

A review of patient and public involvement at the British Paediatric Surveillance Unit

The British Paediatric Surveillance Unit (BPSU www.rcpch.ac.uk/bpsu) supports research into rare childhood conditions and disorders. This research takes the form of national epidemiological surveillance. This is a summary of the findings from a recent review of the effectiveness of patient and public involvement (PPI) within the BPSU and the studies it supports.

PPI within the BPSU

An Executive Committee oversees the strategic development of the organisation and approves studies for inclusion on the BPSU system. Two lay members play a crucial role in evaluating applications sent to the BPSU, in particular providing a lay perspective on the likely public perceptions of a topic; how well public information sheets have been written; the quality of the PPI in an application; the ethical issues raised by a study and potential links with relevant patient organisations. They also advise applicants about developing PPI in their studies. The role of the lay members on the Executive Committee was found to be innovative and influential.

The current lay members will soon reach the end of their term of office. The Executive Committee has therefore agreed to recruit new members and will follow best practice in ensuring a transparent and open recruitment process.

A number of suggestions for BPSU's future PPI work involved expanding current activity in two key areas. If the BPSU becomes more involved in influencing public health policy, PPI would be very important to provide the patient perspective and to create opportunities for partnership working with patient organisations. BPSU could also begin to involve young people in its work. Investment of resources and careful planning would be needed to ensure this was meaningful and relevant to all.

PPI in BPSU studies

The BPSU promotes PPI in its studies by making PPI a requirement for researchers wishing to use their approach. Lay members of the Executive Committee have had a major influence on the application process. There is scope for further development.

The nature of BPSU studies, in particular the fact that they involve looking at anonymised patient data, means that PPI is important. PPI enables researchers to check out the acceptability of their approach with patients and the public. It is also critical in identifying studies that are controversial or of a sensitive nature that will need to be communicated carefully.

Since all BPSU studies follow a similar format it is possible to map PPI across the different stages of the research process. PPI was felt to be most valuable in assessing the importance and relevance of the research question, writing the public information leaflet and disseminating the findings, where there is as yet untapped potential.

The review suggested that researchers would benefit from more practical advice on *how* to involve patients/ patient representatives in their work. The BPSU is therefore looking to develop guidance and support for researchers about PPI.

Taking forward PPI at the BPSU

The main challenge to taking forward any of the recommendations for future work is a lack of resources – both of funding and time, and in particular the limited capacity of Executive Committee members and BPSU staff to carry out the work required.

The **full report** of this review can be found at <http://www.rcpch.ac.uk/what-we-do/bpsu/patient-and-public-involvement/patient-and-public-involvement>