Public Benefit and Privacy Panel for Health and Social Care

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Mrs Emma Milburn
Lead Analyst Care Experience Survey Programme
Scottish Government
BR, St Andrews House
Regent Road
Edinburgh
EH1 3DG

Date: 23rd October 2017

Our Ref: 1718-0118

Dear Mrs Milburn,

RE: Application 1718-0118/Milburn: Inpatient Experience Survey Version: v1

Thank you for your application for consideration by the Public Benefit and Privacy Panel for Health and Social Care. Your application has undergone proportionate governance review and has been approved, subject to the following conditions:

- Please provide a copy of the signed PIA.
- · Please supply all approved CDRFs.
- Please supply details of the survey contractor, when appointed, and any Data Sharing Agreements / Service Level Agreements and contracts between the survey contractor and Scottish Government.
- Following appointment of the survey contractor then please update Section 5 of the application at the appropriate questions.
- In view of the forthcoming General Data Protection Regulation, please review the questionnaire/participant information to consider whether the legal basis for processing of personal information to enable future linkage has been explained sufficiently to participants and also provides information to patients about how they will be able to access the outcome of the piece.
- As the generic nature of the request for consent for future research, Q52, does not comply with GDPR, or
 informed consent under the Common law duty of confidentiality, removal or rewording of this question should
 be undertaken and PBPP informed of the conclusion. Only if the question cannot be changed at this stage
 should it be included as is and in that case the PBPP must scrutinise every instance of future research and
 judge according to then practice, when the consent may not be considered valid.
- As the survey will run three times over the next five years and it is expected that CHI replacement will be implemented during this time, an application amendment will be required at that point to document any changes required to the processes and organisations involved
- Please note that all legal agreements should be under Scots Law.

The Panel made the following recommendations:

- During the contracting exercise, relevant training in terms of Information Governance should be stipulated.
- The Panel noted that within the document Scottish Inpatient Experience Partnership Agreement (Annex B) under Methodology (para 15) there is mention made of a National Report being published. It would be helpful if this was also produced for a public facing audience.
- It would be useful to include a feedback mechanism on completion of the work, to highlight any lessons learnt and development opportunities. This may be best documented in the PIA: Data Flow & Risk Register within the Data Flow diagram.

This approval is given to process data as specified in the approved application form, and is limited to this. Approval is valid until 31st September 2022. You are required to notify the Panel Manager of any proposed change to any aspect of your proposal, including purpose or method of processing, data or data variables being processed, study cohorts, individuals accessing and processing data, timescales, technology/infrastructure, or any other relevant change.

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I would take this opportunity to remind you of the declaration you have made in your application form committing you to undertakings in respect of information governance, confidentiality and data protection. In particular you should be aware that once personal data (irrespective of de-identification or other controls applied) has been extracted from NHSS Board(s) and transferred to you that you will then become the Data Controller as defined by the Data Protection Act (1998). Requests for access to NHS Scotland data as part of this approved application should be supported by evidencing a copy of your approval letter and application form to the relevant local board contacts/data providers.

Please note that summary information about your application and its approval, including the title and nature of your proposal, will be published on the panel website (www.informationgovernance.scot.nhs.uk).

I hope that your proposal progresses well,

Yours Sincerely

Ashley Gray Panel Manager

NHS Scotland Public Benefit and Privacy Panel for Health and Social Care

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