



To: Health and Social Care Scrutiny Board (5)

Date: 2nd April 2014.

Subject: 'Care Data' – NHS England Plan to Share Patient Data

1 Purpose of the Note

- 1.1 NHS England has been developing a plan to share patient data with a view to making improvements in the quality of patient care. This introduction of this proposal - 'Care Data', has recently paused to allow further time for information to be shared and to create more public support. NHS England will be attending the meeting to discuss the matter.

2 Recommendations

- 2.1 To note this briefing note, and to consider providing NHS England with appropriate feedback following the meeting.

3 Information/Background

- 3.1 Members will note the attached information leaflet prepared by NHS England (Appendix 1) which outlines the perceived benefits of the NHS sharing patient data to help improve patient care and health outcomes.
- 3.2 The proposals are to share date of birth, postcode, NHS number and gender along with certain care records with the intention being that the new care record does not allow identification of individuals, with the sharing of this being controlled by both law and strict confidentiality rules. Information would be held by the Health and Social Care Information Centre.
- 3.3 The proposed benefits of sharing this anatomised data have been contrasted with the potential impact on privacy. A number of patient groups have raised concerns about people with more unusual conditions being identified by the data, and for the potential for this to be used in a potentially detrimental way by private sector companies for example insurance providers. Other concerns relate to the safety of data and who would be able to hold it.
- 3.4 In response to this the Health Secretary announced on February 25th that he was introducing a six month pause in the implementation of Care Data, with the intention being that there would be more publicity regarding the case for sharing the data and the safeguards which would be in place. GPs have been urged to encourage patients to support this proposal and there has also been discussion of a patient opt-in policy. This would however fall some considerable way short of the Governments original vision.
- 3.5 Frequently Asked Questions sheets for both GPs and patients are attached as Appendices 2 and 3.
- 3.6 The Scrutiny Board meeting will be attended by Richard Hancox Assistant Director – Clinical Strategy at the NHS England Arden, Herefordshire and Worcestershire Area Team.

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