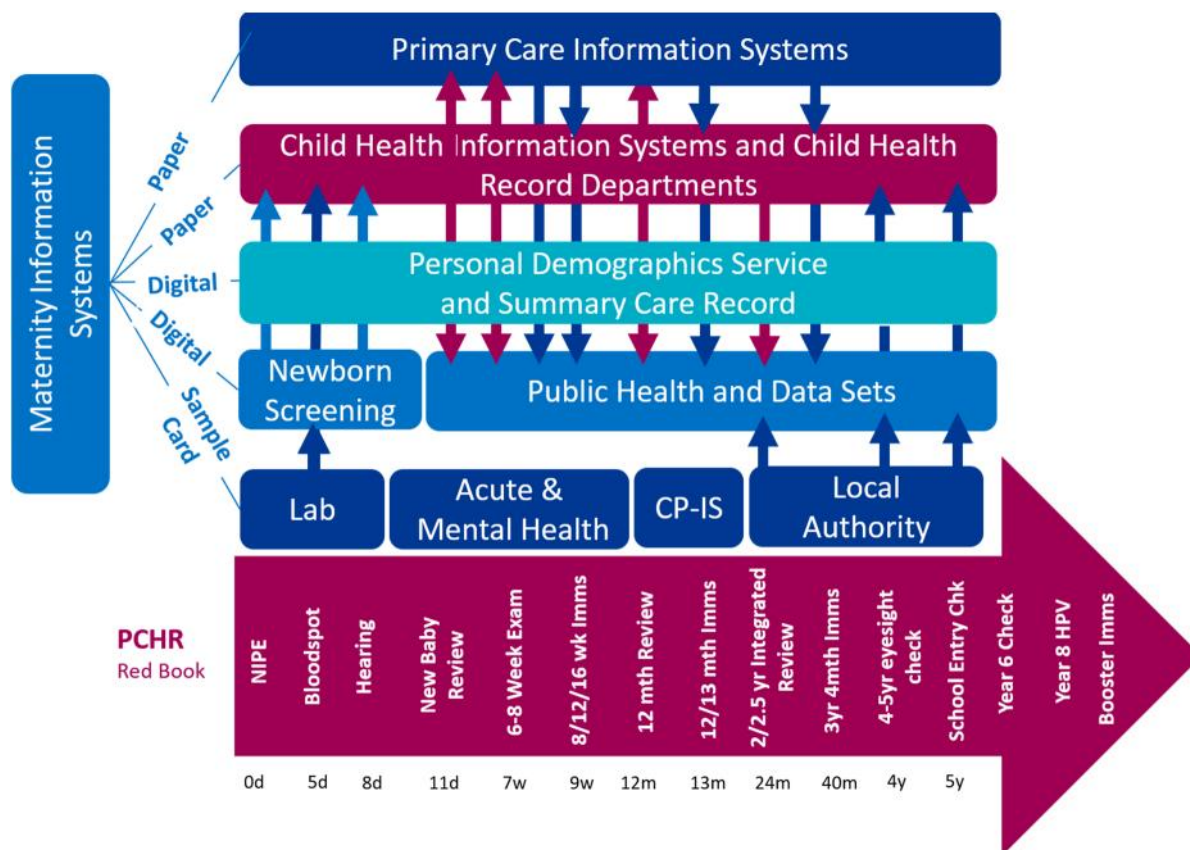
With the abolition of Primary Care Trusts in 2013 and the subsequent change to commissioning arrangements, child health record departments were subsumed into other provider organisations, in many cases no longer in the same organisation as those providing the public health services to children.

The function of child health information services in assuring the delivery of the Healthy Child Programme and in tracking the movements in the child population to ensure this were not necessarily well understood in their new organisations. Responsibility for managing and commissioning population health was now partitioned between CHRDS, the new Clinical Commissioning Groups and Directors of Public Health in local authorities, a model which fragmented both the assurance process and the ability to manage and track local child health populations. One of the aims of the forward view is to restore the ability to assure and evidence delivery of population-based health services for children and to bridge the artificial gap between these services and services delivered elsewhere to children.

What does a Healthy Child Pathway look like?

The diagram below is a graphic summary of how the main information services for children interact from the point at which a child is born. This is essentially a pathway for a healthy child, many other information systems become involved if a child is ill or vulnerable

Figure 15: Child Health Information Systems: Healthy Child Pathway



PCHR Red Book

The sequence of events for a healthy child is set out below. The purpose in detailing this within the forward view is so that readers understand the diversity of health provision for children and the need for information exchange between professionals providing care to the child.

- A child is born (most often) under the care of maternity service and the details of their birth are recorded onto a maternity information system.
- The maternity information system or a related web application sends an electronic message to the Personal Demographic Service (PDS) informing it of the child’s details and the child is assigned a unique HS number. PDS is the system in which demographics for all registered children reside. Some children temporarily residing in England or moving to England may not be registered with an NHS Number on PDS immediately.
- The maternity information system also generates a paper birth notification form (in some areas electronic message) and a maternity discharge notification to the mother’s GP practice. In many areas these same forms are sent to the Child Health Record Department (CHRD).

- Simultaneously PDS informs CHRDs by email of children born in their geographic area and they are registered on a Child Health Information System (CHIS).
- Newborn screening systems also take a feed of children born from PDS to provide a population cohort for universal screening services: Hearing, Newborn & Infant Physical Examination, and Bloodspot Testing, to ensure all children are offered these preventative services. These typically take place within the first 8 days of birth.
- Having registered the child onto CHIS, a CHRD will inform health visiting services of the new birth and a health visitor will undertake a visit by day 14. The details of this visit will either be recorded on a CHIS or may still be kept in paper health visiting records.
- At 6-8 weeks, the parent is prompted to take the child to the GP for a health review and it is at this point that a child is formally registered as having a GP and a Summary Care Record is initiated. The GP will usually record this review in the electronic primary care system (Primary Care Information System).
- From this point forward the child will receive the other aspects of the Healthy Child Programme, including immunisations and health reviews in the GP setting, children's centres, schools and community clinics.
- All these interventions should be entered into the PCHR (the Red Book at the bottom of the diagram) and it is best practice that they should be recorded in the CHIS to maintain an active health record for the child. Often carbon copy tear off slips from the PCHR facilitate this and the information on those slips is re-keyed into the CHIS by members of the CHRD.
- At this time, some CHIS may still be record school health checks and immunisations but in other areas this information is collected elsewhere.

One can see, even from this brief overview how many different information systems/services are involved in just recording the details of routine child health interventions for healthy children. Should a child be ill or vulnerable, the number of organisations, professionals and information systems/services involved can increase dramatically, yet important information is not routinely shared.

These professional information services each hold a picture of a child's health interventions at a snapshot in time in a particular care-setting. It is often important for a professional treating the child at a later juncture to know the outcomes of these previous interventions. However data is flowed from service to service most often on paper and is often only partially available, representing a clear risk to professionals having the data they need to treat the child at different points in the timeline.

What doesn't the red book show?

If we look critically at the domain of professional health we can clearly see they do not provide:

- An information service which knows where every child is and how healthy they are.
- Appropriate access to child health information for all involved in the care of children.

The key defect in professional health information services is not the systems themselves as they record health interventions with children excellently in some cases and perfectly adequately in others, but in their failure to exchange essential information between professionals involved in a child's care and the failure to provide or consolidate this into a summary view which can be consulted quickly and easily.

Crucially the information services many people think of as providing this summary view are not a comprehensive overview of a child's health status:

- A CHIS mainly records a summary of the Healthy Child Programme interactions. Some CHIS may record Child Protection status or A&E attendances, but the episodes of care in hospitals or other settings will not be present. Few care professionals have access to CHIS.
- The Summary Care Record (SCR) is a summary view of only the primary care interactions with a child, it does not contain all the Healthy Child Programme information and will not necessarily contain information about episodes of care occurring elsewhere. Care professionals with smart cards can access the SCR. It will not be available for a child who is not registered with a GP.
- The Personal Child Health (PCHR) record may contain the fullest summary of a child's health care to date, but this is a paper record owned by the parent or guardian and which cannot be accessed independently by health or care professionals.
- When a child moves to a different GP or to a different region, these partial summaries take time to transfer. Moreover it is often only when a child presents to a new GP or to a new local hospital that the change of location is picked up so essential information on the child's health can arrive considerably behind the treatment given.

The current configuration of information services for children therefore cannot guarantee knowing where a child is and how healthy they are, nor can they guarantee appropriate access to information for professionals.

Annex B: Actions to support new models of care for children

The following suggested actions are taken directly from the Nuffield Trust's review, 'The Future of Child Health Services: New Models of Care', (February 2016). Alongside this we include ways in which a digital strategy can support the recommendations:

Figure 16: Understanding children, young people and their families' specific needs

Examples of specific recommendations/ solutions	How a digital strategy can help
Segmenting the population allows us to understand children and young people's general and specific needs, including the broader determinants of their health, so that these together with their expectations can be met, and resources targeted more efficiently.	Recognition that no one single information service/system will meet the different needs of children and young people and their families so flexibility and plurality need to be built into our approach.
Use a segmentation approach that links population groups coherently to forms of service (pathways).	Designing information services that can support different population groups and service pathways, combining and exchanging relevant data into new modules/views as needed.
Identifying how good care should look from the perspective of groups of children with different needs and their families.	Ensuring that children and young people and their families are given a strong voice in the direction and content of their care through use of collaborative care records, for example, not just access to their records online but the ability to contribute and shape those records.

From the Future of Child Health Services: New Models of Care, 2016, p27

Figure 17: Enabling access to high quality paediatric/child health expertise in the community

Examples of specific recommendations/ solutions	How a digital strategy can help
<p>Providing safe and responsive, as well as equitable, coordinated and continuous paediatric care in the community through:</p> <ul style="list-style-type: none"> • Direct (phone/email) access for the GP to a named paediatrician/specialist nurse. • Multidisciplinary case discussion meetings. • Primary care paediatric clinics. • Community care under one roof (physical or virtual): a 'one-stop shop' in the community, whether the GP practice or a child health centre, is where all the needs of the future mother, family, baby and child, as well as young person could be met by a community multidisciplinary workforce. 	<p>These types of networks of care require the ability to communicate and exchange information easily outside of organisational settings.</p> <p>A digital strategy can help by introducing a platform that supports inter-organisational shared care and the necessary interoperability which supports the shared care model.</p> <p>That platform and interoperability model should support the 'one stop shop' virtual model as well as enabling the 'family health' view, whether in personal health records or professional health records.</p>

From The Future of Child Health Services: New Models of Care, 2016, p31

Figure 18: Linking up information, data and communication and care

Examples of specific recommendations/ solutions	Further recommendations from the Nuffield review
<p>Introduce up-to-date communication and good information/data flow with the child/young person and their family, not only across the different health professionals (for example GPs, school nurses) and professionals in other sectors (for example education, social care, justice) in the community, but also with secondary and tertiary care, so that services can be tailored to the needs of the child and the family.</p>	<p>Technology should be used by providers as a tool to reach out to other providers, or by patients for them to obtain quick access to advice, rather than having to wait unnecessarily for a face-to-face appointment.</p> <p>Communicate with young people directly via the channels that they use; apps, online, chat, where it is easier to communicate online than on the phone, and less intimidating.</p> <p>There should be a common child health record and integrated data to allow for continuous quality improvement, accessible by all through a single point.</p> <p>Ideally, the common record, including the NHS number as a unique identifier and patient data, would be across the different systems of care (for example including education).</p>

The Future of Child Health Services: New Models of Care, 2016, p32

Figure 19: Health Literacy and Education

Examples of specific recommendations/ solutions	How a digital strategy can help
<p>Ensure that children and young people and their families, as well as professionals, know where to get information and advice from and to have a 'shared language'.</p> <p>Educate and engage parents so they understand the health care system and how to navigate it, as well as how to manage their child's acute and chronic illness where appropriate and actively listen to their needs.</p> <p>Educate staff about the roles and responsibilities of other staff in the system. Different professionals need to understand each other's perspectives, roles and responsibilities, and create a partnership; the goal of which is to improve the health of the child/young person.</p> <p>Use the school system more effectively for health promotion and literacy. This would work through multiple channels for different groups of children (for example healthy children, children with complex needs) and would involve:</p> <ul style="list-style-type: none"> • Educating all children about the multiple aspects of their physical and emotional health and how to stay healthy, as well about the health care system and what it can do for them • Actively working with and educating teachers to help improve the health and education outcomes of all children, as well as of children with special health needs <p>Through the children, reaching out to parents to educate them and involve them in improving care for their children.</p>	<p>Transformation of information services to enable navigation of health and care services through use of local directories as well as providing health promotion materials in accessible language in multiple formats. Delivery of such services should be accessible to all, through a single point, but also available in a distributed way if needed.</p> <p>Information services should include the ability to view other professionals and organisations involvement with children and families so that the network of care is transparent. This kind of mapping can be enabled by technology such as national patient record locator services.</p> <p>Use the capability of a new digital platform for children's health information to deliver apps and information which are co-created with children and young people and with Education services and which are suitable for teaching and use in schools as part of an ongoing curriculum of self-care.</p>

From The Future of Child Health Services: New Models of Care, 2016, p33

Annex C: Operational Issues

Throughout a six month programme of consultation, stakeholders provided us with examples of problems they experienced with child health information and information. We indicated that these difficulties cluster around four main deficiencies:

- Lack of effective population failsafe management; how can we know with certainty where a child is to make sure they are offered preventative programmes of care?
- Lack of up to date, accurate and consolidated records; how can we know how healthy a child is?
- Lack of access to information; how can we ensure appropriate access to information for all involved in the care of a child, including families and children themselves?
- Lack of guidance and collaboration

In the sections below we summarise the problems encountered in more detail and indicate what new capabilities are required to bridge these gaps in personal, professional and public health services, highlighting whether these are part of the National Information Board's (NIB) work streams or whether they require a separate solution to be defined as part the forward view implementation work.

Figure 20: Knowing where a child is

Issues raised	We need information services that.,,	NIB Programme	Forward View
Procedures vary widely for how population movements are handled and how cohorts are identified and managed (lives in, treated out etc.). This can lead to some children being outside of the care of the usual agencies.	Have a standard operating procedure for population identification and management and are aligned with PDS and Local Authority demographic tracking mechanisms.	x	✓
It is possible to lose track of children as they move between population footprints or to lose them in the gaps between local footprints.	Track responsibility for providing health services to children electronically on a whole (England) population basis.	x	✓
Different population cohorts/caseloads under different professional care exist simultaneously, e.g. midwife, health visiting and GP, and overlap.	Allow multiple population cohorts to exist simultaneously and be flagged. Easy re-configuration of population footprints possible.	✓	✓
When a child moves area or GP, their information does not move with them in a timely manner.	Ensure the information flows with the patient.	✓	✓
In local population cohorts it is impossible to identify children who are not known to care services.	Provide failsafe mechanisms to flag/alert that a child is outside of the care of the usual responsible agencies.	x	✓
In a health and care economy of many providers, it may become confusing for parents and young to find the services they need. It may also become difficult for professionals to refer appropriately	Provide online signposting of the availability of services and allow electronic contact with professionals	✓	✓

A new population failsafe management capability is required to provide an information service which knows where every child is and can offer them the preventative programme of care to which they are entitled. Localised directories of available health and care services are already proposed under the 'NHS.uk' programme.

Figure 21: Knowing how healthy a child is

Issues raised	We need information services that...	NIB Programme	Forward View
No consolidated summary view for the health of children 0-19. Child records fractured across care settings and organisations and regions.	Have the same online summary view of a child or young person's health for professionals, parents and young people.	x	✓
Different models for what is needed in a summary for a child.	Consolidate existing agreed datasets into a core record dataset	x	✓
Paper records and notifications introduce delays to child health information being available at point of care. They also carry a large administrative burden to maintain. Partial records and 'lost' information.	Exchange routine information (datasets) electronically in real time (Interoperability) Plan and phase interoperability by prioritised datasets to build to an agreed core dataset	✓	✓
Insufficient data being shared from GP systems and if shared, largely paper based, for example, immunisations	Mandate electronic information flows from GP systems for specific datasets pertinent to children's health	✓	✓
In unscheduled care episodes, it is unclear which/how many other services/professionals a child is involved with.	Use passport-style information under the control of parents and young people. Use patient record		

Lack of linkage between mother and baby records can lead to babies not receiving appropriate and timely care, for example Hepatitis B vaccination.	Ensure new information services provide mother/baby linkage as well as creating a foundation for joined up maternity and newborn records.	✓	✓
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A new core record dataset for children and young people is required to provide the summary view currently lacking across all systems: this will provide an information service which knows how healthy every child is. The NHS already has agreed datasets for maternity, children and young people and child and adolescent mental health and an agreed shared record also exists in the form of the PCHR. These data items could be used to provide the core in the first instance combined with essential datasets such as medications, allergies, and diagnosed conditions, already much used in primary care systems.

Consideration must also be given to the ability to link mother and baby information creating a foundation for joined up maternity and newborn records.

This work would be underpinned by phased interoperability to populate the core record dataset as needed across systems.

Figure 22: Appropriate access to all involved in the care of children

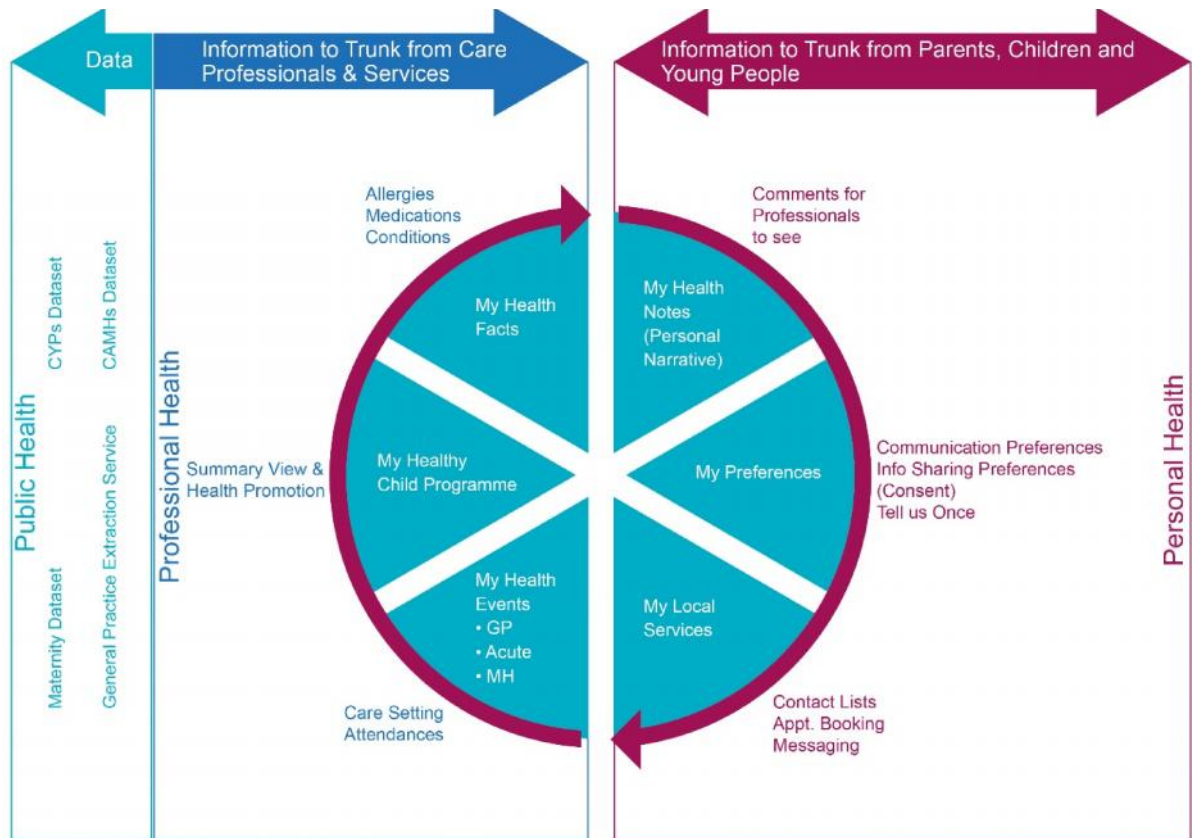
Issues raised	We need information services that.,,	NIB Programme	Forward View
There is still a lack of clarity over what is 'appropriate' information sharing to support children's health. Information Governance still being used as a defensive practice which slows down attempts at interoperability.	Have a standard national framework for information sharing for children that organisations can subscribe to or localise.	✓	✓
Lack of clarity over who 'owns' child health data and therefore who can share it.	Have transparency as to what data is held on children, provide a framework and systems that put parents and children in control over how this data is shared.	✓	✓

Lack of approved/kite-marked authentication methods to ensure access to information is secure for both professionals and parents/young people outside of organisational boundaries.	Provide standardised authentication methods for access to a core clinical record dataset. Have a framework / guidance which outlines how secure access to information can be guaranteed.	✓	✓
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We require information services that have defined what ‘appropriate access’ is, so that it isn’t left to individual interpretation or local determination, possibly to the detriment of the care of children. Parents and young people must be involved in co-creating that definition with health and care professionals and any new services we introduce should have the capability to handle consent and information sharing preferences. Additionally we must ensure that access to information and the information itself are secure.

Annex D: Hub and Events Model

Figure 23: Business Operating Model - Digital Child Health Hub



The diagram is an example of what events a hub could exchange, events that can be subscribed to and which receiving systems would display to the user of that system

This is conceptual design example only and the actual design of how events would display in receiving systems would be for the suppliers and users of that system to determine. The six suggested sectors we've illustrated have the following function/rationale:

- **My Health Notes:** the capability for families and young people to contribute their own story and comments and have this appear alongside the information recorded by professionals. These would be personal events.
- **My Preferences:** the capability for families and young people to record their communication preferences (how they want to be contacted), their preferences for who they share information with and the consent to do so and to notify health or care services once about address and contact details changing. These would be communication events and consent events.
- **My Local Services:** the capability for families and young people to access local service directories and have contact lists and details of the

professionals they receive services from and to be able to message or email those people. The ability to book appointments online in a variety of care settings. These would be contact events.

- **My Health Events:** a list of appointments past and present from all care settings and services. These may be purely transactional events, the fact that an event at a particular care setting has taken place. The ability to see more detailed information from these services may be handled as a log-in to the patient access areas of a GP record, Mental Health record, etc.
- **My Healthy Child Programme:** shows the timeline and status for all the activities in the Healthy Child Programme, prompts when they are due, alerts when they are overdue and shows when they are complete. These would be failsafe management events.
- **My Health Facts:** the essential information that a professional needs to know before treating a child or young person. It would include medication and medication history, any conditions diagnosed and any allergies. These health events contain clinical information.

The list is not exhaustive and we expect ideas and priorities to emerge as we consult on implementing the forward view.

Annex E: Types of Personal Health Records

There are several different models of PHR in use currently and below we describe these:

Access Only PHR

An access only model gives parents or young people a view of what information is held on them in a particular professional health system. We refer to this as a 'tethered' record, the parent or young person is tied to accessing a particular system to view the record and may have to view several such systems to see all the information held on them.

The Summary Care Record, which is a summary of the information held on a person by their GP, is an access only PHR model. This model can assist health and care professionals to get a rapid overview of a child's history and provide assurance to parents and young people as to what information is held about them. This type of record is controlled by professional health services. It is provided and managed by a particular care setting.

Access and Interaction PHR

Essentially the same model as above, although this type allows some forms of interaction with the health professionals who use this system or the services available, for example appointment booking, ordering repeat prescriptions or sending emails or recording preferences.

The Patient Online initiative for primary care services is an access and interaction PHR and it will work for those sections of the child health population who are registered with GPs and for whom the GP provides the majority of their health care interventions. This type of record is controlled by professional health services.

For those who are not GP registered or who have multi-agency complex needs it is not necessarily a suitable model as it is tethered to a particular system and cannot function as a 'hub' from which to manage multiple interactions with different health and care service providers, instead this would have to be done with each professional health system in turn. This type of record is controlled by professional health services.

Passport Style PHR

A passport is a summary of key facts that children and young people using health and care services can use to help them access services more easily and avoid having to repeat their history and preferences to multiple professionals. It can be held on paper or mobile phone.

The passport idea, which combines professional clinical information with personal information, was conceived by young people and parent/carers involved with Mental Health Services who wanted to be empowered to share their own information to improve communication and integration between different services and help access to future services.

Each passport is created by a young person or parent/carer (for younger children) with the support of their care professional. It provides a summary of their care in the service which will be controlled by the young person themselves or parent/carer and shared with other professionals when they wish.

Collaborative PHR

In this model parents and young people share a summary view of the information different professional health services in different organisations have recorded about them, whilst being able to record their own information to sit alongside that held by professional health services. It differs from the passport model in that the summary view is dynamic and is based on information being consolidated from the different services the parents and young people receive care from. It accesses information from professional health systems but it also operates independently of them.

eRedbook is a collaborative PHR which is in use at Liverpool Community Health Trust and is being trialled in London.

eRedbook is the first PHR to meet the standards set by the Royal College of Paediatrics and Child Health for a Personal Child Health Record and it contains the same core dataset. It is designed to present information entered by parents alongside information entered by professionals so that there is much richer view of a child's early years.

The eRedbook and information about the child can be accessed anywhere at any time via smartphone, tablet or laptops/PC's. Parents can choose to share data directly with family members or those individuals directly involved in caring for the child and family. The online calendar provides alerts and reminders for when a development review or immunisation is due.

In this collaborative model, digital tools such as health promotional films, messaging, prompts, and diary reminders, are available to help the parents and young people manage their own health. It becomes a primary tool for parents and young people to manage interaction with health and care services but also becomes a channel by which professional services can directly contact them. It is controlled by families and young people but receives an information feed from professional health services.

Health Promotion PHR

In this model, parents and young people use an application which helps them monitor and understand their own health or that of a child through strong interactive digital tools such as avatars, contextual video and audio and incentive programmes ('reward' messages). The application promotes/encourages behaviours that result in wellbeing primarily by communicating with the user in an engaging, intuitive or information-driven way.

Baby Buddy is a free health promotion app available for smartphones from the charity Best Beginnings which guides women through pregnancy and the first six months of the new baby's life. The app has been developed with input from professional bodies and is endorsed by the Department of Health.

The app provides information on pregnancy, birth and parenting delivered through the creation of a digital 'buddy' and aims to increase women's confidence in actively managing their health and the health of their baby, encouraging engagement with and uptake of locally available services.

This type of PHR is controlled by the parents or young people and is not interoperable with professional health systems but email or messaging contact with peers or professionals may be enabled.

Although we have presented these as different models of personal health record, in practice there is nothing to stop the different models combining. For example, it is possible to have a collaborative personal health record which has a passport style function with a strong health promotional functionality and interface. This model may yet emerge in the market.

Annex F: Service Improvements through use of Personal Health Records

Figure 24: Service Improvements in Child Health

Service Improvement Examples	
Communication	<p>Improved communication with care providers</p> <p>Diversity of communication types suiting personal preference: voice calls, video calls, secure email, secure instant messaging, discussion forums, secure email</p> <p>Online consultations via PHR</p> <p>Transactional services via PHR, e.g. appointment booking, repeat prescriptions</p> <p>Personalised health promotional materials: prompts, alerts, health information videos</p>
Joined-up Services	<p>Child-centred assessments</p> <p>Child-centred Education, Health and Care plans</p> <p>Identification of shared goals and outcomes across teams supporting children and families</p> <p>Notification of special education needs or disability</p>
Immunisations Management	<p>Reminders that immunisations for a child are due</p> <p>Overview of immunisation schedule for a child (what is due when)</p> <p>Full immunisation history available, especially reconciling immunisations given by different providers</p> <p>Reducing risk of duplicate immunisations</p> <p>Getting information about the purpose of immunisation</p> <p>Receiving alerts for immunisation in the event of health scares</p>

<p>Health Check Management</p>	<p>Reminders that screening/health checks/ reviews for a child are due</p> <p>Overview of health check schedule for a child (what is due when)</p> <p>Full Healthy Child Programme history available, especially consolidating interventions made by different providers</p> <p>Reducing risk of missing interventions</p> <p>Getting information about the Healthy Child Programme and its purpose</p>
<p>Medicines Management</p>	<p>Reminders to take medication</p> <p>Overview of current medications</p> <p>Reconciling medicine regimes, especially reconciling prescriptions from different providers, verifying accuracy</p> <p>Ordering repeat prescriptions</p> <p>Getting more information about medicines prescribed, side effects</p>
<p>Self-Management (or managing health of child)</p>	<p>To do lists and reminders</p> <p>Recording information to track healthy development or improvement in conditions</p> <p>Recording questions to ask care professionals</p> <p>Recording information to be used in an emergency/crisis</p> <p>Setting personal goals and prompts</p> <p>Access to test results</p> <p>Access to referrals or post-consultation summaries</p> <p>Linking to monitoring devices/telemetry/health and lifestyle apps</p> <p>Recording health outcomes</p>
<p>Support for parents and young people in finding information and care services</p>	<p>Finding out about illnesses and conditions</p> <p>Information on types of treatment or care options</p> <p>Finding out about local services and support options</p>

<p>Accessibility/availability/ accuracy of health information about a child</p>	<p>Summary health information available 24/7</p> <p>Health information in a portable online format</p> <p>Data quality improves due to personal oversight by parents and young people</p> <p>Consolidated information provides ‘the bigger picture’ of a child’s health and care history</p>
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In addition, those people already using PHRs report the following benefits and improvements related to health care:

- Greater empowerment: Feeling more in charge of their health and being seen as partners in their healthcare
- Better understanding of their condition
- Ability to share care with professionals
- Better health related outcomes
- Increased trust in healthcare
- Identifying errors, hence preventing harm
- Better adherence to medication and advice¹³

¹³ [Personal Health Record \(PHR\) Landscape Review: Final Report, Royal College of Physicians, May 2016](#)

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