

Chair:

Helen Whately, MP

Co-Chair:

The Rt. Hon Lord
Norman Warner

Vice Chairs:

The Rt. Hon. Lord
Philip Hunt
Lord Narendra Patel
Chi Onwurah, MP
Sir David Amess, MP

Treasurer:

Lord George Willis

Secretariat

PHG Foundation
2 Worts Causeway
Cambridge
CB1 8RN

All-Party Parliamentary Group on Personalised Medicine

Personal data and privacy statement

July 2018

APPG data audit

Operations of the APPG are handled by the Secretariat (provided by the PHG Foundation) in partnership with the office of the Chair, Sir David Amess MP. There are three groups of personal data involved:

- **Data relating directly to APPG members**

Both the Chair's office and selected staff members of the Secretariat have access to email and/or telephone contact information pertaining to members of the Group and their office staff. All formal invitations and notices are sent to members by email from the Chair's office.

- **Data relating to other Parliamentary staff**

The Chair's office (but not the Secretariat) has access to email contact information pertaining to other parliamentarians (members of the House of Commons and the House of Lords who do not currently belong to the APPG on Personalised Medicine), and may extend formal event invitations to these individuals by email.

The Secretariat has access to personal contact details for selected organisations and individuals in Parliament who provide business or related services to the Group; for example, Parliamentary events and catering teams and the Office of the Parliamentary Commissioner for Standards.

- **Personal data relating to non-APPG members**

The Secretariat may additionally have access to personal contact details for organisations and individuals whose expertise and areas of operation are directly relevant to the remit and operation of the Group; for example, health professionals and policy makers, academic, clinical and commercial researchers and innovators, patients and other stakeholders.

The Secretariat as a data processor for the APPG

As provider of the Secretariat function to the APPG on Personalised Medicine, the PHG Foundation also acts as data processor for the Group. Working with the Chair, the secretariat undertakes to handle data in a manner that is fully compliant with the General Data Protection Regulation, as set out below:

1. **Personal data relating to APPG members and Parliamentary staff**

In addition to formal communications to members from the Chair's office, the Secretariat may send additional communications, normally via email, where there is a legitimate reason to do so. These either relate directly to activities of the Group and/or provide timely information of potential interest to members (*ie.* pertaining to personalised medicine and the stated remit of the Group). In addition, contact information may also be held and used for other relevant Parliamentary staff as set out above. Most of these data (names and email addresses) are publicly available via the UK Parliament website.

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2. Personal data relating to non-APPG members

The Secretariat may contact non-members in direct relation to Group events and activities where there is a legitimate reason for us to do so, such as identifying experts and other stakeholders from the health, research and policy communities.

From June 2018, all non-APPG members contacted in relation to APPG activity are explicitly informed that they must actively opt in to retention and potential future use of their personal data by the PHG Foundation in relation to the APPG (for example, to receive news about the work of the Group). Unless this option is exercised, their personal data is not retained. Any contact information is held securely in a third-party communications platform.

3. General data protection measures

As secretariat to the APPG on Personalised Medicine, the PHG Foundation takes data privacy very seriously.

All contact information is held securely in a password-protected database accessed solely by selected PHG Foundation staff undertaking activity in direct relation to provision of the APPG's Secretariat function.

Personal data pertaining to Group Members is not shared with third parties.

Other data is only shared with third parties where there is a clear business need to do so pertaining to operation of the APPG – for example, providing a list of external meeting attendee names to the Houses of Parliament security teams, or sending news updates to self-selected recipients via a communications platform provider. In these instances, we ensure that data is passed to recipients in a secure manner.

Privacy policies are displayed on both the APPG on Personalised Medicine and the PHG Foundation websites setting out how and when data is processed and how to contact us should there be queries related to this processing.

The PHG Foundation's IT systems and infrastructure are provided by the University of Cambridge, who provide robust measures to protect the data we process. This includes hardware safeguards, access controls, solutions for combating spam, malware and viruses, as well as monitoring software and the carrying out regular tests to check the defences that are in place from a cyber-attack. The database of APPG specific information is held on the PHG servers maintained by the University.

In addition to the above measures, the PHG Foundation also reviews all key business functions regularly to check we are processing personal data securely and in accordance with the regulations, and provides training for relevant staff to ensure they understand systems for data protection and always process personal data safely.

Further queries

Any inquiries about how the PHG Foundation, as provider of the Secretariat to the APPG on Personalised Medicine, processes and protects personal data should be directed to: appg@phgfoundation.org