

Response ID ANON-7YW8-YU5Q-K

Submitted to **SCCI2210 De-Identification Data Items**

Submitted on **2016-12-09 15:02:59**

About you

1 Is this a co-ordinated response on behalf of a specific organisation or group?

Yes

If Yes, please specify the organisation's name::

Renal Association

2 Is this response on behalf of an SRO or group responsible for a national patient-level data set?

Yes

If Yes, please specify the data set::

National Renal Dataset

3 Please choose the description that best describes the type of organisation you work for:

Not Answered

Other [please specify below]

Other:

Professional Association

4 Please select the area that best describes your role:

Clinical

Other area:

5 If you are happy to be contacted so that we can follow up your response, please provide your email address:

email address for follow up:

james.medcalf@nhs.net

6 If you would like to be notified when the outcome of the consultation is available, please provide your email address:

email address for outcome:

james.medcalf@nhs.net

About the proposal

7 Are the four purposes clear and easy to understand?

Yes

Reasons items are not clear:

8 Is the scope of the requirement clear and easy to understand?

Yes

Reasons scope is not clear:

9 Are the background information and reasons for the requirement clear and easy to understand?

Yes

Reasons the background information is not clear:

10 Do you think that any of the data sets identified as being in scope of the requirement should be excluded from the list?

No

data-sets-exclude - Assuring Transformation:

data-sets-exclude - Children and Young People's Health Services Data Set:

data-sets-exclude - Commissioning Data Sets (CDS):

data-sets-exclude - Critical Care Minimum Data Set:

data-sets-exclude - Diagnostic Imaging Data Set:

data-sets-exclude - Improving Access to Psychological Therapies Data Set:

data-sets-exclude - Maternity Services Data Set:

data-sets-exclude - Mental Health Services Data Set:

data-sets-exclude - National Cancer Waiting Times Monitoring Data Set:

data-sets-exclude - National Childhood Measurement Central Return:

data-sets-exclude - Neonatal Critical Care Minimum Data Set:

data-sets-exclude - Paediatric Critical Care Minimum Data Set:

data-sets-exclude - Sexual and Reproductive Health Activity Data Set:

Please provide your reasons for excluding::

11 Please review the list of data sets identified as being "potentially in scope" of the requirement and let us know whether they should be added to the "in scope" list:

potential-data-sets-include - Cataract Data Set:

No preference

potential-data-sets-include - Diabetes Audit Data Set:

No preference

potential-data-sets-include - Diabetic Retinopathy Screening Data Set:

No preference

potential-data-sets-include - National Drug Treatment Monitoring System Data Set:

No preference

potential-data-sets-include - Neonatal Data Set:

No preference

potential-data-sets-include - Radiotherapy Data Set:

No preference

potential-data-sets-include - Renal Data Set:

No preference

potential-data-sets-include - Systemic Anti-Cancer Therapy Data Set:

No preference

potential-data-sets-include - Trauma Audit and Research Network Notification Data Set:

No preference

Data sets to add to the scope with reasons why:

12 Are there any other national data sets which should be added to the scope of this requirement?

No

If Yes, please specify which ones should be included and why::

13 Do you think any of the De-Identification Data Items are unnecessary for the stated purposes and should be excluded?

No

data-items-exclude - NHS Number:

data-items-exclude - NHS Number Status Indicator Code:

data-items-exclude - Patient Name:

data-items-exclude - Patient Usual Address:

data-items-exclude - Postcode of Usual Address:

data-items-exclude - Withheld Identity Reason:

data-items-exclude - Local Patient Identifier:

data-items-exclude - Organisation Code (Local Patient Identifier) or Organisation Identifier (Local Patient Identifier):

data-items-exclude - Organisation Code (Code of Provider) or Organisation Identifier (Code of Provider):

data-items-exclude - Activity Date:

data-items-exclude - Age at Activity Date:

data-items-exclude - Person Birth Date:

data-items-exclude - Person Stated Gender Code:

data-items-exclude - Person Phenotypic Sex:

data-items-exclude - General Medical Practice Code (Patient Registration):

data-items-exclude - Organisation Code (Code of Commissioner) or Organisation Identifier (Code of Commissioner):

data-items-exclude - Organisation Code (Residence Responsibility) or Organisation Identifier (Residence Responsibility):

Data items which are unnecessary and reasons why:

14 Do you think that there are any additional new data items, not currently specified within the NHS Data Model and Dictionary, that could support the objectives of this requirement and which should be added to the list of De-Identification Data Items?

No

New data item 1:

Reasons for inclusion of new data item:

New data item 2:

Reasons for inclusion of new data item:

New data item 3:

Reasons for inclusion of new data item:

Implementation issues (all stakeholders)

41 Do you agree with the proposed implementation strategy?

Yes

If No, please specify why::

42 Is the suggested commencement date of 1 October 2017 realistic?

Yes

If No, please specify why::

43 Is the suggested completion date of 31 March 2019 realistic?

Yes

If No, please specify why::

44 Can you think of any barriers to the implementation of this information standard?

No

If Yes, please specify below::

45 Do you have any views on the impact on providers of implementing DIDI in the national data sets they currently submit?

No

If Yes, please specify below::

Information Governance

46 How would you best describe your level of Information Governance expertise?

Reasonable knowledge

47 Do you think that there are any significant new privacy risks associated with the proposed standard?

No

If Yes, please elaborate, identifying any mitigating security measures where possible: :

48 Could the aims of the proposed standard be achieved without the collection and flow of personal confidential information?

No

If Yes, please elaborate::

49 Could the aims of the standard be achieved without the sharing of personal confidential information with NHS Digital?

No

If Yes, please elaborate: :

50 Are the proposals regarding collection and flow of personal confidential information proportionate to the expected benefits?

Yes

If No, please elaborate::

51 Will the proposal result in your organisation collecting more personal confidential information than you do currently?

Not applicable

If Yes, please elaborate::

Final comments

52 Please provide any further comments or suggestions you have about this proposed information standard:

Any other comments:

The Renal Association supports the aims of this standard – namely to use NHS number where available to link data to support commissioning decisions, and to only use other identifiable data (namely SURNAME and ADDRESS) items when the NHS number is absent or not validated.

At present a small number of data items from the Renal Dataset are used to support the best practice tariff for chronic renal dialysis, but there is no central flow for these data items. A further subset of the items in the Renal Dataset are collected from Renal Units in England by the UK renal registry (UKRR) and reported in an annual report, through a data portal and on-request. These data are already used widely by renal units and specialised commissioners to commission high quality renal services. The Renal Registry forms part of the Renal Association but as a data-provider are providing a separate response to this consultation

We are keen to highlight that the Renal Dataset is currently not actively maintained – and as such contains data items no longer considered useful for the purpose of national collection, commissioning or quality improvement. For this reason it would be difficult in practice to bring the dataset "in scope" even if in principle we agree with the proposal on de-identification data items.