Protecting personal health and care data

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

August 2014

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

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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]
Q2. Are there any other regulatory controls that you think should be imposed?	No
Q3. What are your views on the maximum amount of the civil penalty that we should set for breach of the controls proposed above in relation to ASHs?	The civil penalty focusses on the individual not the organisation. We recommend further thought should be given to whether the organisation should be fined. We would welcome clarification whether the Data Protection Act should be used as per paragraph 56.
Q4. Should there be any restrictions as to the type of body which might become (in whole or in part) an ASH, for example, a social enterprise, a private sector body or a commercial provider (working under a data processor contract)? Please let us know what you think.	It would be helpful in view of the public concern to have some explicit detailed restrictions e.g. insurance companies or companies who could use the information for marketing
Q5. Is there a maximum number of	A limited number of ASHs would help public

accredited safe havens that you would consider to be acceptable? Please give your reasons	concern in assuring that there is a capacity to regulate.
Q6. What are your views on the level of the civil penalty that we should set for providers who do not comply with this duty?	£5000 fine for a provider is inappropriately low. We would welcome clarification whether the Data Protection Act should be used as per paragraph 56.
Q7. Do you agree with the circumstances in which commissioners (case managers) should be able to obtain confidential patient information of an individual for whom they commission care?	Paragraph 40 concentrates on the circumstances of the client or organisation not allowing sharing rather than the reasons that the commissioner requires that confidential information. Details contained in paragraph 40 needs to be clarified including: 1 Wherever possible explicit consent should be obtained 2 Clients to be informed that their data needs to be shared with commissioners when entering a residential home 3 There is no mention of the use of third parties to give consent e.g. Parents / carers/ power of attorney etc
Q8. What controls do you think should be in place in respect of such access? Please provide details.	The regulatory controls should be the same as an ASH.
Q9. What are your views of the controls set out above?	As above
Q10. What are your views on the level of the civil penalty that we should set for any breach of these controls?	The civil penalty focusses on the individual not the organisation. We recommend further thought should be given to whether the organisation should be fined. We would welcome clarification whether the Data Protection Act should be used as per paragraph 56.
Q11. Are there any other controls that you think should be imposed? If so, please set out what you think these should be.	

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