

Response ID ANON-2BBS-3US1-N

Submitted to **New data security standards and opt-out models for health and social care**

Submitted on **2016-09-07 15:33:17**

Foreword

Introduction

1 Please tell us which group you belong to.

Group title:

Other

Other - Please specify:

Voluntary Sector Partnership

2 If you are a member of an organisation or profession, please tell us if you are responding in a personal or private capacity.

Capacity in attending:

3 If the Department of Health or other organisations were to create further opportunities to engage on data security and the consent/opt-out model, would you be interested in attending? If so where would you find it helpful an event to be held?

Not Answered

Event location:

Data Security

4 The Review proposes ten data security standards relating to Leadership, People, Processes and Technology. Please provide your views about these standards.

Which Standard Do You Wish To Comment On? - Which standard do you wish to comment on?:

1

Comments:

5 If applicable, how far does your organisation already meet the requirements of the ten standards?

Standard Requirements - Where 0 = Not at all and 10 = Fully Compliant:

Please provide examples which might be shared as best practice:

6 By reference to each of the proposed standards, please can you identify any specific or general barriers to implementation of the proposed standards?

Please provide your views about these standards.:

As a general point about the ten data security standards as a collective, Voluntary & Community Sector organisations (VCSO) in particular should be given appropriate support to meet these requirements. This might include: practical one-to-one support from relevant colleagues in the CCGs, financial resource (where appropriate), facilitation of peer networks and good practice sharing within VCSOs to ensure they are able to meet the standards.

Which standard do you wish to comment on? - Which standard do you wish to comment on?:

7 Please describe any particular challenges that organisations which provide social care or other services might face in implementing the ten standards.

Please provide your views about these standards.:

Where Voluntary & Community Sector organisations are not already meeting the standards, consideration must be given to the time and resource it takes to implement changes and the implementation of them should be negotiated in partnership with the organisation in question.

8 Is there an appropriate focus on data security, including at senior levels, within your organisation? Please provide comments to support your answer and/or suggest areas for improvement.

Not Answered

Please comment on your answer:

9 What support from the Department of Health, the Health & Social Care Information Centre, or NHS England would you find helpful in implementing the ten standards?

Please provide your views about these standards.:

As discussed above, specific guidance on how this should be implemented and delivered within Voluntary & Community Sector organisations is essential.

10 Do you agree with the approaches to objective assurance that we have outlined in paragraphs 2.8 and 2.9 of this document?

Yes

Please comment on your answer.:

We agree with the approaches to objective assurance, and believe that alongside the primary care community, Voluntary & Community Sector organisations are also likely to benefit from additional tailored support.

The importance of data sharing

Proposed Consent/Opt-out Model

11 Do you have any comments or points of clarification about any of the eight elements of the model described above? If so please provide details in the space below, making it clear which of the elements you are referring to.

Which standard do you wish to comment on? - Which standard do you wish to comment on?:

clarification of the eight elements:

12 Do you support the recommendation that the Government should introduce stronger sanctions, including criminal penalties in the case of deliberate re-identification, to protect an individual's anonymised data?

Not Answered

Please comment on your answer:

13 If you are working within health or social care, what support might you or your organisation require to implement this model, if applicable?

Organisation support:

14 If you are a patient or service user, where would you look for advice before making a choice?

patient or service user, where would you look for advice :

15 What are your views about what needs to be done to move from the current opt-out system to a new consent/opt-out model?

What are your views about how the transition from the existing objection regime to the new model can be achieved?:

As suggested in the guidance, it must be made more clear what the data provided by patients or service users will be used for. This will ensure they are able to make an informed decision around opting-out. In addition, training should be provided to staff to ensure they can competently answer questions around data usage, reasons for monitoring each indicator that is monitored, and the opt-out model more broadly.

Particular consideration should be given to the processes in monitoring both trans status and sexual orientation as this information is currently not routinely monitored. Staff should be trained to be able to competently ask questions about the uses of peoples' data such as sexual orientation and trans status, and they should feel confident in initiating these conversations and creating an open environment. A direct and tangible benefit to the patient who discloses they are lesbian, gay or bisexual, or that they are trans, is that they do not have to 'come out', disclose or otherwise re-tell their story to every health care professional they come in contact with. Patients and service users might not feel confident in disclosing the first time they are asked their sexual orientation or their trans status but may feel confident doing so later on as a culture of openness around these two areas grows. This should be built in to the new consent/opt-out model.

A recent study conducted by an independent researcher (Rickards, 2016) showed that participants were supportive of trans status monitoring, but only if conducted sensitively by organisations using measures such as suitable questions with explanatory texts, and developing a positive LGBT culture through staff training. The question and answer format recommended by the National LGB&T Partnership - and the format which will be implemented by Public Health England and HSCIC in 2017 - can be found at: <http://lgbt.foundation/som> . This should be taken into account when transitioning to the new consent/opt-out model.

Equality Issues

16 Do you think any of the proposals set out in this consultation document could have equality impacts for affected persons who share a protected characteristic, as described above?

Please comment on your answer:

Concerns around illegally disclosing patients' trans status have been raised by trans communities in previous attempts to digitise data. It would be useful to have available a specific guidance on how the new opt-out/consent model supports trans individuals and protects their rights to non-disclosure.

17 Do you have any views on the proposals in relation to the Secretary of State for Health's duty in relation to reducing health inequalities? If so, please tell us about them.

Please comment on your answer: