Statistics Public Benefit and Privacy Panel

Terms of Reference

The Statistics Public Benefit and Privacy Panel (PBPP) is a governance structure of the Scottish Government.

The panel has a formal mandate to scrutinise the information governance (IG) relating to requests for access to:

- Scottish Government datasets
- National Records of Scotland (NRS) census data
- Linkage to Scottish Government datasets and NRS census data
- Research and other well-defined and bona fide purposes

The Statistics PBPP has delegated decision making authority of requests which fall within its remit, except for those involving NRS census data, but does not replace any existing or future requirements for ethical review or approval. For NRS census data, the Statistics PBPP will provide recommendations to the Register General, who will have the final decision making authority for those requests.

The remit of the panel relates to data which carry a risk of identifying individuals whether living or dead, and the creation of new linkages whether consent has been obtained or not. The scope of the panel is detailed in Annex A.

The panel's focus on public awareness, concern and benefit demonstrates a commitment to the protection and promotion of privacy as a public good and in the public interest.

Aims of the panel:

- Provide a single, consistent, open and transparent scrutiny process allowing Scottish Government data and National Records of Scotland census data to be used for a range of purposes including research and statistics,
- Ensure balance is struck between safeguarding the privacy of all people in Scotland and the fiduciary duty of Scottish public bodies to make the best possible use of the data collected
- Provide leadership across a range of complex privacy and information governance issues, so that the people of Scotland are able to gain the benefits from research and wider use of

data, while managing emerging information risks, addressing public concern around privacy, and promoting the protection of privacy as in the public interest

Panel Membership and Composition

The panel membership is as follows:

- Tier 1 panel:
 - Panel chair (permanent member)
 - Panel Manager (permanent member)
 - Information Governance practitioners from Scottish Government and National Records of Scotland
 - o Panel members from Scottish Government and National Records of Scotland
 - o Independent members
- Tier 2 panel:
 - Chief Statistician
 - Register General or representative

The selection of panel members is based on the person specifications contained in Annex B. Panel members, must participate in appropriate training, agreed by the panel, in order to fulfil their role throughout their term of office.

Panel Meetings and Process

Applications received will be assessed depending on the data being requested e.g.:

 Requests for single Scottish Government datasets, which will not be linked to other datasets, will initially be assessed by Analytical Division Heads prior to review by the Statistics PBPP

The flow chart detailing the process is contained in Annex C.

Applications being reviewed by Analytical Division Heads

Applications requesting single Scottish Government datasets without linkage will be circulated to the relevant Analytical Division Head. Analytical Division Head's will assess the risk associated with the application using agreed risk criteria, detailed in Annex D. If the agreed risk criteria score is over a threshold value, the application will be reviewed by the Statistics PBPP.

Applications going through Statistics PBPP process

Where an application requires Statistics PBPP review, it will be circulated to at least three Tier 1 panel members for review by correspondence, as and when an application is received by the panel manager.

PBPP members require two weeks to review the application, each conducting an independent assessment using agreed proportionate governance criteria detailed in Annex E, to agree an outcome for the application.

An application requesting census data, will be reviewed by the NRS privacy group and Statistics PBPP in parallel. The statistics panel will also include at least one member from NRS. Applications requesting access to census data will also be reviewed by the Register General or assigned deputy.

An application requesting Education data, will be reviewed by the Education Data Access Panel privacy group and Statistics PBPP in parallel.

If no consensus is met, all panel members will meet to discuss the outcome of the application or the application will be escalated to the Tier 2 panel.

All applications

Information of the various applications approvals are detailed in Annex F.

For approved applications, the panel manager issues the agreed communication to either the applicant or the research coordinator and the data controller.

Where the panel determines to not approve an application, it may seek timely clarification or additional information from the applicant, in whatever form it deems necessary, in order to support its deliberations. This is facilitated by the panel manager, with a view to the panel members agreeing an outcome for the application (or alternatively the application returning to a subsequent panel meeting), upon receipt of the necessary clarification or additional information. The panel will only seek clarification on an application which has a realistic chance of receiving approval upon receipt of the necessary clarification or additional information.

Where an application clearly has little or no chance of approval, such as when data requested is not consider suitable for the proposal, the panel manager or secretariat will advise the applicant of this on behalf of the panel, with a recommendation to re-submit the application.

All application outcomes will be issued to applicants by the panel manager within an agreed timescale of the determination being reached.

The panel manager, on behalf of the panel Chair, maintains a register of approved applications, which is made available on the panel website.

Expected Performance (Applications)

The panel recognises the need for timely scrutiny of applications, and ensuring that this is being achieved is the responsibility of the panel Chair.

For the purpose of monitoring performance, the panel manager logs the key events in the application process by date. Time elapsed whilst awaiting clarification or additional information from the applicant will not be included within the recorded turnaround time (see below) for the application (ie the 'clock' will deemed to have been 'paused' whilst the applicant is responding).

Applicants are informed of the panel decisions to approve (with or without conditions) applications within an agreed timescale after the panel's decision. It is the normal expectation that such applications will be concluded within 30 working days of receipt of an administratively complete application. Where clarification is required, this will be longer.

ANNEX A – Scope of Statistics Public Benefit and Privacy Panel applications

The Statistics PBPP has the authority to scrutinise any request to use Scottish Government controlled data, and the census data controlled by the Registrar General, for research, audit, or other well-defined and bona fide purposes. Its full, current, scope is laid out for potential applicants in the following terms:

You <u>must</u> complete an application if your proposal requires any of the following in respect of Scottish Government originated data or NRS census data which carry a risk of identifying an individual.

The panel remit relates to all uses of data from Scottish Government Datasets or NRS census data, which carry a risk of identification of an individual, whether living or dead, including but not confined to:

- Access to Scottish Government data
- Access to NRS census data
- Linkage of Scottish Government data
- Linkage of NRS census data
- Procedure is followed to assess and mitigate risk
- Linkage of Scottish Government data to data from other sectors
- Linkage of NRS census data to data from other sectors
- Linkage of Scottish Government data to primary data collected by researchers with or without consent
- Linkage of NRS census data to primary data collected by researchers with or without consent

You may complete an application for:

- Any other use of Scottish Government originated data which you consider to be complex, contentious, having wider national implications, or requiring the scrutiny of the panel
- Any other use of Scottish Government originated data or NRS census which you consider to be complex, contentious, having wider national implications, or requiring the scrutiny of the panel

The following relevant factors do not remove the requirement to complete an application (and should be fully explained at the relevant point in the application form):

- Consent of data subjects
- Whether data subjects are alive or deceased
- Purpose of the proposed work audit, management, performance, research or other
- Statutory or regulatory requirement for the proposed work

ANNEX B - Panel Role and Member Specifications

Panel Participant

The role of panel participants is to:

- Review applications for access to Scottish Government, NRS census data and other personal or sensitive data, as outlined in the panel terms of reference
- Review applications in light of the panel's own precedents, including its proportionate governance criteria, and other instruments concerning privacy protection
- Bringing to bear their relevant experience, indicating as required their opinions or decisions in respect of such applications

It is essential those members:

- Currently hold a dedicated Information Governance role and are of a suitably qualified nature to fully participate in the decision making of the panel (the panel Chair will make any determination required)
- Exercise dispassionate and unbiased judgement regarding ethically and practically complex and finely-balanced issues
- Express the reasons for their decision making concretely and concisely
- Rapidly to assimilate and understand large amounts of information about social project proposals
- Are familiar with the current legislative and advisory environment regarding personal data.
- Contribute to panel activities as requested, responding in a timely manner
- Are suitably equipped to participate fully in the work of the panel by electronic means
- Undertake any training as might be deemed appropriate by the panel Chair

It is **desirable** those participants:

• Have an excellent level of current knowledge of the relevant legislative and advisory landscape

Panel Chair

The **role** of the panel Chair is to:

- Ensure that the panel operates within its terms of reference
- Ensure that the panel meets any performance targets or obligations set out in its terms of reference
- Ensure that the panel is adequately resourced with suitably qualified members
- Ensure that any issues of competing interests among members are dealt with appropriately

- Ensure that the panel is effective in its role as final arbiter of submitted applications, providing appropriate, proportionate and consistent scrutiny over time
- Ensure that the panel's deliberations and discussions are informed by all relevant current legislation, guidelines and policies, as well as the panel's own precedents
- Ensure that the panel's deliberations account for the interests and opinions of the wider public, and acts in its interests
- Provide strong and effective leadership to the panel in fostering productive relationships with both the public and the applicant community

It is essential that the Chair:

- Maintains a strong interest in a field relevant to the Panel's work, such as patient rights, privacy law or data protection, research ethics, or statistical research
- Is familiar with the current legislative and advisory environment regarding personal data,
- Displays strong leadership and influencing skills and can focus the deliberations of a diverse and well-qualified panel on constructive and clear decision making
- Exercises dispassionate and unbiased judgement regarding ethically and practically complex and finely-balanced issues
- Expresses the reasons for their decision making concretely and concisely
- Rapidly assimilates and understands large amounts of information about medical and social project proposals

It is desirable that the Chair:

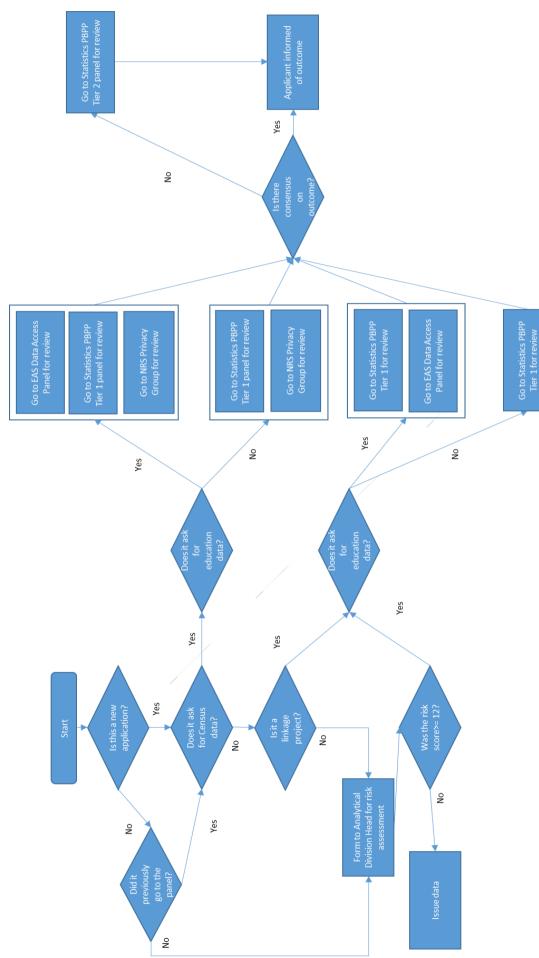
• Has an excellent level of current knowledge of the relevant legislative and advisory landscape

Panel Manager The role of the panel manager is to:

- Assist the panel chair in ensuring that the panel operates within its terms of reference
- Assist the panel chair in ensuring that the panel meets any performance targets or obligations set out in its terms of reference
- Assist the panel chair in ensuring that the panel is adequately resourced with suitably qualified members
- Ensuring the smooth administrative operation of the panel's work
- Assist the panel members in undertaking their responsibilities in an effective and timely manner
- Participate in full in the work of panel operation

It is essential that the manager / secretariat:

- Is familiar with the current legislative and advisory environment regarding personal data
- Displays excellent organisational and communications skills
- Undertake any training as might be deemed appropriate by the panel Chair



ANNEX D – Application Process Map

ASD Categorisation tool for assessing data access applications

Enter a score from 0 to 3 for each of the risk areas.

Nisk area Data	uescription The data requested		Kationale	 oundance 0 - Anonycised, disclosure controlled data 0 - Anonycised, disclosure controlled data 1 - Low impact (e.g. non-sensitive de-identified or aggregate data) 2 - Medium impact (e.g. non-sensitive indidivual level data) 3 - High impact (e.g. sensitive individual level data)
People	The accreditation of the analyst or researcher			 Researcher or analyst with accredited safe researcher training Researcher or analyst working for a recognised insitution in the UK (e.g. SG, local authority, university, national research contractor) Researcher or analyst working for an independent research contractor in the UK or a recognised insitution in a state with which UK has data protection treaty Member of the general public or institution outwith UK with which UK has no treaty
Environment	The security of the research environment	/		 Recognised research 'safe haven' within the UK Institutional research environment in the UK with proportionate security measures Institutional research environment with proportionate security measures within state with which UK has data protection treaty No clear security arrangements in place (e.g. independent contractor storing data at home) or in state with which UK has no treaty
Privacy	The likelihood of breach		/	 0 - No likelihood of breach 1 - Low probablity of a breach 2 - Medium probability of a breach 3 - A high likelihood of breach axists Consider all information about applicant available, including other factors assessed here
Impact	The privacy impact of a breach			 Insignificant Low impact Medium impact High impact High impact Consider both the impact to data subjects and reputational impact
Public Interest	Serving the public interest			 Clearly in the public interest / provides public value Strong public interest or public value Some public interest or value No clear public interest
Research	The research question(s)			 Closely aligned to SG policy or research interests. Fills clear evidence gap. Aligned to SG policy or research interests. Adds to evidence base Within broad SG policy interests. No alignment with SG policy interests.
TOTAL SCORE			0	

Category	Description	Score	Action
Category 2	Medium-high risk	12+	Review by panel
Category 1	Low risk	0-11	Review by Branch Head

ANNEX D – Panel Risk Matrix

ANNEX E – Statistics PBPP Guiding Principles and Proportionate Governance Criteria

Principles that guide the Statistics PBPP

The following principles guide and inform the deliberations of the Statistics PBPP when considering applications to use Scottish Government originated data or NRS census data:

Privacy

The starting point for considering any application to use Scottish Government originated data or NRS census data is to recognise that everyone has a right to respect for their privacy.

Public interest

Before approving access to data, the Statistics PBPP must be satisfied that the public interest will be furthered by the proposal at hand, that there is both a demonstrable social need for such processing and a reasonable likelihood that it will result in tangible benefits for society.

Appropriate science

If applicants wish to process data in ways that may increase risk to privacy, then they must demonstrate that their research is scientifically-sound and ethically robust. This may be evidenced, for example, by approvals from an ethics committee and/or a scientific peer-review committee.

Transparency

Processing of data should fit with data subjects expectations, guidance including privacy notice information, and in consent forms relevant to the processing.

Anonymisation

Anonymising data before release can considerably help to reduce risk to privacy. Anonymised data are data from which an individual can no longer be identified because information such as name or date of birth, have been removed or masked. The Statistics PBPP operates on the basis that data should be anonymised as fully as possible consistent with their use. However, as with consent, sometimes it is not appropriate to fully anonymise the data because this will interfere with legitimate processing. In such circumstances, a clear explanation and justification should be given.

Privacy impact

The Statistics PBPP must be satisfied that any impact on individual privacy is clearly outweighed by the public benefit resulting from the processing, and in any case is reduced to the absolute minimum necessary to achieve the outcomes of the proposal. Any likely impact on individual privacy should, therefore, be fully explained to allow a meaningful assessment of the risk.

Safeguards

If special safeguards are to be used to protect individual privacy, these must be described and meet acceptable standards.

Security

The Statistics PBPP must be satisfied that data will be held securely as long as they remain in the custody of the recipients.

Proportionality

Processing of data must be proportionate to the objectives. This can only be assessed on a caseby-case basis but it signals that processing should be no more than necessary to meet the social need. Relevant factors include the type and amount of information to be use or linked, and the nature and number of parties to whom it is to be disclosed. Use of data will be approved only for the purpose/s detailed in an application, and will not extend to any use for additional or secondary purposes.

Precedent

The Statistics PBPP will reflect on the precedents which its own past decision making, and the decision making of its antecedents (as far as these can be deemed to be relevant and in keeping with good practice and its own principles), represent, and will take these into account where they are relevant to the application at hand.

Marking criteria

The Statistics PBPP uses a colour scoring system which reflects the strength of the evidence provided:

- Green enough evidence has been provide
- Amber more evidence is required
- Red no evidence provided

Safe People

Question 1

Is the researcher and those applying to access the linked data trained in Information Governance? **Please note** updated requirements for census data. (Approved training courses are listed in Table 1 - applicants must submit training material for any other courses undertaken to be assessed by Tier 1 panel)

Green	Yes, has completed or will undertake approved training or verifiable	
	appropriate training	
Amber	Reports training but difficult to assess, or only some participants trained	
Red	Unable to establish training status or efficacy of training	
Comments		-

Question 2		
Are all organi	sations engaged in the proposal verifiable as bona fide?	
Green	Yes, known partner organisations, NHSScotland boards, NHS trusts, UK public bodies, UK academic organisations, other recognisable UK organisations, which are registered with the ICO as a data controller	
Amber	Yes, based outside UK	
Red	No	
Comments		

Safe Projects		
Question 3		
Is funding in pl	ace for the project?	
Green	ALG or ADRC funding has been approved. Or for non-linkage work,	
	another public sector body has approved funding.	
Amber	Not yet, but funding is pending	
Red	No funding approved	
Comments		

Question 4		
Has the applicant demonstrated how their research will benefit the public?		
Green	Yes, or statutory duty exists	
Amber	Insufficient consideration given to issue or difficult to establish	
Red	No evidence of public benefit	
Comments		•

Question 5		
Is the proposa	al design and method appropriate to its objectives?	
Green	Yes	
Amber	Doubts, queries or issues with proposed design or method, given	
	objectives. Proposed processing goes beyond that required to achieve	
	objectives	
Red	Unlikely the objectives will be met	
Comments		•

Question 6		
Do all the variables being requested appear relevant to the objectives?		
Green	Yes	
Amber	Doubts, queries or issues with proposed variables. Unclear which variables are being used to answer multiple research questions.	
Red	Variables appear irrelevant. Large volumes of data being requested.	
Comments		-

Question 7		
Is there any commercial interest or involvement in the research?		
Green	No commercial interest or involvement	
Amber	Commercial interest in the research	
Red	Questionable commercial interest in, or motivation for, the research (eg commercially funded) considered to outweigh public interest and/or presenting privacy concerns	
Comments		

Question 8		
Does the proposal require any direct contact with individuals?		
Green	No, is for research and statistics purposes only.	
Amber	Yes, contacting individuals who have consented to be contacted for the purposes outlined in the proposal.	
Red	Yes, contacting individuals who have not consented to be contacted for the purposes outlined in the proposal, or have not consented to be contacted at all	
Comments		

Question 9

Is the lawful basis for the proposal clear and appropriately evidenced? This is required for individual level or identifiable data requests and for all census data requests.

Green	Yes, GDPR Article 6 conditions are relevant	
	□ Data Subject's consent □ Performance of a contract □ Necessary to	
	comply with legal obligation of the data controller \Box Necessary to protect vital	
	interest of the data subject \Box Necessary for task carried out in the public	
	interest or exercise of official authority of the data controller \Box Necessary for	
	legitimate interests of the data controller or third party and doesn't prejudice the	
	data subject	
	If special category data is being requested, GDPR Article 9 conditions are	
	relevant,	

	\Box Data Subject's explicit consent \Box Necessary for statutory functions \Box	
	Necessary to protect the vital interests of the data subject \square Carried out in the	
	course of legitimate activities with appropriate safeguards \Box Manifestly made	
	public by data subject action \Box Necessary for establishment, exercise or	
	defence of legal claims \Box Necessary for reasons of substantive public interest	
	\Box Necessary for purposes of preventative or occupational health, for	
	assessment of working capacity of employee, medical diagnosis, provision of	
	health or social care or treatment or management of health or social care	
	systems \Box Necessary for reasons of public health in the area of public health	
	\Box Necessary for research or statistics in accordance with GDPR Article 89	
	And if necessary, GDPR Article 10 conditions are relevant (see table 2).	
	Relevant parties are data controllers, data processor permission is in	
	place and any data transfer beyond the UK is adequately controlled.	
Amber	Some concerns remain - the basis for lawful processing may be unclear,	
	data controller permissions or registrations are unclear, or other concerns	
	remain	
Red	Risk that proposal may result in unlawful processing is evident	
Comments		•

Question 10

If the lawful basis is noted as 'public task' or 'legitimate interest' has an appropriate legislation or ethical approval being given.

Green	Yes, legislation is appropriate for the organisation requesting that data for	
	use with 'public task'	
	Ethical approval has been granted for those using 'legitimate interest'.	
Amber	Some concerns remain - the legislation to allow the organisation to	
	process data is unclear, no ethical approval sought or granted	
Red	Risk that proposal may result in unlawful processing is evident	
Comments		-

Question 11

Are individuals aware of the use of their data or is the use wholly compatible with that for which the data was originally collected?

Note:

Consent of data subjects is an important consideration, although is not a necessary requirement for data linkage under the Data Protection Act. Where obtaining consent is not practicable, then (a) removal of direct identifiers should occur as soon as is reasonably practicable and/or (b) approval from an appropriate oversight body should be obtained which can confirm that the public interest in data linkage is met and appropriate safeguards are in place. Data collected for the purpose of administering public services is likely to warrant a privacy notice or other evidence of fair processing.

Green	Populations of individuals involved are clearly informed or robust attempts	
	to inform have been made (e.g. clear patient information about and/or	
	consent for purposes of the proposal) . Implied consent may be relevant	
	in limited circumstances.	
Amber	Limited evidence that individuals are aware that their data may be used in	
	this way and limited attempts to inform, but with understandable practical	
	difficulties to doing so. The purpose is in line with the original purpose of	
	collection and is one they might reasonably expect	
Red	No evidence that individuals are aware that their data may be used in this	
	way and limited attempts to inform, where it is reasonably practical and	
	possible do so. The purpose is not in line with the original purpose of	
	collection and is not one they might reasonably expect.	
Comments		

Safe Data		
Question	12	
Is the data	sensitive or special category personal data?	
Special ca	tegory personal data are listed in table 3.	
Green	No	
Amber	Some sensitive data will be used but this is not the focus of the proposal.	
	Some sensitive data will be used and/or vulnerable populations involved,	
	but controls appear adequate and commensurate with	

	sensitivity/vulnerability. Focus of research may be considered sensitive although not on list	
Red	Highly sensitive data or vulnerable populations are the focus of the proposal and/or there is insufficient evidence of adequate controls	
Comments		

Safe Outputs			
Question 13			
ls risk of unin	Is risk of unintended disclosure minimised, with appropriate controls applied (for example a		
separation of	separation of functions model, anonymisation of linked data, etc)?		
Green	Yes, no outstanding concerns regarding unintended disclosure		
Amber	Some residual risk remains giving concern. Residual risk difficult to assess		
	or assessment based on highly unpredictable factors. Very low risk		
	competing with very serious potential consequences.		
Red	Residual risk to individual identifiable data remains unacceptably high		
	given likely benefit. Harm or potential harm to individuals is reasonably		
	foreseeable. Residual risk has the potential to be reasonably reduced		
	further.		
Comments			

Safe Setting	js	
Question 14	. /	
Are informat	ion security and access controls adequate?	
To provide a	dditional assurance where explicitly technical risk is evident	
Green	Data will be accessed exclusively through an accredited safe haven, or	
	there is no residual risk resulting from lack of technical controls,	
	outstanding technical vulnerability, or reasonably foreseeable technical	
	threat	
Amber	Data will be processed using technology which might expose it to	
	reasonably foreseeable technical threat or where there is outstanding	
	technical vulnerability or lack of controls giving some concern	
Red	Outstanding concerns regarding technical threat, vulnerability or control	
	which cannot be satisfactorily addressed	
Comments		

Question 15		
Are data transfer methods secure and appropriate?		
Green	Appropriate data transfer methods are in place, e.g. encryption	
Amber	Limited evidence or insufficient detail of data transfer methods available	
Red	Outstanding concerns regarding data transfer which cannot be satisfactorily addressed	
Comments		

General			
Question 16	Question 16		
Does the application pose any privacy or ethical concerns not addressed above?			
Green	No		
Amber	Yes, mild to moderately serious concern remains, needs ethics approval		
	from a panel		
	Please describe the concern		
Red	Yes, there is serious concern, needs ethics approval from a panel		
	Please describe the concern		
Comments			

Annex 1.

Table 1 – Recognised Information Governance Training

ADRN SURE training

NHS Scotland Information Governance eLearning

Scottish Government Data Protection elearning and Responsible for Information General User

MRC Research Data and Confidentiality online module

ONS Safe Researcher Training

Researchers accessing census data are required to have either ONS Safe Researcher training or ADRN SURE training.

Training dates must be less than 3 years old unless otherwise stated

Table 2. Personal data relating to criminal convictions and offences -

the commission or alleged commission or any offence, or

any proceedings for any offence committed or alleged to have been committed, the disposal

of such proceedings or the sentence of any court in such proceedings

Table 3. Special category of personal data means personal data consisting of information as to -

racial or ethnic origin of the data subject,

political opinions,

religious beliefs or other beliefs of a similar nature,

whether a member of a trade union (within the meaning of the Trade Union and Labour

Relations (Consolidation) Act 1992),

genetic data

biometric data for identification

physical or mental health or condition

sexual life

ANNEX F – Application Outcome Criteria

Approval -All members agree on approval (based on proportionate governance assessment).

Approval with conditions – One or more members requests additional safeguards (based on proportionate governance assessment), e.g. more evidence required, such as supply of additional documentation with the provision of training certificates, outcomes of ethical approvals.

Clarification - including a strong recommendation to re-submit, can be used for applications which the panel or Application Coordinators consider unlikely to gain approval, e.g. more information required to assess security procedures; details of training conducted along with training certificates; additional justification on requirements for data requested.