

# Connecting child health systems is child's play

Early Years ~  
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# What is CHISystem?

A series of clinical and demographic servers which collect data, collate information and report intelligence.

**1** *'Knowing where every child is and how healthy they are'*

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**2** *'Appropriate access to information for all involved in the care of children'*

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NHS England, Public Health England, the NHS Outcomes Framework 2015/16, the Five Year Forward View and the Children and Families Act 2014 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 every child.



# Children's Health: key facts

1

## Whole population focus

- The 'caseload' is all children born or moved into England
- There is a nationwide programme of health interventions for children 0-19 called the Healthy Child Programme which has to be offered to all children and delivered .

2

## Whole eco-system delivery

- Children's services are delivered by all health, social services and education agencies. Children's health interventions happen in all care settings.
- Children's services cannot be delivered effectively without widespread information exchange – currently paper based - this method is too slow and too fragmented to provide up to date, reliable, point of care information

3

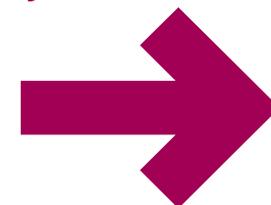
## Personal Health Records are already a part of children's health

- The Personal Child Health Record (PCHR or red book) which is owned by parents and young people has been in use for 20 years
- This has provided a 'failsafe' overview of a child's health and development in the absence of joined up, up to date care records.

4

## Very public failings in child health information provision – urgent need to rectify

- Victoria Adjo Climbié 2002, Baby P 2007 et al
- National Incident Team Report on 'missing' children, 2015



# Current Challenges in CHISystem

## 1 Fragmentation

- Partial records in several different systems – Maternity; GP; HV; FNP; Child Health Information Systems; NICU; Acute
- No single picture of a child's health interventions
- Local Authorities are retendering HV service without due diligence re CHISystem
- FNP uses Open Exeter and the advent of Local Configuration

## 2 No Failsafe for population management

- Children unregistered to CHIS systems (National Incident Team Report), they 'disappear'
- Possible for children's information to be mislaid/delayed when they move to a new area

## 3 Limited Access

- Very limited access to information for our partners outside the NHS, for example, Social Services or Education
- Some providers of public health services for children have no access to IT systems

## 4 Paper Heavy/Manually Intensive

- Information still largely recorded on paper and sent from care-setting to care-setting
- Information re-keyed from systems to system creating large administrative burden



**Public Health**

Public Health England

Commissioners

Research & Policy

Directors of Public Health & Children's Services

National Audit

CYP Dataset

GPES

Maternity Dataset

CAMHs Dataset

Emergency & Acute Services

Mental Health Services

Voluntary Services

Education Services

Neonatal Services

Community Services

Social Services

Justice Services

Midwifery

Health Visiting

Primary Care

School Nursing

Maternity Information Systems

Screening Information Systems

Primary Care Systems

SCR

CHIS / CHRd

# Map of Child Health Info

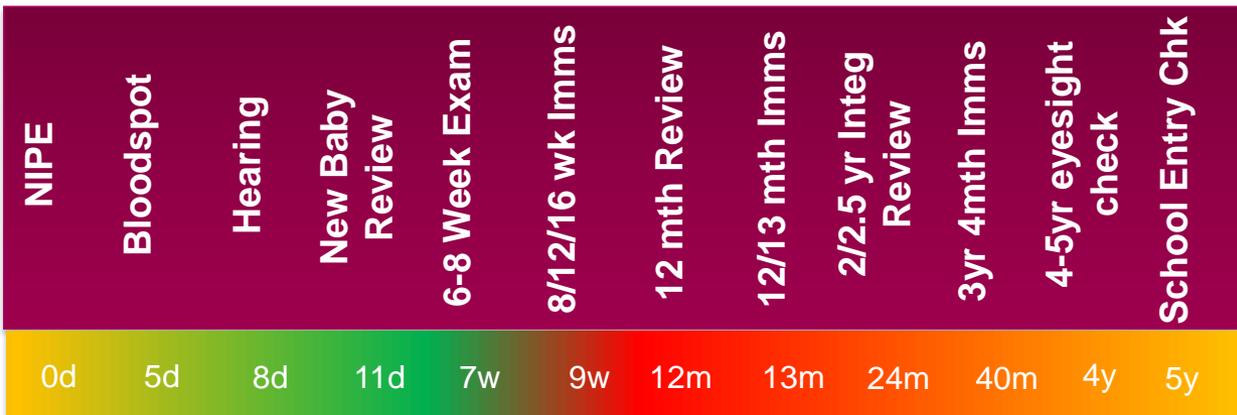
Delivery of all other care services (Some Children)

Delivery of Healthy Child Programme (All Children)

146 CHRdS

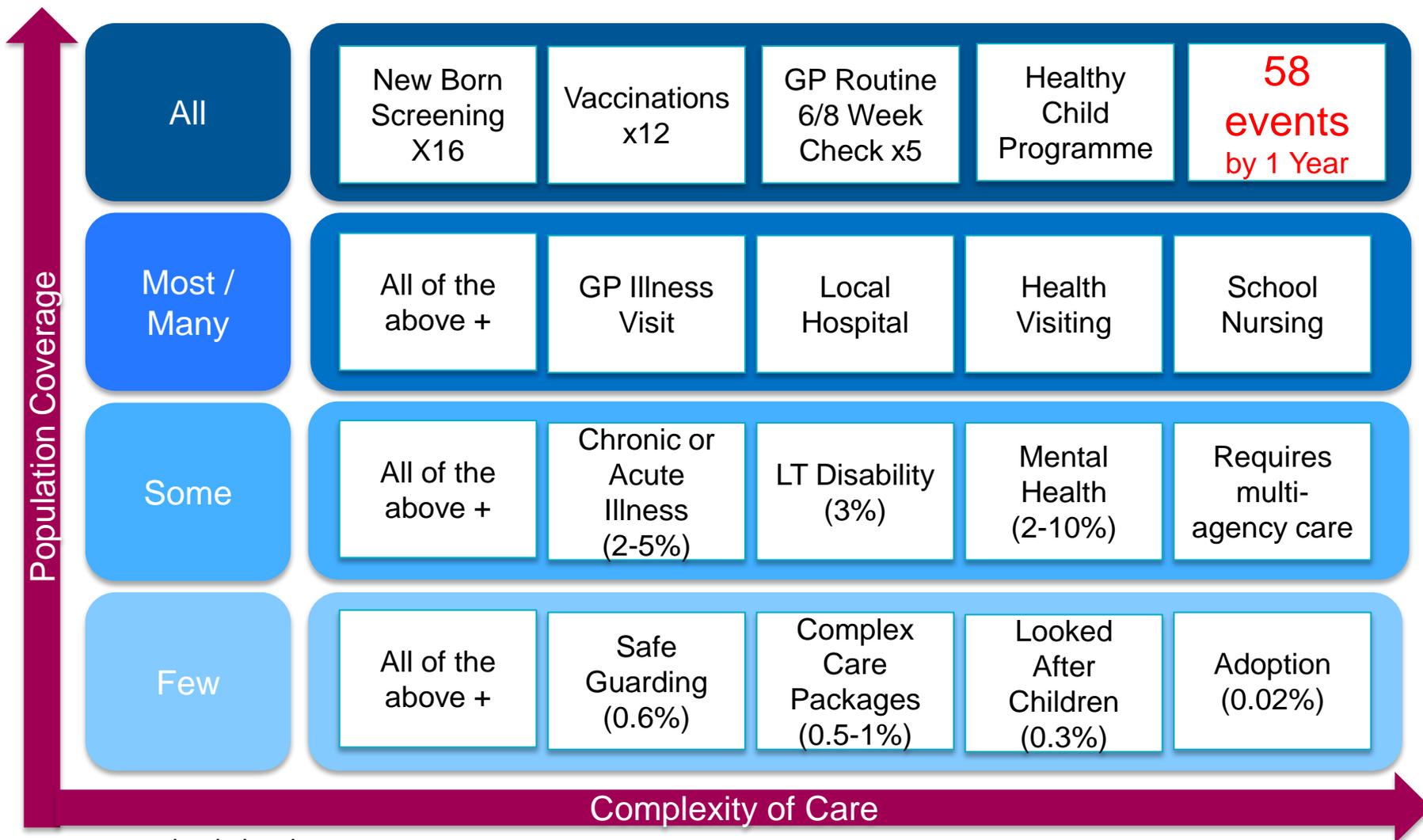
**Professional Health**

**Personal Health**



**PCHR**

# Complexity/variety of child health services



# A Whole Population Approach: Patient Segments in Child Health

## Healthy Child

- *Advice & prevention* eg: Breast feeding / Immunisation / Mental well-being / Healthy eating / Exercise / Dental health

## Vulnerable child with social needs

- eg: Safeguarding issues / Self-harm / Substance misuse / Complex family & schooling issues / Looked after children

## Child with single long-term condition

- eg: Depression / Constipation / Type 2 diabetes/ Coeliac Disease / Asthma / Eczema / Nephrotic syndrome

## Child with complex health needs

- eg: Severe neurodisability / Down's syndrome / Multiple food allergies / Child on long-term ventilation/ Type 1 diabetes

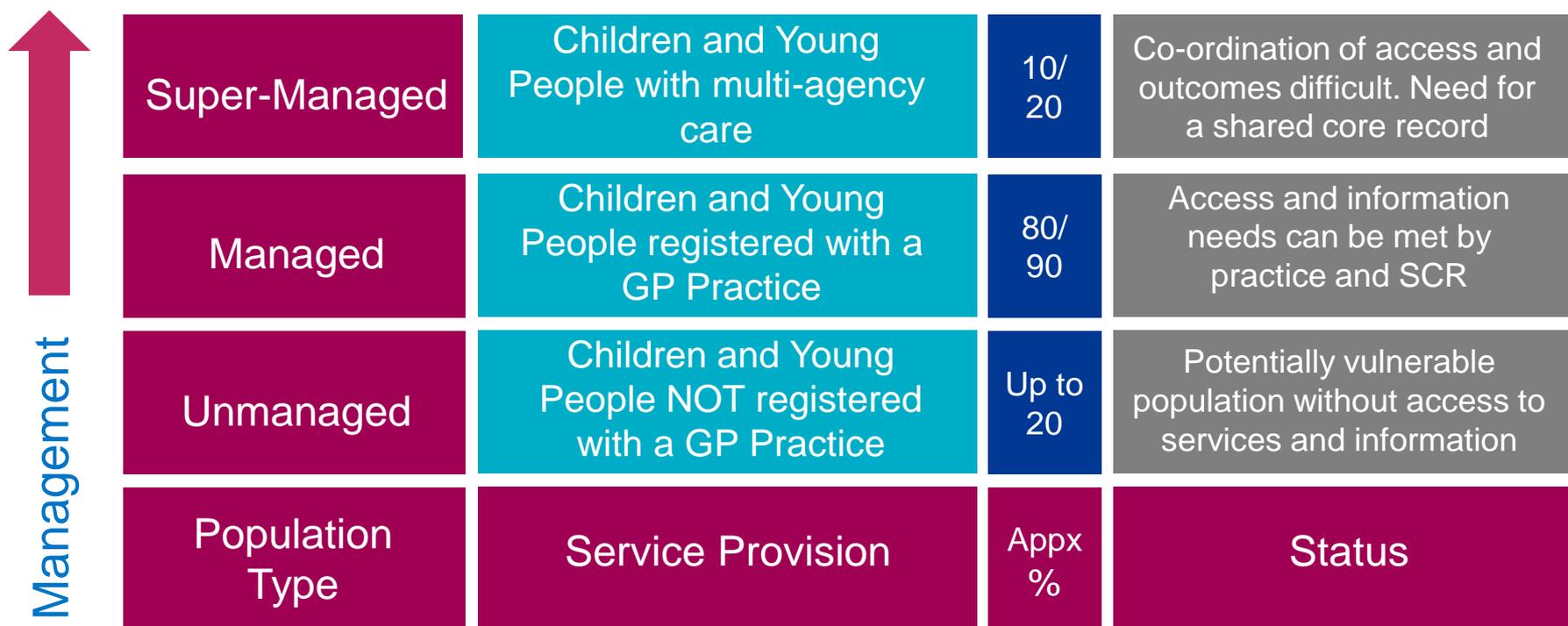
## Acutely mild-to-moderately unwell child

- eg: Croup / Otitis media / Tonsillitis / Uncomplicated pneumonia / Prolonged neonatal jaundice

## Acutely severely unwell child

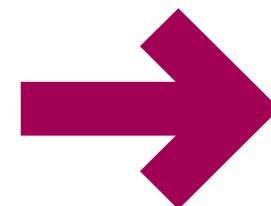
- eg: Trauma / Head injury / Surgical emergency / Meningitis / Sepsis / Drug overdose / Extreme preterm birth

# Managing care for whole populations



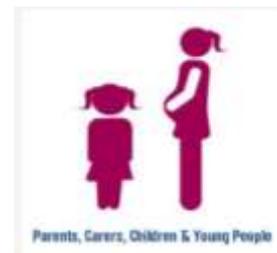
↑ Management	Super-Managed	Children and Young People with multi-agency care	10/20	Co-ordination of access and outcomes difficult. Need for a shared core record
	Managed	Children and Young People registered with a GP Practice	80/90	Access and information needs can be met by practice and SCR
	Unmanaged	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

CHIService report 20-30% churn in population for 0-5 year olds



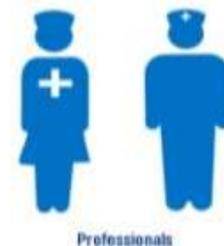
# New information services for parents, families, carers, children and young people

- 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 There is a common (core) view of the health information recorded about children and young people in different health and care organisations that is shared by parents, families, carers, children, young people and professionals.
- 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.



# New information services for professionals

- 1 Professionals will have access to a core view of child health information at the point of care.
- 2 Up to date health events will be available in their own health record systems, they will not need to access other systems.
- 3 Professionals with a responsibility for a child will have real time access to events occurring for that child in other organisations, where it is appropriate to do so.
- 4 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.
- 5 A failsafe management service will make it easier to identify when a child has fallen outside of the care of the usual responsible agencies, such as a GP or Health Visitor.
- 6 A failsafe management service will alert those delivering preventative programmes of care when an intervention is due or has been missed.



# New information services for public health

- 1 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.
- 2 Administration of public health programmes and call and recall can be standardized to a high degree through applying immunisation rules and schedules nationally as a series of events rather than locally.
- 3 As interoperability of events becomes routine, public health professionals will have access to real time population data for analysis.
- 4 As parents, families, carers and young people begin to use personal health records routinely, it becomes possible to deliver personalized health promotion materials to people and enter into dialogue with them



# Personal Health

# Professional Health

# Public Health

Contributes to

Is source for

Info for use by: Parents, Children, Young People, Carers

Info sharing controlled by: Parents, Children, Young People, Carers

Info type: per child records with personal identifiers and personal data. Recorded by parents and young people and professionals

Info grouped by: families, extended family, social groupings

Info Systems in use: PCHR, Health Passports, eRedbook, Baby Buddy, Patient Knows Best and many others

Info for use by: professionals in Health, Social Care and Education caring for parents, children and young people

Info sharing controlled by: the organisation in which the care takes place, e.g. GP practice, hospital, children's centre, etc

Info type: groups of individual, identifiable health records e.g. caseloads, medical notes. Recorded by professionals

Info grouped by: organisation providing the care

Info Systems in use: CHIS, PAS, Maternity, MH Systems, GP Systems, SCR, CP-IS, A&E, Screening Systems and many others

Info for use by public health professionals and commissioners providing care services to populations

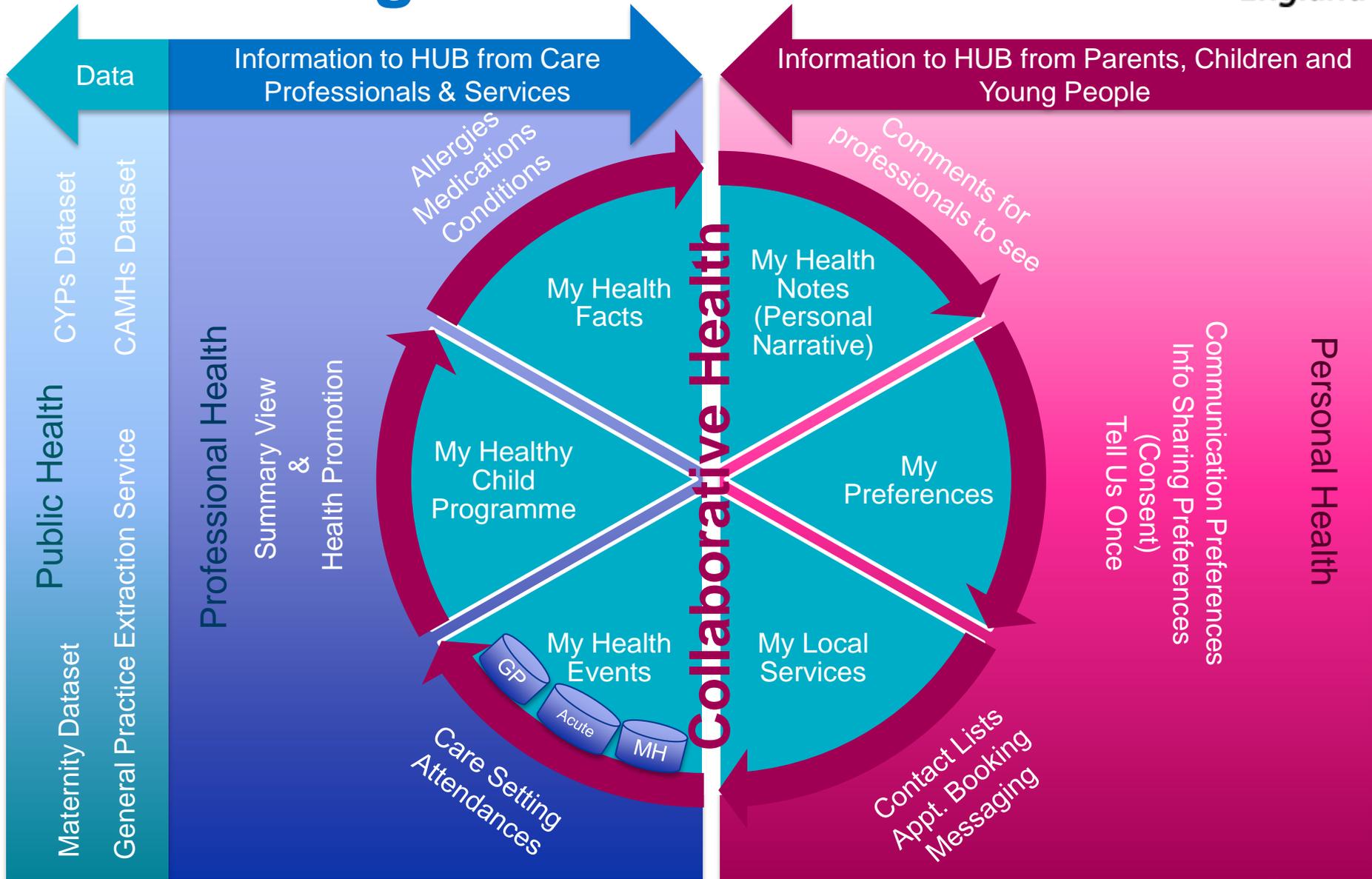
Info sharing controlled by: national and local agreements

Info type: anonymized data, does not identify individual children. Often aggregated or statistical. Analysed rather than recorded.

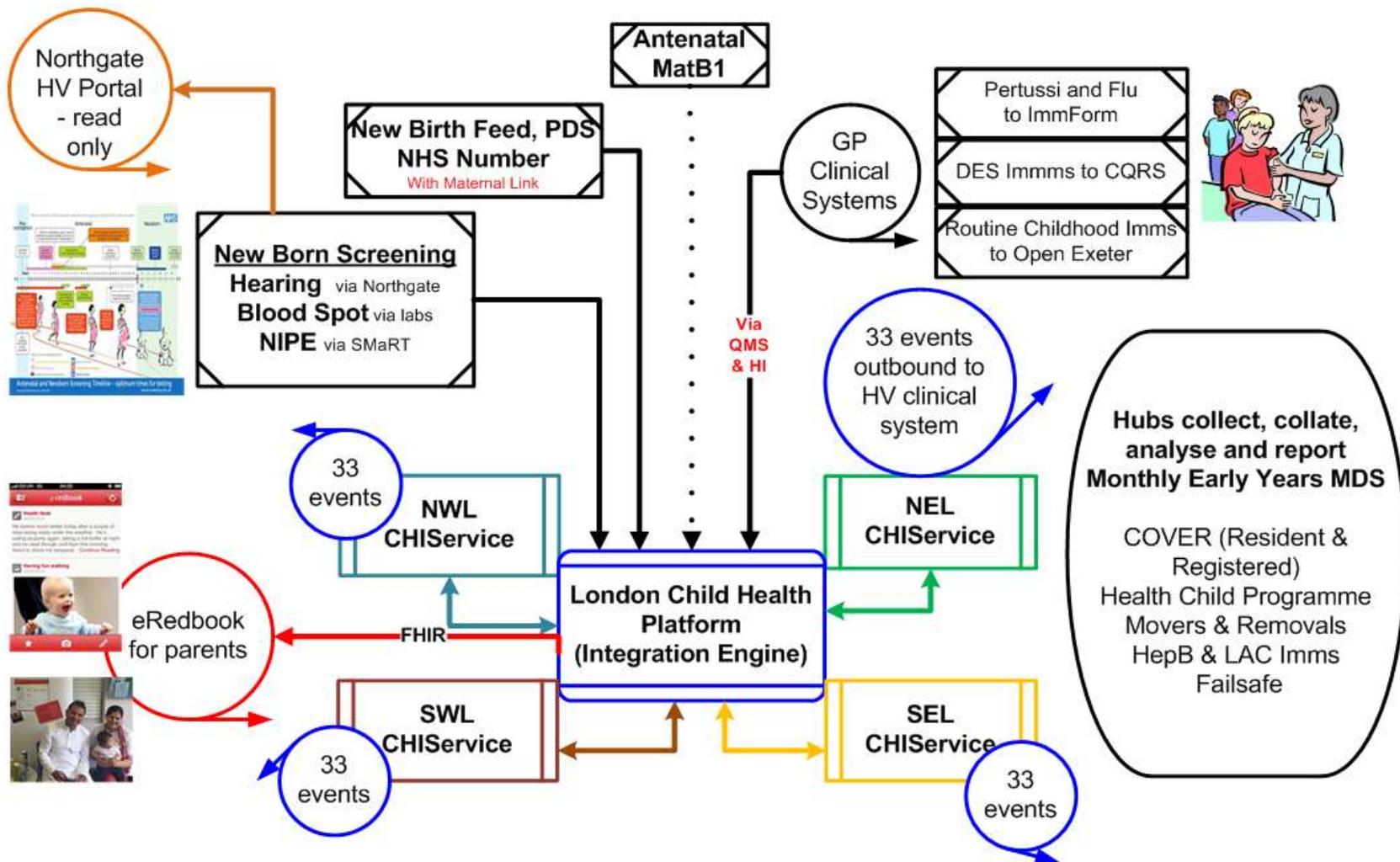
Info grouped by: national, regional, or local populations. Sometimes by disease or condition

Info Systems in use: Maternity and Children and Young People's Datasets, Immunisation Cover reports, Screening Key Performance Indicators and others

# Vision: Digital Child Health Hub



# The London CHIService Platform Prototyping Project



# Pragmatic Information Governance

## How we handle information

We want to make sure that your child has the opportunity to have his/her immunisations and health reviews when they are due. We also want to be able to plan and provide any other services your child needs. Therefore, we enter some of your child's details from this record on to our computer system.

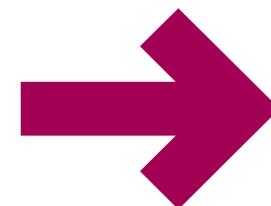
We treat this information as strictly confidential and only release it to:

- Yourself as parent(s)
- Your child's health care professionals, who work directly with your family.

This information may be used anonymously so that we can plan services for all children.

We will not normally release any information that could be linked to your child to any other person or organisation without asking your permission first. However, it is sometimes necessary to use this sort of information for audit purposes and public health reasons such as monitoring the effectiveness and safety of vaccines.

We are subject to the terms of the Data Protection Act 1998 in respect of personal data held by us. You have the right under the Act to ask to see details of the information held regarding your child.



# Pragmatic Information Governance

## 1 Problem: No 'owners' of data

- In the Data Protection Act there are no 'owners' of data
  - You are either a "data subject" – the data is about you
  - Or you are a "data controller or processor" – you hold data about subjects
- If there are no owners, who is to say whether data should move and who to?

## 2 Solution: Recognise the different domains/audiences for health information

- a personal domain, where the patient is, in effect, the "owner" of any data about them in a record
- a statutory or institutional (professional) domain, where a trust/organisation might hold data about a patient as a data subject but has a responsibility to ensure appropriate use and allow the patient to access the data electronically.
- different care organisations can be "data controllers in common"
- a public health domain where anonymized data is analysed for a variety of 'greater good' purposes

## 3 Consent:

- Make it the default assumption that the patient is the owner or controller of all data relating to them. They can then share this data with whichever parts of the health and care and public health services they wish.

