
Developing a national paediatric surveillance unit

General Principles

Engagement and support of the majority of paediatricians in a particular area it is absolutely essential for the establishment of the paediatric surveillance unit (PSU).

Surveillance research draws its strength from the commitment of participating paediatric community. Every report counts. Support of paediatricians and paediatric sub-specialists is crucial. They are the ones who fill the monthly card and complete the detailed questionnaire that enable researchers to gather the necessary information on rare diseases and conditions.

Support and collaboration from the College or national specialty society during the establishment of a new PSU is also highly recommended as their involvement engenders credibility amongst the community of paediatricians and researcher, Not only for supporting the infrastructure, but also for credibility amongst the community of paediatricians and researchers. Furthermore string links with a national speciality society and public health agent are necessary for infrastructure support, funding, dissemination of information about the PSU, and advocating for policy that may be supported by the study results.

To raise awareness and gain interest from paediatricians we recommend that the idea of a PSU is widely presented at conferences and meetings and the support from the national society or college is visible on these occasions. The usefulness of PSUs should be demonstrated by presenting information about the already successful PSUs around the world and the impacts they have had on policy and practice.

The activities of PSUs need to be monitored and principles of good governance need to be applied. Most of the PSU's have an Executive Committee, Steering Committee, Board or Advisory Committee. Whatever name is chosen, the committee will have a clear terms of reference and will consist of clinicians, epidemiologists and representatives of constituent institutions. Committees usually meet face-to-face on a regular (yearly/bi-yearly basis) to discuss new study proposals and administrative issues. Correspondence by email takes places during the year or some units prefer to use regular teleconferences.

Criteria and process for the evaluation of proposals suggesting conditions for surveillance should be set and made available to potential researchers and other participants. Usually conditions that are high in disability, morbidity, mortality and economic cost to society, despite their low frequency are studied by PSUs. Workload for participating paediatricians/sub-specialists must be taken into account when evaluating study proposals. Smaller units have by necessity included studies with conditions of higher incidence in order to collect enough data for meaningful analysis. A process for evaluating proposals must be established and usually consists of a review by the Steering Committee or a sub-committee with appropriate expertise.

Funding is required to support central coordination of the PSU. In some instances, costs are absorbed by the institutions where the PSU is sited and in other instances, funding is provided by the national public health agency. Not all the PSU's have or require full-time staff, however, a PSU cannot run efficiently without at least some dedicated support staff time. This is of utmost importance to keep paediatricians actively engaged - paediatricians who volunteer to participate soon lose interest if activities are run erratically or inefficiently. Costs of printing, postage, software and hardware and their maintenance, and costs for PSU accommodation must also be covered.

To run a PSU efficiently you will need to:

- Have engaged with paediatricians, have their Interest, good will and willingness to report and to provide information on the conditions under surveillance
- Have established governance structures and procedures, including regular review of these
- Maintain a current and accurate database of all paediatricians in active clinical practice in the jurisdiction who have elected to participate
- Coordinate the timely and efficient distribution of monthly surveillance cards or emails to paediatricians
- Have protocols and case definitions for a number of conditions before surveillance starts.
- Monitor response rates to the report cards. Most paediatricians will have nothing to report most of the time, however, a 'nil' response is extremely important and indicates that clinicians are actively engaged in identifying cases.
- Send appropriate questionnaires to participants and notify research teams when cases are identified and follow-up on any questionnaire not completed
- Promptly respond to general inquiries from participating paediatricians
- Provide support to researchers wanting to develop protocols for new conditions
- Disseminate information on the surveillance unit and study results via peer-review publications, presentations, annual reports and websites. Timely and wide dissemination of study results and recommendations is essential to demonstrate the value of a PSU.