



Suggestions for Establishing a National Paediatric Surveillance Unit

Some general principles

- 1. It is absolutely essential that the majority of paediatricians in a particular area support the establishment of a local surveillance unit.** The paediatricians are the surveillance unit. They are the ones who return the monthly cards (or e-mails). They also complete the questionnaires, and if they do not support the principle of having a surveillance unit, it will not function properly. The following are therefore essential:
 - There needs to be an up-to-date list of all paediatricians who are in established practice.
 - The surveillance card (e-mail) needs to get to each paediatrician in an efficient manner.
 - The conditions that are put on the card must be of interest to the paediatricians who are going to return the card/e-mail.
 - There should not be too many conditions under surveillance at any one time, which can be confusing.
 - The conditions have to be relatively rare. If paediatricians see one or two cases a year, they will be prepared to take part. If they have to report cases every month, and complete a questionnaire having sent back the surveillance card, fatigue will occur with subsequent loss of interest.
 - Some of the small units have, by necessity, included studies with conditions of higher incidence in order to collect enough data for meaningful analysis. You may like to discuss this further with certain of the unit coordinators.
 - It is essential that the paediatricians who fill in the card are informed about the results of the study.
- 2. There needs to be central coordination for the following activities:**
 - To maintain an up-to-date register of paediatricians together with a current address.
 - To send the monthly surveillance card to paediatricians.
 - To inform each surveillance group when a particular paediatrician has notified a case.
 - To monitor the response rate. Each surveillance card has a number of conditions that are under surveillance. If a paediatrician has seen a child with a condition under surveillance the paediatrician should pick the appropriate box on the card. However if no cases have been seen, it is equally important for paediatricians to return the card and indicate so.
- 3. The activities of the surveillance unit need to be monitored, and requests for new studies need to be considered.** Most surveillance units have established executive or steering committees who:
 - Ensure that program objectives are met.
 - Advise on organizational infrastructure and provide technical expertise.
 - Stimulate research into uncommon paediatric conditions.

- Review and evaluate study proposals for inclusion in the program.
 - Safeguard the interests of participants.
 - Review an annual summary of the activities of the program.
 - Promote and facilitate publication of research results from individual studies.
 - Promote the dissemination of study results for professional education and standard settings, as appropriate.
 - Promote the scientific excellence and public health relevance of studies and participate in ongoing evaluations of the overall program.
 - Support international collaboration with the International Network of Paediatric Surveillance Units (INoPSU).
- 4. Funding is necessary.** Not all the surveillance units have full-time staff or require them. However it is necessary to have a central office to send out cards (e-mails) and keep lists of paediatricians up-to-date. It is necessary to have a computer with appropriate software to keep records of compliance rates, etc. It is not reasonable to expect the unit to run efficiently without the support of some support staff.

Conclusion

This brief report gives some guidance, but obviously does not provide a detailed discussion about the organisation of a surveillance unit. Information on the methodology of the system is available on several of the INoPSU members' websites, as well as other useful information. It is also worth visiting the International Network of Paediatric Surveillance Units website (www.inopsu.com) where you will find details on the other existing units.

The most important point, however, is to obtain the support of the local paediatricians. While a College of Paediatrics can facilitate the activity, paediatricians must feel involved in the process.