The power of surveillance data to change Public Health Policy and practice in rare paediatric conditions

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Background

The field of rare disease epidemiology suffers from—a chronic lack of scientific knowledge and public awareness, especially when it comes to rare conditions in children. This knowledge gap is difficult to address by research undertaken on a national rather than a multi-national basis, because the number of children affected by single rare diseases in any one country is small.

In 1998 the International Network of Paediatric Surveillance Units (INOPSU) was formed to collaboratively research the epidemiology of rare childhood conditions.

Methods

Today, at least 13 countries from Europe, Australia and Canada are actively collecting epidemiological data on many rare diseases simultaneously under the umbrella of INOPSU. Those paediatric surveillance units (PSUs) collaborate by conducting similar studies in several countries, sharing protocols and data and publishing jointly. PSUs collect data through comprehensive national networks of paediatricians and/or paediatric clinics with high return rates (>80%). All use a similar surveillance method that applies active case finding and notification on a monthly or weekly basis, via an electronic or postal report card. Both, negative and positive reports are collected. Positive reports are followed by a specific questionnaire that asks for detailed demographic, epidemiological as well as diagnostics and clinical data.

This could be a place for your sources.

Results

Since 1998, the **INOPSU** has facilitated surveillance of over 200 rare paediatric conditions, including over 70 rare infections.

- By active surveillance of **acute flaccid paralysis**, PSUs can prove to WHO that their country is polio-free (all PSUs)
- Several countries have adopted **catch-up vaccinations for pertussis** in adolescents and persons with close contact to infants (Germany, New Zealand, the Netherlands, Switzerland).
- In response to the emerging Zika epidemic several countries rapidly implemented surveillance of congenital **Zika syndrome and microcephaly** (Australia, Canada, New Zealand, UK).

- The study of **haemolytic uremic syndrome** helped understand the variability in shiga-toxin producing serotypes across nations (Australia, Canada, Germany, New Zealand, Portugal, Switzerland, UK).
- Several countries revised guidelines for **toxoplasmosis screening** during pregnancy (Ireland, Switzerland, UK).
- Several countries have developed new screening policies for **invasive group B Streptococcal disease** (Canada, Germany, Netherlands, Portugal, UK)
- The surveillance of **neonatal herpes simplex virus** has demonstrated the need for an HSV1/HSV-2 effective vaccine (Australia, Canada, Switzerland, UK)

Conclusion

Studies performed under the umbrella of **INOPSU** have contributed significantly to the advancement of paediatric public health across the globe. Dozens of papers have been published in peer-reviewed journals and many national and international guidelines and recommendations cite them.

We welcome enquires from those who wish to join the INOPSU.

Selected publications:

Pinhas L, Nicholls D, Crosby RD, Morris A, Lynn RM, Madden. Classification of childhood onset eating disorders: A latent class analysis. *Int J Eat Disord*. 2017 Jun;50(6):657-664

Grenier D, Lynn R, Zurynski Y on behalf of all national paediatric surveillance unit investigators. Public health impacts of the International Network of Paediatric Surveillance Units. *Paediatr Child Health*. 2009; 4(8):499-500.

Grenier DJ Elliott, Y Zurynski, R Rodrigues Pereira, M Preece, R Lynn, R von Kries, H Zimmermann, N P Dickson, D Virella. Beyond Counting Numbers – Public Health Impact of Studies Conducted through National Paediatric Surveillance Units.. *Arch Dis Child Jun* 2007; 92:527-533 :

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