

# An Evaluation of the Surveillance System of the British Paediatric Surveillance Unit 2008-09

## Summary Report

- 1 The British Paediatric Surveillance Unit (BPSU) was established in 1986 to undertake active surveillance of rare conditions affecting children. BPSU is a joint undertaking between the Royal College of Paediatrics & Child Health, The Institute of Child Health, London and the Health Protection Agency.
- 2 A monthly Orange Card is mailed to around 3000 consultant paediatricians in the United Kingdom and Republic of Ireland containing a list of up to thirteen conditions of interest. Paediatricians are asked to return the card indicating whether they have seen a case of any of the conditions in the past month or if not, to indicate nothing to report. Researchers wishing to study a condition via the BPSU submit an application to the Executive Committee which considers the proposal on scientific merit to determine whether it is suitable for BPSU surveillance. Notifications from Orange Card returns are passed to investigators who then contact the respondent directly to request further details and confirm case ascertainment.
- 3 A formal evaluation was undertaken during 2008 to assess the effectiveness of the BPSU system in carrying out its surveillance role and to explore its acceptability among researchers and notifying paediatricians, seeking to identify areas of both strengths and weaknesses to inform the continuing development and improvement of the BPSU. The evaluation was carried out in two phases – an internal review of the BPSU system applying CDC (Atlanta) guidelines for evaluating public health surveillance systems and a postal questionnaire survey of a sample of responding paediatricians and of researchers who had carried out a study via the BPSU. The findings form the basis of this summary. A full copy of the evaluation report is available via the [BPSU website](#).
- 4 The overall response rate for Orange Cards is consistently over 93% and a similar response rate is seen for requests for additional information about notified cases. The Orange Card has been sent out without fail every month since the BPSU was established. The majority of respondents to the questionnaire survey indicated the paper Orange Card remained their preferred option for contact and notification to the BPSU.
- 5 The majority of studies remain on the Orange Card for duration of thirteen months but the system has been flexible to allow more sustained surveillance of conditions of major public health importance, including paediatric HIV infection, new variant Creutzfeldt Jakob disease and congenital rubella infection. Joint studies with other bodies have also been undertaken to facilitate studies of conditions involving both paediatricians and other disciplines outside of the usual BPSU reporting base. Responses to the questionnaire survey have confirmed the willingness of paediatricians to respond to urgent surveillance questions in response to a public health emergency and e- mail contact was the preferred format by the majority in this situation.
- 6 Since its inception, a total of 60 studies have been completed via the BPSU of which 51 have published their findings in a peer reviewed journal. To date, BPSU studies have given rise to a total of 169 peer reviewed publications. Responses to the questionnaire survey indicated that over 80% of respondents considered the surveillance of rare conditions in children to be important and 40% indicated that the outcomes of BPSU studies had changed their clinical practice.
- 7 Specific points for action have been identified as priorities based on the findings and outcomes from the evaluation exercise. These are summarised overleaf.

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Chair of the BPSU Evaluation working party



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# Summary of recommendations taken from Evaluation report January 2009

## Key finding

The BPSU surveillance system is a simple and effective system for the surveillance of rare childhood disorders in the UK and Ireland, which should be maintained and developed.

## 10 key priorities for action:

In response to the evaluation of November 2008, the key priorities for the BPSU are to:

1. Evaluate public involvement and engagement with patients, the general public and the research community.
2. Implement a policy and process for monitoring all BPSU applications from initial enquiry to completed surveillance study, including the development of a new database to collate these data and to
  - a. create a minimum dataset for each completed study
  - b. provide a basis for archiving individual study information, including BPSU Phase 1 and Phase 2 application forms, PIAG and ethics applications
  - c. facilitate audit and monitoring of BPSU operations on a regular basis.
3. Review and update the current research and information governance arrangements within the BPSU, in the light of wider regulatory and ethical changes, to reflect its responsibilities with regard to confidentiality and data security.
4. Further develop the capacity for a 'rapid-response' to public health emergencies by ensuring that e-mail addresses are accurately held, and that there is provision for the addition of studies to the Orange Card at short notice.
5. Support investigators in publishing their studies in peer review journals and develop links with Press Offices in all partner organisations to publicise BPSU activities.
6. Review the application procedure, particularly to assess the timeliness of processes and the accessibility of current documentation for applicants.
7. Support good communications between the BPSU office and investigators by inviting all applicants to attend a meeting of the BPSU EC to discuss their proposal and encouraging them to have regular contact with the BPSU office and medical advisers during the application process.
8. Prioritise the development of a standardised format and layout for all questionnaires that could be used across different BPSU studies.
9. Maintain an active leadership and co-ordinating role within international (INoPSU) and UK surveillance unit networks to enhance collaborative and complementary surveillance activities.
10. Review the Sir Peter Tizard bursary award.



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