

Proportionate review of Privacy Advisory Committee applications: Assessment record

PAC index / Information Request number	PAC 08/13; XRB12092
Title of study	Looked After Children – Access to Dental Services and Oral Health in Scotland: a pathfinder national cross-sectoral record-linkage study
Name of main contact	Katharine Sharpe
Name of assessor	
Summary Risk assessment	Low to medium

Differentiating question	Green	Amber	Red	Roles	Key Question	Status R/A/G	Where in form is evidence to answer this question
Safe people							
1. Is the data custodian (where SHIP safe haven not used) and everyone who will have contact with the data trained in Information Governance? Approved training courses are listed in table 1. Applicants must submit training	Yes has completed or will undertake SHIP or other approved training	Reports training but difficult to assess		Research coordinators ensure this information is provided on form and that course material is provided where course not on list of SHIP approved training. PAC IG lead identify whether course acceptable if not already approved for SHIP. Using course materials	NO But No approval will be given without evidence that training completed. An amber response requires further work to establish if applicants'		Qs 1.1-1.7

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material for any other courses undertaken to be assessed by IG lead.					adequately trained. If not possible to establish whether adequately trained, researchers must complete one of the approved courses.		
2. Are members of the research team able to demonstrate track record of working with administrative data by providing references for up to three	UK Academic institution Or UK Public body with one or more publication within last three years.	Yes based outside UK	No	Research coordinators Check information has been provided. PAC IG Lead will assess	No		Question 1.8

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relevant publications within last 5 years.							
Public Interest							
3. Has the applicant demonstrated understanding of the context and how their research will add to the current state of knowledge relating to a public health issue?	Yes	Doubt whether will add to current state of knowledge	Highly unlikely to add to current state of knowledge	PAC IG lead assess whether plausible case is made . Refer to Lead Clinician in the relevant work area if there is doubt.	Yes. Red response indicates referral to full PAC Information Consultant or Lead Clinician to communicate with the applicant where there is doubt about value of study		Section 2 Study Overview
4. Is the study design and method appropriate to the objectives	Yes	Doubt whether the objectives will be met	Highly unlikely the objectives will be met.	IG lead will assess based on information from the Research Coordinator. If no concerns reported	Yes If study preparation well advanced		Section 2 Study Overview Section 3 Data request

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of the study				<p>then assess as green</p> <p>Research Coordinator Will work with applicant to ensure that study design and methods of using data are appropriate to the objectives of the study. This should take place at advisory stage or when new applications are checked by Research Coordinators.</p> <p>Research Coordinators will Refer to the Information Consultant and/or Lead Clinician in the relevant work area if there is who may then discuss with</p>	and redesign not possible, send to PAC, inform PAC of concerns		

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				applicant. If doubt remains Research Coordinator will inform the IG lead.			
5. Is there concern that public interest is outweighed by commercial interest	Public Health interest clearly predominates.	Commercial interest in the project as well as public health interest. eg involvement of health technology or pharmaceutical company	Strong commercial interest in the project with unclear short to medium public health benefit	PAC IG lead. Refer to Caldicott Guardian if there is doubt. All Check that the application has also gone to the ISD Governance Committee	Yes For time being red or amber indicates referral to PAC, in view of SHIP evidence of public concerns regarding commercial use of data.		Q 2.12
6. Has the work been funded by an established research funding body and subjected	Yes	No	No	Research coordinators check that this is completed. PAC IG Lead assess	No		Q 2.11

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to peer review? Established funding bodies are listed in table 2.							
7. Does the applicant intend to use data provided to contact individuals either directly or through their clinician, with or without the support of NSS.	No		Yes The purpose and practical aspects are new or constitute a risk to the reputation of NSS.	PAC IG lead	Yes		Q 3.6
8. Has PAC previously approved linkage to the non-NSS data involved for similar purposes?	Yes non-NSS dataset well known to PAC and privacy issues have been considered acceptable before	Yes, non-NSS dataset well known to PAC but this use is different. Or Previous application to PAC for	Non-NSS dataset is not well known to PAC and there is potential concern regarding purpose and	PAC IG lead	Yes. Red response indicates referral to full PAC		Q 3.11 – 3.13

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		linkage to the non-NSS dataset Or Non-NSS data not well known to PAC. However, there are no obvious privacy issues and no new cross sector linkage.	privacy. Or Application is for a New cross sector linkage				
9. For studies involving only administrative data, are subjects aware of the use and/or is the use in line with that for which it was collected originally?	Robust attempts to inform populations involved regarding this use of their data eg mass media, website, posters and leaflets in relevant outlets	Some attempts to inform data subjects that data may be used in this way or This purpose is in line with the original purpose of collection and is one data	There is no evidence that data subjects are aware that data may be used in this way and This purpose is not in line with the original	PAC IG lead. Refer to Caldicott Guardian if there is doubt	Yes If red refer to PAC		Q 4.2 – 4.5

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		subjects might reasonably expect.	purpose of collection and is not one they might reasonably expect.				
10. Where linkage is requested between administrative data and data collected from individuals as part of research, is there concern regarding data subjects' awareness and consent?	Research participants informed regarding linkage or use of national data to follow-up and consented	Research participants informed that health data will be used but the use requested in application was not clearly highlighted or consented. However, use requested is in line with the original purpose of collection and is one they might reasonably expect.	There is no evidence that participants are aware of the use of their data requested in application. and The use requested is not in line with the original purpose of collection and is not one they might	PAC IG lead. Refer to Caldicott Guardian if there is doubt	Yes. Red response indicates referral to full PAC		Q 4.2 - 4.5

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			reasonably expect.				
Safe Data							
<p>11. Are the data highly sensitive or do they relate to vulnerable population</p> <p>Sensitive data and vulnerable populations are listed (non-exclusively) in table 3.</p>	No	<p>Some sensitive data will be used but this is not the focus of the research.</p> <p>Or</p> <p>Focus of research may be considered sensitive although not on list</p>	<p>Yes data which is focus of research is highly sensitive</p> <p>Or</p> <p>Vulnerable populations are the focus of the research</p>	PAC IG Lead	<p>No</p> <p>But red response indicates discussion with CG</p>		<p>Section 2 Study Overview.</p> <p>Question 3.16 Variables to be included in output</p>
<p>12. What is the risk of disclosure from linked output file for analysis?</p>	<p>Moderate to low.</p> <p>No full dates.</p> <p>Geographical variables at health board or above.</p> <p>No rare conditions.</p>	<p>Moderate to high: Includes full dates, high level geographical variables</p>	<p>High risk because data relate to rare conditions and/or geographical areas equivalent to datazone level or below or</p>	<p>PAC IG Lead.</p> <p>Consider the combination of variables</p> <p>Research Coordinator</p> <p>Confirm that detail is essential to meet study objectives.</p>	No		Question 3.15

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			individual hospital level.				
Safe Environment							
13. What is the level of Information Security?	Data will be accessed through SHIP National Safe Haven	Data will not be accessed through a SHIP Safe Haven Information Security is satisfactory	Information Security appears satisfactory. Data will be stored outside UK.	PAC Information Security Advisor	No		Section 5
14. Does the applicant intend to make data available to a third party without further reference to PAC?	No	Yes. Appropriately constituted approvals body	Yes Not clear that appropriately constituted approvals body	IG lead Research coordinators will provide link to PAC advice regarding onward disclosure when this is available	Yes Red or Amber responses require full PAC assessment		
15. In general, does the application pose any privacy or	No	Yes mild to moderately serious concern Please describe	Yes serious concern Please describe the	IG Lead			

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ethical concerns not been addressed by the questions above?		the concern	concern				
16. If you think that the questions included in the assessment are not sufficient to support a comprehensive assessment of the application, please add necessary additional questions below? (Add rows as required)							

Checklist of conditions to be met before approval can be given

Condition	Met
Received evidence of ethical approval (where necessary)	
Received evidence of approval from data controllers each non-NSS dataset	
IG arrangements satisfactory	
Training completed by data custodians and those in contact with data	
Disclosure risk is as low as possible while meeting objectives of research	

Table 1

SHIP approved training
University of Edinburgh SHIP training
ADLS training

NHS Information Centre On-line training

Table 2

Funding body
MRC
CSO
Wellcome Trust
British Heart Foundation

Table 1.

Highly sensitive data pertains to	Vulnerable populations
Abortion	Adults with Incapacity
Pregnancy in age < 16 years	Minority ethnic groups
Sexually transmitted disease	Drugs users
Mental health	Specific religious affiliation
Drugs and alcohol misuse	
Suicide	
Rx mental health, contraceptives	
Crime related statistics	
Ethnicity	

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