Call for applications

BPSU Scientific Committee
Patient and Public Representative
To serve 2024 - 2027

Description of Committee

The British Paediatric Surveillance Unit was set up in 1986, to undertake active surveillance of rare and uncommon paediatric conditions and infections across the UK and Republic of Ireland, and now also acts as an advocate for rare diseases in children. Internationally known, it is a joint initiative between the Royal College of Paediatrics and Child Health (RCPCH), Department of Health and Social Care (DHSC), University College London Institute of Child Health (UCL-ICH), the latter in conjunction with the Great Ormond Street Hospital Charity. Each of these organisations contribute to the funding of the BPSU and oversee its strategic direction via the BPSU Partnership Board.

The Scientific Committee reports to the BPSU Partnership Board and all three organisations noted above (RCPCH, DHSC, UCL-ICH) are also represented on the Scientific Committee, along with representatives from Health Protection Scotland and the Republic of Ireland. Other members of the Scientific Committee are appointed to provide a broad range of paediatric clinical expertise, which include community health, neonatology, infectious disease, general paediatrics, epidemiology, and public health. In addition, the Scientific Committee includes paediatric trainee representatives, Patient and Public Representatives for public involvement in research, and two medical advisors, one from the UCL-ICH and one from DHSC, who help with the review of study applications. The Scientific Committee also supports the Chair and staff at the BPSU.

The responsibility of the Scientific Committee is to deliver and implement the aims and objectives of the BPSU in terms of the studies that it supports and its reporting system. Its objective is to advance knowledge of rare or uncommon childhood conditions, disorders or infections, which are of public health importance, through active monthly reporting by paediatricians participating in a national reporting scheme that runs across the United Kingdom and the Republic of Ireland.

The Scientific Committee is responsible for:

- Inputting into the yearly budget
- Signing-off the annual report
- Reporting to the Partnership Board on the activities of the BPSU
- Receiving regular financial reports from the Head of the BPSU
- Implementing the aims and objectives of the reporting system
- Inputting into and drafting the three-year strategic plan for BPSU
- Ensuring the BPSU adheres to good data governance practices

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The business of the Scientific Committee is:

- The implementation of the aims and objectives of the BPSU
- Guiding and monitoring the operation of the BPSU
- Providing peer review of and approving applications from investigators proposing conditions to include on the BPSU reporting system
- Advising on the design and conduct of research studies
- Developing written and other guidance for potential applicants, to include the process for applying and expected good practice in relation to research governance and public involvement by study investigators
- Receiving and reviewing draft reports and publications from investigators
- Supporting the wide dissemination of BPSU outputs and impact to a variety of stakeholders
- Encouraging engagement of paediatricians in surveillance activities and promoting awareness of conditions being researched
- Approving reports of the work of the BPSU, including the annual report and annual plan, in addition to encouraging and monitoring public involvement in BPSU studies

Role purpose and responsibilities

The appointment of this role is for 3 years, with the option for extending for a further 2 years. The Patient and Public Representative is primarily accountable to the BPSU Scientific Committee Chair, but will also work closely with the Head of the BPSU and the BPSU Project Coordinator, along with other members of the Scientific Committee.

The role of the Patient and Public Representative on the BPSU Scientific Committee is to:

- Ensure adherence to the BPSU PPI Statement of Principle: 'The BPSU is committed to ensuring that patient and public involvement is embedded in its work' through regular attendance and participation of the Patient and Public Representatives in Scientific Committee meetings.
- Contribute effectively and constructively to discussions that take place during Scientific Committee meetings.
- Prepare for meetings by reviewing and commenting on applications and any other meeting papers and raising any issues for clarification with BPSU staff.
- With other Patient and Public Representatives, provide a lay perspective on applications submitted to the Scientific Committee, in particular:
  - The likely public perceptions of a topic
  - How well public information sheets have been written
  - The quality of patient and public involvement (PPI) in an application and how it might be strengthened
  - The ethical issues raised by a study
  - Potential links with relevant patient organisations.
- Participate in appropriate training and support activities to develop patient and public involvement.
- Declare any conflict of interest in accordance with the policies of the BPSU.
- Maintain the confidentiality of agenda papers, discussion and decisions, in accordance with BPSU guidance.
- Participate in any evaluation and/or review of this role or the activities of the Scientific Committee.
- Liaise promptly with BPSU staff regarding all administrative matters relating to the Committee, e.g. expenses, meeting dates and confirming attendance.
- Be an advocate for the work of the BPSU.

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Eligibility

Patient and Public Representatives of the BPSU Scientific Committee are required to have either personal experience of disease during childhood, be the parent or carer of a child who has/had a significant disease or chronic condition, or have some other significant link to rare diseases and conditions, e.g. involvement with a rare disease charity in a non-professional role. It would also be desirable that Patient and Public Representatives have experience of both working on a committee and reviewing documents.

Time commitment

The Patient and Public Representative will be required to attend either in person or via MS Teams six meetings of approximately 3.5 hours duration per year, plus prepare appropriately for meetings by reading the papers and reviewing any study applications. The majority of committee meetings are held virtually via MS Teams, but 1-2 longer meetings per year are held in person, usually hosted by the Royal College of Paediatrics and Child Health in London.

Attendance at Scientific Committee meetings is monitored. Membership is reviewed if individual attendance drops below fifty percent or if Members are absent from more than three consecutive meetings. It is expected that at least two-thirds of Scientific Committee members are in attendance at each meeting. Members may also be asked to represent the BPSU at other internal or external meetings of each of the parent bodies of the BPSU.

Support provided from the BPSU/RCPCH

The first point of contact for the Patient and Public Representative will be via the Head of the BPSU.

Patient and Public Representatives will be eligible for renumeration for their time, skills and expertise, in terms of preparation time for attending meetings, including reviewing study applications, plus meeting attendance, in line with the latest guidance from the National Institute for Health and Care Research (NIHR) (Payment guidance for members of the public considering involvement in research | NIHR)

For those meetings that require attendance in person, Patient and Public Representatives will also be reimbursed for the cost of travelling expenses and subsistence (in line with the RCPCH expenses policy).

Knowledge, skills and experience required

Essential:

- Personal experience of disease during childhood, parenting or caring responsibilities for a child with a significant disease or chronic condition, or some other personal experience and knowledge of rare diseases.
- An ability to raise relevant personal experience and knowledge to inform the work of the Scientific Committee, and to draw on a broader range of patient/public perspectives beyond their own personal experience.
- A demonstrable commitment to health research and to Patient and Public Involvement.
- A demonstrable understanding of and interest in the objectives of the BPSU.
- Experience of reading and reviewing written documents.
- Experience of using email, internet and MS Office packages, including MS Teams.
- Experience of participating in committee meetings.

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- An ability to work with the wide range of professionals involved in the work of the BPSU
- An ability to work and communicate effectively and appropriately as part of a committee.
- A willingness to learn the skills of the role and to develop as a Scientific Committee member.
- Attendance at Equality, Diversity and Inclusion training within the last 3 years (if you have not attended training in the last 3 years, this will be provided by the RCPCH upon successful appointment of the role).

Desirable:

- Experience of being actively involved in health research as a member of a research committee.

Process

To apply for this role, please send an email to bpsu@rcpch.ac.uk with a statement of up to 250 words outlining your relevant experience and why you feel you would be well suited to the role.

When undertaking a role affiliated to the RCPCH all role holders must agree to respect and uphold the charitable objects, vision, and values of the RCPCH and uphold the code of conduct which embodies of the values that the RCPCH holds, the breaking of which could lead to sanction. Core to RCPCH's values is the exemplary behaviour of its members and representatives, both as professionals and also as individuals.

Appointed candidates will be asked to register their interests. This is to ensure that personal circumstances that might compromise a volunteer's ability to be seen as acting correctly are properly disclosed.

The role holder must be committed to following the RCPCH's safer working practices guidelines when working with children, young people and vulnerable adults. Safeguarding is everyone's responsibility, with the role holder required to comply with the College's Safeguarding policy. Appointed candidates must also have attended Equality, Diversity and Inclusion training within the last 3 years.

The BPSU and RCPCH may – at its discretion and with the agreement of the candidates – choose to offer this role as a job-share between more than one candidate once the appointment process is complete. Details will be discussed with candidates at the time should this arise.

The BPSU and RCPCH want to represent all the communities we serve. Appointment will be made solely on merit. However, the BPSU and RCPCH are particularly keen to receive applications from Black, Asian and minority ethnic candidates, and/or candidates with a disability who are currently under-represented at this level of the organisation. To ensure our records for committee members are up to date, Equality and Diversity details will be collected and held in line with the RCPCH Privacy Policies (Privacy notice - equality, diversity and inclusion (EDI) | RCPCH). For further information please contact edi@rcpch.ac.uk.

Personal information about unsuccessful candidates will be held for 6 months after the position has been filled, it will then be securely destroyed. Personal information about successful candidates will be retained on file. The information contained in this will be kept secure and will only be used for purposes directly relevant to that person's responsibilities as a Scientific Committee member in line with the UK Data Protection legislation (Data protection and confidentiality policy | RCPCH).

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Dr Peter Davis
Chair of the British Paediatric Surveillance Unit Scientific Committee

Professor Steve Turner
President of the Royal College of Paediatrics and Child Health
2024

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