NHS Scotland (NHSS) Public Benefit and Privacy Panel for Health and Social Care

Minutes of the Committee meeting held on 13th June 2023 by MS Teams

Present:	Dr Lorna Ramsay (Chair) (LR)
	Dr Tara Shivaji (TS)
	Dr George Fernie (GF)
	Dr Arun Chopra (AC)
	Kenneth McLean (KMcL)
	Carole Morris (CM)
	Professor Alison McCallum (AMcC)
	Professor Colin McCowan (CMcC)
	Alan Ferrier (AlF)
	Penni Rocks (PR, from 11.15)
	Julie Ramsay (JR, observing)
Apologies:	Dr Mark McGregor (MMcG)
	Dr Pamela Johnston (PJ)
	Chioma Dibia (CD)
	Martin Walsh (MW)
	Dr Stacey Noble (SN)
	Professor David Felix (DF)
	Martin Bell (MB)
In Attendance:	Dr Marian Aldhous (MA)
	Phil Dalgleish (PD)
	Susan Kerr (Secretariat)

1. Chair's welcome and apologies

LR welcomed all to the meeting.

Personnel changes:
LR stated that this will be Alan Ferrier's last meeting.
AlF explained that due to changes of personnel at the National Records of Scotland (NRS), both he and Julie Ramsay (JR) have obtained interim promotions: JR will be taking the role of Head of Demographic Statistics in NRS and will now replace of AlF on this committee. AlF has really enjoyed his time on this committee.
LR thanked AlF for his valuable support and welcomed JR to the committee, as an observer for this meeting and as a member from the next meeting.

Quorum
The meeting is not quorate today so any decisions that are made will be ratified by correspondence with those who were unable to attend.

ACTION 13-06-23/01: MA to ensure that decisions are ratified.

Conflicts of Interest

CM stated she did not have a direct conflict but has contacted the applicant regarding the application being discussed today. LR feels CM will still be able to input in discussions but should not be included in any decision making.

AMcC stated she did not have a direct conflict but when worked as Director of Public Health she gave a significant amount of time to data preparation relating to diabetes, so has a view. LR thinks it is fine for AMcC to be involved.

2. Minutes and actions from previous HSC-PBPP Committee Meeting

2.1. *Minutes of meeting held on 26th April 2023*

The minutes of the previous meeting were approved as a true and accurate record.

2.2. *HSC-PBPP Committee Action Log and Matters Arising*

2.2.1. Action 26-04-23/01: Updated paper on definitions, scope and routes of approval.

TS and MA have done a lot of work on this paper and tried to illustrate some of the flows and overlaps as previously discussed. This is not the final version and it will still need some continued development.

A number of comments and suggestions were made:

- There have been ongoing conversations with PHS about surveillance and with Scottish Government (SG) about patient registries, and these should be added.
- In general terms, UK-wide agreements are in place, but need to explain the differences in Scotland, e.g. embedding research as a core purpose.
- A description of patient pathways would be helpful.
- NHS REC approval is not needed to set up a Research database but it is required for their further use and so it is usually easier if this is obtained at the start.
- It would be worth referencing the online tool from the Health Research Authority (HRA), which is used to distinguish research from other types of applications and therefore decide whether ethical review is required.
- It was suggested that on the diagram Ethical approval and Public Engagement should be marked as 'Yes, unless not required'.
- Regarding approval at one NHS Board, is it clear or consistent what one NHS Board Caldicott Guardian would approve compared with another? Audits will often start within one NHS Board and then grow.
- An updated version of the definitions could be more widely circulated, with the suggestion that they could be standardised and adopted across other organisations, so there is clear wider understanding of these terms, which could help researchers to navigate the complexity of these areas.
- At a future stage it would be helpful to share this paper with others, e.g. Caldicott Guardian Forum, RDS.

ACTION 13-06-23/02: ALL to send any further comments to TS / MA.
ACTION 13-06-23/03: TS/MA to update and keep on the agenda for further discussion.

2.2.2. Action 26-04-23/02: Update on joint Development session with Tier 1.

TS updated the committee: PHS have stated that potentially funding is available for a hybrid day-long workshop. High level proposals for morning and afternoon sessions are progressing. Once the budget is confirmed, costing from different venues will be looked at. The aim would be to Autumn 2023 or beginning of 2024. The intention is to return to an annual training day in the future.

ACTION 13-06-23/04: TS / MA and Ops Group to develop ideas.

2.2.3. Action 26-04-23/03: Update on 2223-0074 Smith

This application was discussed at the last meeting and a resubmission requested. LR and TS had a constructive meeting with the applicant and others from Scottish Government, with good discussion as to what needs to be changed. The application will be resubmitted soon. The data will be requested at different levels (individual-level or more aggregated) depending on who will process the data.

It was agreed when they resubmit, the changes in the new application will be checked by the Panel Manager against the Committee response letter and then circulated to Committee members for review by email, and not by Tier 1.

ACTION 13-06-23/05: MA to circulate the resubmitted application to the full Committee.

2.2.4. Action 26-04-23/04: Summary of discussion with RDS regarding pandemic preparedness

A paper was circulated to summarise the discussion that LR and MA had with Research Data Scotland (RDS) colleagues and how lessons learned from the pandemic response could help improve processes.

Roger Halliday (RH) from RDS will attend later and will maybe talk further about this later in the meeting.

3. Review of Application 2223-0165 Barnett

The applicant was unable to attend the meeting but had given a further written response to some of the questions from Tier 2 members.

The application concerns SCI Diabetes data, a clinical dataset for which all the territorial NHS Boards are data controller, but is held in NHS Education for Scotland (NES) who act as data processor on behalf of the territorial boards. The application requests that a copy of this dataset be made available so that data can be easily provided for Diabetes research.

LR gave some of the historical background to the development of the SCI Diabetes as a clinical system.

DF, the Caldicott Guardian for NES, had not been sighted on the application, but also could not attend this meeting. Two analysts from NES attended the meeting and outlined that currently NES does not have the resources to consistently provide data for research.

Discussion took place, but in the absence of the applicant, it was difficult to understand some of the rationale behind the details of the proposal, the governance in place, the specific data requested and the transparency to and engagement of patients.

It was agreed this application could not be approved in its current state and that a resubmission would be requested following further work. Discussion with the applicant would be recommended to discuss the concerns of the committee and suggest a way forward and who else should be consulted.
> **ACTION 13-06-23/06: LR/ TS / MA to send a response on behalf of the committee.**
> **ACTION 13-06-23/07: LR / TS / MA to facilitate required discussions to take this forward.**

4. For Information

4.1. *Panel Manager Report*
MA gave an update. There were no particular comments.

4.2. *Health Data Research UK (HDRUK) update*
CM gave an update, there has been a review commissioned of lessons learned through the pandemic. CM has met with Cathie Sudlow to discuss further.
The HDRUK National Core Studies Programme has ended.   HDRUK are now looking ahead to how to enhance things like the HDRUK Gateway, the data catalogue and processes for the research community and how this will work across the UK.
CM will keep committee up-to date with future developments.

4.3. *Scottish Government update*
PR gave an update on the SG Data Strategy.   There is a lot of work being taken forward looking at a delivery plan on data strategy commitments.
The main Data Strategy Board is chaired by Carol Sinclair. Two sub-boards are being set up:
  i.   Data Standards Board, to produce a set of national standards and related guidance for organisations
  ii.   Data Delivery Board to monitor the progress in the delivery of data.

Relating to the National Information Governance (IG) work, there are a number of ongoing activities:
  i.   The National IG Programme has a number of workstreams in progress:
        • IG Competency Framework
        • Definitions of roles and skills required for the Senior Information Risk Owner (SIRO) and Caldicott Guardians.
  ii.   National IG guidance
        • Updates of the Confidentiality Code of Practice and Records Management Policy.

iii. IG Code of Conduct: this is a proposal to give assurance to stakeholders of requirements for access to data.

iv. IG Maturity: what questions need to be asked to assess an organisation's IG maturity. There is some pilot work ongoing in health and care organisations.

v. Questions of how to communicate with stakeholders and the public about data usage and data protection.

vi. Federated IG models: this feeds into work with RDS and data access protocols as well as the Cybersecurity Centre of Excellence which gives strategic direction for IT security.

vii. There is an increasing requirement to understand and ensure involvement of SIROs and what they need to do in/for their organisation. A SIRO Forum has been put in place and Terms of Reference for this are under development.

A few questions were raised:

- For the IG Code of Conduct, is this for use for direct care purposes or will it include non-operational purposes? There may be some wider communication required across NHS Scotland about this.

There is a delivery plan and also looking at a wider scope for operational and research use.

- Is there progress on a senior post heading up the IG Programme?

PR is now partially retired. The Head of IG Assurance and Cybersecurity will be taken by Lisa Hill, who will oversee the IG work (led by Elena Beratarbide) and Cybersecurity work (led by Cara Archibald). Lisa will take the SG representative role on this Committee, from July 2023.

ACTION 13-06-23/08: LR/MA to invite Lisa Hill to the next HSC-PBPP Committee

- Regarding the data standards, does this have a plan behind it to address data quality, data coverage and practice and use of data for health and care as well as research?

The sub-boards will look at these to operationalise data standards and how that will allow access and use of data across health and care.

LR thanked PR for her contribution over the last few years.

5. Development Session: Research Data Scotland (RDS)

Roger Halliday (RH, CEO of RDS seconded from Scottish Government (SG)) and Kate McBay (KMcB, Information Governance Manager and DPO) joined the meeting, to give an update on the processes for making data available through RDS.

RDS is jointly owned by SG, PHS and the Universities of Edinburgh, Dundee, Aberdeen and Glasgow with the focus to make public sector data more accessible to researchers without compromising on privacy.

Access to the service will be via eDRIS and NRS, and the Research Access Service will be delivered by eDRIS in 2024.

RDS will provide guidance to researchers and is integrating metadata catalogues to build digital access process.

RDS is currently focussing on:
  i. Review of data access approvals
  ii. Setting up the RDS Research Data access process
  iii. Working with the Alliance Technical Group for 'fast track' access to data in the National Safe Haven (NSH)
  iv. Implementing appropriate governance via the RDS IG Steering Group

The aim is build on and develop what already exists.

Data access by commercial companies will also be addressed in due course.

Questions and discussion were raised by Committee members:
  • Will there be access to education data for health-related work, with robust identifiers in place?

RH: Administrative Data Research Scotland (ADRS) has a range of datasets around children for use in the NSH. These have gone through the process of indexing and should be research-ready to link with health and other datasets. This is part of the proactive data sourcing and cleansing for use within IG processes and data flows for individual datasets. Should be visible and available in metadata catalogue.

  • Will this apply to all Safe Havens or just approaches to RDS?

RH: Good question. RDS has officially been commissioned to look at Scotland-wide approval processes rather than more local ones, though we're looking to align with some thinking done by DataLoch [SE Scotland Regional Safe Haven] on delegation of approvals based on common standards.

  • What about Data Protection and IG alignment with the rest of the UK? If the UK moves away from EU and other standards how will this affect things across the public sector in Scotland? Where do the risks lie and what equivalence will apply? There is also a need to be aware of the difference of how Scotland applies its legislation to access to data which will be different at a UK level.

KMcB: The second Data Protection bill will have implications for all who hold research data. RDS will need to link with the Information Commissioner's Office (ICO) and partners in Scotland and be involved and give feedback to the ICO. Also looking at the safe commercialisation of data with same standards of data protection and governance for ease of carrying out research across and beyond the UK, but need to uphold and balance rights of patients with outcomes of data.

  • For datasets with proven research utility, will you horizon scan and have conversations about the future and how these would evolve, or add/find new datasets that might be required? What happens around that?

KMcB: This is important and RDS cannot be static about variables and their use. All data providers will have discussions about how data will evolve, and also in line with research priorities and requirements. These will be factored into current and future plans and such conversations with the data providers will be required, so that data has utility to researchers and researchers can get the data they need.

RH: We will speak to different researchers for their priorities, particularly with data relating to health and care, GPs, prescribing, laboratory and imaging. The changes we have seen so far for these datasets have been via iterations from researchers.

- What about conversations with third sector organisations who may finance or provide support for research?

RH: Yes these conversations have been starting with Cancer Research UK, Cathy Sudlow and British Heart Foundation and other non-health charities. Citizen's Advice Scotland have data that may be useful and enhance value.

- From earlier discussions in today's meeting, we are trying to put together better definitions of application types and are beginning to get to fairly good place about what needs to come to HSC-PBPP and other orgs. It would be good to chat with RDS so that we have common language and definitions and this will be shared at some point.
- We had an application for new health data asset. When a new data asset is put in place how is that to be done in a way that aligns with the strategic direction of SG and RDS. Has RDS thought about best practice and how this should be done clearly and collaboratively, rather than purely in terms of speed?

RH: RDS would be interested in both these things. Is there value in this for research? The investment in making it available and to align with national processes to make it so would be good. Not sure we have captured what best practice looks like but good piece of work to be done to deal with similar situations in the future.

LR thanked RH and KMcB for coming, There has been progress made over the course of a year and can begin to see where RDS fits and how it will work. It is good to have somewhere where we can have further discussions. HSC-PBPP appreciates the ongoing updates and dialogue.

The slides from the presentation will be circulated around the Committee.

ACTION 13-06-23/09: KMcB / MA to circulate slides

6. Any other business

No other business was raised.

7. Date of next meeting

The next meeting will be held on 13 September 2023

Action List

Action Reference	Item No.	Action	Responsible person
13-06-23/01	1.0	As the meeting is not quorate, the decisions made need to be are ratified.	**MA**
13-06-23/02	2.2.1	Any further comments on the definitions, scope and routes for approval to be sent to TS / MA.	**ALL**
13-06-23/03		Update the paper and keep on the agenda for further discussion.	**TS / MA**
13-06-23/04	2.2.2	Develop further ideas of a joint T1/T2 development session	**TS/MA/Ops Group**
13-06-23/05	2.2.3	Resubmission of 2223-0074 Smith to be circulated to whole committee when it arrives.	**MA**
13-06-23/06 **13-06-23/07**	3.0	Response to be sent on behalf of the committee Facilitate the discussions required to take this forward and inform best practice for new data assets.	**LR/ TS / MA**
13-06-23/08	4.3	Invite Lisa Hill to join the HSC-PBPP Committee	**LR / MA**
13-06-23/09	5.0	Slides from RDS presentation to be circulated to the Committee members.	**KMcB/MA**