



BAPEN Terms of References

Data Governance Group

1. Background to The BAPEN Data Governance Group

The Data Protection Act 2018 and the UK GDPR, which implements EU GDPR regulations in the UK, makes provision about the processing of personal data. Individuals are protected with regard to the processing of personal data, in particular by requiring “personal data to be processed lawfully and fairly, on the basis of the data subject's *consent or another specified basis*”. The UK GDPR further defines data controllers and data processors and their differing roles and responsibilities.

BAPEN stores personal data from surveys, membership applications, conference and meeting attendance, and medical research. BAPEN does not have its own administrative staff or offices but sub-contracts to Medivents Ltd who hold conference and membership data on behalf of BAPEN. The IF Registry, historic BAPEN survey data and UKMAW data is currently held by separate organisations and the GDPR compliance is not always clear. In addition, BAPEN comprises various committees, core groups and special interest groups, all of which potentially hold personal data on their computer systems/laptops. In future BAPEN will wish to sponsor further research projects and best practice appears to be the implementation and maintenance of a central repository for research data and a standardised method of conducting and storing all such material.

BAPEN is registered with the Charity Commission and the Information Commissioner's Office and is regulated by these institutions.

In January 2025, a brief was provided by the President of BAPEN and the Chair of Trustees seeking the creation of a Data Governance Group to determine what data sets BAPEN holds, whether BAPEN is compliant with GDPR legislation and what risks the organisation could face in future.

2. Aims and Objectives of The BAPEN Data Governance Group

Aims

- To establish what data sets are held by BAPEN and where they are held.
- To ensure that BAPEN understands the UK GDPR legislation and is GDPR compliant across all sets of personal data within the organisation.
- To ensure that all members of BAPEN and those taking part in BAPEN surveys and research are confident that their private data is being handled and stored legally.
- To avoid the risk that a GDPR compliance issue arises within BAPEN or its partner organisations.
- To ensure that all members of BAPEN committees, core groups and special interest groups who process personal data are aware of the standards and procedures necessary to ensure GDPR compliance.
- To introduce a standard platform for BAPEN research and survey data going forward.

Objectives

- To provide an inventory of all data stored by BAPEN and its associates including where that data is stored. The inventory should include detail of who owns (the data controllers) and who manages the data (data processors), who has access to it and what is the lawful basis for the retention of that data.
- To produce a data management risk assessment of the data held by BAPEN including GDPR requirements for each data set, the intellectual/property value and the storage/access controls.
- To review BAPEN policies related to data privacy and GDPR.
- To develop a structure and procedures for ensuring data governance compliance in the future, including any contracts signed by BAPEN.
- To review the different platforms available for the standardisation of BAPEN research data storage.

3. General Activities of BAPEN Data Governance Group

The Data Governance Group would meet to produce and maintain a list of BAPEN's data sets and where they are held and any associated risks. The Group will assess any activity within BAPEN which is not GDPR compliant and suggest remedial action. The Group will produce policies to ensure that all BAPEN members and staff are aware of their roles and responsibilities when managing personal data in order to ensure there are no breaches of GDPR legislation. The Group will assist BAPEN to ensure that all partner contracts signed by BAPEN include GDPR compliance clauses. The Group will assess the suitability of the privacy policies published by partner organisations who hold data on BAPEN's behalf or who hold data provided by or shared with BAPEN.

MAG have recently been awarded a grant to develop a cross-organisation Data Repository and BAPEN Medical a grant to develop a multi-disciplinary Clinical Research Group to coordinate, organise and support multicentre research and audit studies across the UK. The Data Governance Group should assist and support this work.

4. Accountability of the BAPEN Data Governance Group

The Data Governance Group will be accountable to the Board of Trustees and Council and will produce a written report to the Board of Trustees and Council in good time for Board meetings.

5. Chair of the BAPEN Data Governance Group

- a. The Chair of the Data Governance Group will initially be a member of BAPEN's Board of Trustees and be appointed by the Trustees.
- b. The Chair will serve for an initial tenure of 18 months.
- c. After the initial tenure, the Trustees will seek applications and appoint a new Chair. Members of the Data Governance Group, BAPEN Council and the BAPEN Executive Committee will be eligible to apply.

6. BAPEN Data Governance Group membership

Any member of BAPEN Council and BAPEN Executive Committee may become a member.

7. Expectations of the BAPEN Data Governance Group members

- a. The expectation is that all members will attend at least two of the Data Governance Group meetings per annum and contribute to the Group achieving its aims and objectives.
- b. All Group members activity will be conducted in line with the BAPEN values and ED&I policy - <https://www.bapen.org.uk/pdfs/policies-and-procedures/bapen-edi-policy-2021.pdf>
- c. All information discussed regarding personal data will be kept private and confidential.

8. BAPEN Data Governance Group meetings

- a. Four meetings a year will be organised for the first year of the Data Governance Group.
- b. Agenda items should be forwarded to the Chair two weeks prior to the meeting
- c. Apologies will be sent to the Chair if possible one week before a meeting.
- d. All in attendance are required to declare any conflict of interest for each of the Group meetings which will be noted on the action notes of the meeting.
- e. Most meetings will be conducted online. However if a meeting is scheduled in person, all Group members can claim travel expenses from BAPEN as per standard BAPEN travel expenses policy <https://www.bapen.org.uk/claim-form-for-reimbursement-of-expenses>. Any travel claims or expenses relating to other business need prior approval from the Chair and the BAPEN treasurer.

9. BAPEN Data Governance Group Terms of reference

These Terms of reference will be reviewed by the Chair every two years and are required to be signed off by and ratified by the Board of Trustees. - Review date February 2027.