

## Making data and information work for children and young people

### Electronic health records and 'real time' working

- Collect information once and record it electronically
- Use electronic systems to safely share relevant information with those professionals who provide care.
- Children and young people with long term or complex conditions must have an electronic care plan which can be accessed whenever needed, including in an emergency.

### Make the most of modern technologies

- Children, young people, their parents and carers must have access to their own 'on-line' records so that they can manage their own health and care.
- They should also have access to good quality, definitive information about lifestyles, health behaviours, preventative services, condition management and how to access services when required. This should be presented in a way which makes sense to the child or young person and uses everyday technologies.
- Professionals must have the mobile equipment and facilities to access the electronic child health record from all settings.

### Make effective use of data and information

- Train professionals at pre-qualification and via continuous professional development in the accurate, timely collection of data, analysis of data, its use in evidence based decision making and appropriate information sharing.

### Provide intelligence across the system

- Establish a child health intelligence network which works across all settings within the NHS and beyond.
- Ensure the evidence and intelligence function of PHE takes a life course approach which includes 'starting well' and 'developing well'.
- Build on the success of the Child and Maternal Health Observatory, ChiMat as a system wide enabler of evidence and intelligence.

### What we are trying to achieve

- To provide the right people with the right information at the right time so they can make the best possible health and healthcare decisions.
  - To drive up standards for the collection of data and provide the infrastructure for turning this into high quality evidence and intelligence.
- To ensure that the best possible information and intelligence is used systematically to support and drive improvements in outcomes for children and young people.

### Establish a unique identifier

- Use one unique number, issued at birth, to link records across health, education and social care.

### Improve the quality of routinely collected data

- The data used for direct patient care should also be used for secondary purposes such as service planning and research, in an anonymised form.
- User friendly reporting facilities should provide on line access to all data collections.
- Routinely collected data should form the basis of clinical appraisal and revalidation.
- Local organisations and regulators should make use of data to investigate variations in service performance and health outcomes across the country.

### Improve the content and use of existing datasets

- Make information from primary care, including that stored in GP systems, available on a national basis. This will provide information on prevalence of specific conditions, speed of diagnosis, quality of care and longer term outcomes.
- Make information from Child Death Overview Panels available as a national dataset. Use this to inform service improvement and preventative strategies.
- Extend the maternity and child health dataset to cover children and young people with disabilities and complex conditions, improving access to psychological therapies and child development outcomes.
- Improve the quality and availability of data on children and young people with disability, life limiting conditions and complex needs. This requires standardisation of disability registers and coding, including the use of clinical coding in outpatient settings.

### Resources:

NHS Information Strategy – <http://informationstrategy.dh.gov.uk/>  
Maternity and Children's Data Set – [www.ic.nhs.uk/maternityandchildren](http://www.ic.nhs.uk/maternityandchildren)  
Child and Maternal Health Observatory – [www.chimat.org.uk](http://www.chimat.org.uk)