

Protecting personal health and care data

Written evidence submitted by the Royal College of Paediatrics and Child Health

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Introduction

The RCPCH welcomes the opportunity to respond to the consultation on protecting personal health and care data. This response has been developed and written by Dr David Low, Chair of the RCPCH Informatics for Quality Committee and Clinical Informatics Adviser, NHS England. The Informatics for Quality Committee comprises paediatricians nominated to lead informatics and data sharing issues for the College. The response focuses on questions of the consultation where we have specific expertise and knowledge to comment and input.

We are concerned that there is no explicit mention of the specific issues of data sharing & confidentiality concerning children and young people and the need to involve parents & carers [the latter may be statutory] and the competency attained by young people during adolescence with regards to their data

Q1. Are these purposes the right ones? Are there any other purposes that it is acceptable for an ASH to use data for? Please set out what you think the purposes should be.

Yes.

We suggest adding the following:

- 1 For public health purposes
- 2 To clarify the relationship between maternal health & social factors & child health by linking mother & child & subsequent siblings [Reference Maternal & C&YP Datasets]

accredited safe havens that you would consider to be acceptable? Please give your reasons

concern in assuring that there is a capacity to regulate.