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## Summary of RCPCH Response to DHSC strategy

### [Data saves lives: reshaping health and social care with data \(draft\)](#)

July 2021

#### Introduction

RCPCH welcome the draft strategy as far as it goes, but we are concerned that it is incomplete. We have identified four areas for improvement.

- The strategy should actively and meaningfully consider and reflect children and young people's rights and needs
- The strategy should include a commitment to improve data capture, particularly for children and young people's health
- The strategy needs to build trust in its approach to using and sharing data
- The strategy needs to support the workforce and integrated care systems to deliver benefits and improvements

We expand on each of these below.

#### 1) **The strategy should actively and meaningfully consider and reflect children and young people's rights and needs**

Children's health and care can be fragmented in different ways to that of adults, and there are specific issues around access, data sharing, consent and safeguarding that the strategy should show it understands and is engaged with. At present, the strategy is silent on these issues that, as it admits, affect 25% of the population.

RCPCH keeps children and young people at the centre by having a rights-based approach. We take seriously our role in supporting children and young people's dignity, participation, development, non-discrimination and best interests within engagement in health and paediatric service design, their right to interdependence and indivisibility, and our role in being transparent and accountable across their engagement.

As part of this approach, children and young people have been actively engaged in a number of workstreams through the RCPCH &Us network, looking at different aspects of models of care, condition management, their experiences in health services and their hopes for the future, in line with Article 12 and Article 24 of the UNCRC. Key themes which they are looking for decision makers to take into account in their planning of services, strategies or systems which relate to them, their data or care are:

- Having a coordinated and shared care plan that works between care providers that details their condition, treatment, and condition management actions
- Having information on their rights in health and only having to tell their story once through good data sharing

- Having access to a skilled and knowledgeable health workforce that is able to manage their care and their support systemic changes to enhance the health experiences they have
- The need to integrate systems for health services, but also for patients who have to access a number of different apps to be able to manage their healthcare and interactions with services
- Needing to be reassured about the safety, security, and access of their data
- The language used in discussions about CYP data, how it is used and how they can have access needs to be age and ability appropriate, be jargon free and be provided with time to understand and space to ask questions.

We advocate adopting [the NHS number](#) as a unique, consistent identifier for children and young people to allow professionals to share information easily and provide better care for their needs, supporting transitions between children's and adult services and between different parts of the health and care sector. We would welcome a clearer and stronger commitment within the strategy to the Department of Health and Social Care (DHSC) and Department for Education (DfE) working towards appropriately sharing data across organisational boundaries to integrate education, health and social care data in order to deliver the best, holistic care to children and young people.

Information and data sharing across health, social care, voluntary and education sectors is important for child health and emphasis should be placed on secure and effective information sharing across traditional professional silos and data to support robust integration of care. These principles around information systems and information sharing are reflected in our [Facing the Future service standards](#) for paediatric care. In our view data standards for child health are essential and would be a key component underpinning any strategy.

## **2) The strategy should include a commitment to improve data capture, particularly for children and young people's health**

As we noted in [State of Child Health 2020](#), without high quality data, it is impossible to know how healthy your local population is nor persuasively argue for resources for children and young people in your area. We would like to see commitments that focus on the quality of data inputs, so that there can be confidence in the data outputs.

Data is only as valuable as the time and care spent entering it, and at present this important first step is not well covered by the strategy. We would like to see greater emphasis in the strategy on easy to use data capture interfaces so accurate data can be collected about patient needs at the point of care, using agreed and harmonised terminologies to describe all needs. The strategy can then help to build confidence in the data outputs that are intended to help to drive improvement in local and national services.

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We need to see improvements in infrastructure and we need to see data standards for child health, with harmonisation of terminologies that describe all needs and allow needs to be analysed over time and across settings in a meaningful way. Data should be accessible at the frontline interface to ensure each point of care is effective and safe.

The strategy will not deliver its ambitions if it does not consider these aspects in more depth. Data needs to be consistent and accurate, and without this, the strategy will fall short.

### **3) The strategy needs to build trust in its approach to using and sharing data**

There is a clear need to build and retain public and professional trust in the systems of data capture, storage and use, and there must be transparency around who will have access to the data and controls around who it will be shared with. This includes providing assurances around safeguards in place around sensitive data, such as child protection data.

In terms of how an individual's data is used, there are many elements of the draft strategy that refer to safeguards and protections around sharing, but no mention of actually seeking consent - there is an assumed opt in. A process should be in place to ensure data sharing for research is appropriate and necessary. Access to data should be justified and researchers should demonstrate effective use of the data requested. Data that is available on a whole system basis is fine for generating hypotheses but not necessarily for decision making as it is essentially observational in nature, and it will be difficult to fully account for potential confounders especially if they are unknown or uncommon.

With the CYP perspective largely absent from the draft strategy, there is an implicit assumption that children and young people do not need to be consulted about the use of their data. There are range of issues relating to associated questions around consent to share that need to be explored as part of this strategy. Issues around consent, data sharing and access are different for CYP, but the strategy does not consider these differences.

For example, under the [UNCRC](#) Article 12, it is vital that children and young people are able to inform and influence decisions that affect them such as how their data is accessed, used and how they wish to be informed about the programme. There is also a new [children and young people's rights in relation to the digital environment](#) that would need to be reviewed within the context of this strategy along with the needs, wishes, views and rights of children and young people.

Areas that need to be explored with the support of children and young people's insight and their active role in forming recommendations and solutions are: how will data be shared with children and young people? What does this mean for those with parental responsibility? Who will have access, and when? What support will be available to interpret data and take decisions? What steps will be introduced to prevent coercive sharing? How will disclosures of domestic violence be safeguarded? How will access be supported for those with limited digital capacity and capability?

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The strategy should also outline the support available to patients with limited digital access to their health information, especially for vulnerable groups of children and young people who are sharing devices with parents/siblings, where there is digital poverty or due to other communication and information preferences or accessibility needs such as LLDD /BSL / ESL.

#### **4) The strategy needs to support the workforce and integrated care systems to deliver benefits and improvements**

Ensuring the strategy appropriately reflects the circumstances, experiences and needs of all ages will be essential if Integrated Care Systems (ICS) are to deliver on their obligations around improving population health. Improvement relies on data across three levels - population level, service provision level, and at the user/patient level. A triangulation of these areas should provide a whole-system view of health and the quality of care.

The strategy has a focus on DHSC remit, rather than a citizen-based approach that considers other sectors and geographies, particularly education and children's social care, and other parts of the UK. This will not help ICS deliver on their wider population health obligations.

Service and systems leaders will need support to ensure they get data relevant to their community. We will need to see more collaboration and integrated working to drive improvements in care. Service information and outcome data should be accessible to local healthcare leaders in real-time to drive accelerated and effective improvement.

This strategy will depend on the skills and resources of the health and social care workforce, and on training, support and extra time that will be required initially for health and social care professionals to change their approach to data input and learn to negotiate new systems for staff that are already extremely time pressured. There should be comprehensive training, support and resources for healthcare professionals to know how to input and use data for effective improvement.

In providing due regard to the UNCRC, children and young people should be involved in developing and delivering training for professionals on how to communicate effectively with children and young people on matters contained within the strategy so that they are able to be fully informed and to support consent discussions.

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