



*Collaborative research in
Australia*

RACP ASM 2004

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Why collaborate?

- Game theory
- Funding opportunities
- Sharing knowledge and skills
- To compete with the rest of the world

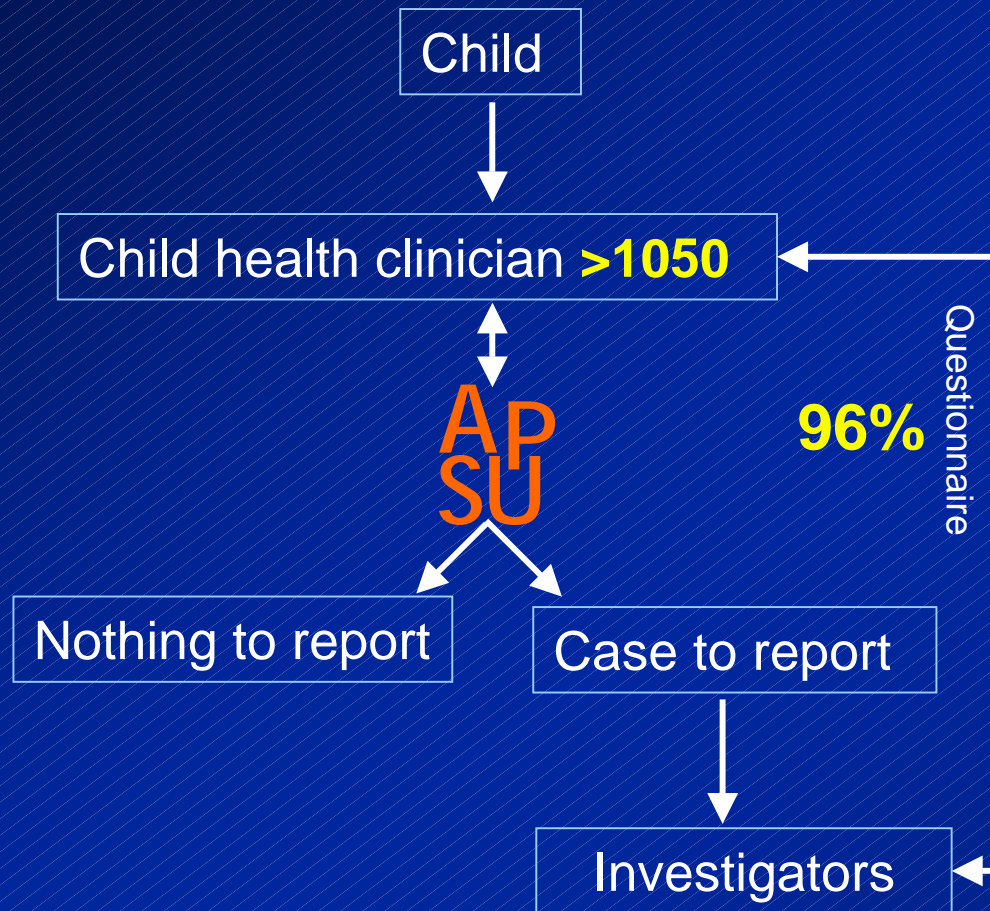
Examples

- The Australian Paediatric Surveillance Unit
- International Network of PSUs

The APSU: an example of collaboration

- Established May 1993
- Unit of the *Division of Paediatrics*, RACP
- Collects *national* epidemiological data
- *uncommon* childhood diseases
- Monthly reporting by all child health specialists

How the APSU works



PLEASE RETURN THIS CARD EVERY MONTH
EVEN IF YOU HAVE NOTHING TO REPORT

APSU REPORT CARD

MAY 2003

Dr's Code

NOTHING TO REPORT: (Please tick box)

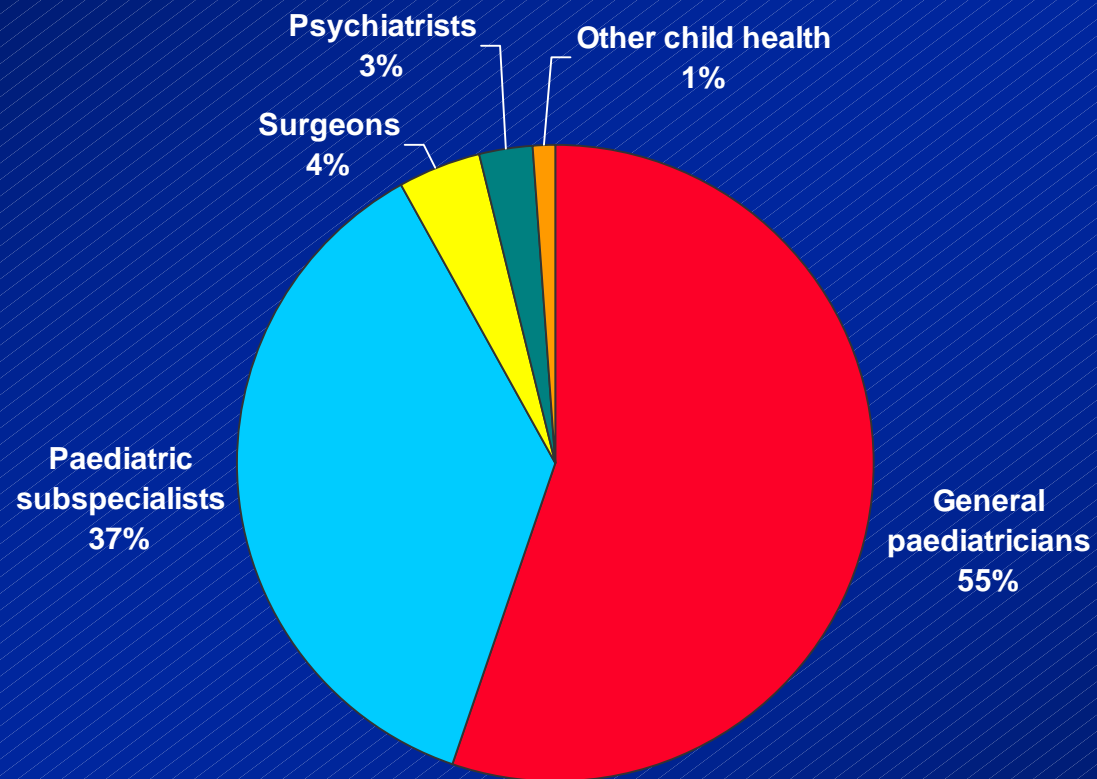
CASE TO REPORT: (Write no. of cases in space below)

- Hepatitis C virus infection
- Anaphylaxis following food ingestion
- Early onset eating disorder (hospitalised)
- Conversion disorder
- Fetal alcohol syndrome
- Adverse effects from complementary or alternative medicine
- Munchausen by proxy syndrome
- RETT syndrome
- Congenital cytomegalovirus infection[#]
- Neonatal herpes simplex virus infection
- Acute flaccid paralysis^{+#}
- HIV/AIDS/Perinatal exposure to HIV
- Vitamin K deficiency bleeding (includes haemorrhagic disease of the newborn)
- Congenital rubella

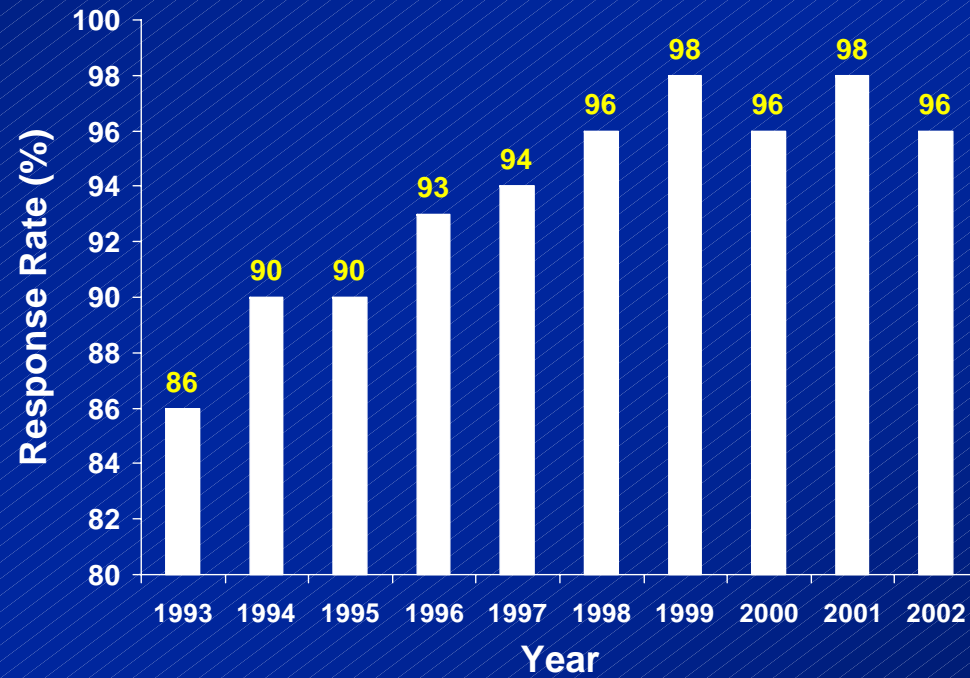
[#]See your protocol sheet for details regarding stool/serum specimens.
+Acute flaccid paralysis includes wild and vaccine acquired poliomyelitis, Guillain-Barre, transverse myelitis, traumatic paralysis etc. Please ALSO report cases of Acute flaccid paralysis immediately by telephone to the Polio Laboratory on (03) 9342 2607/3.

IF YOU REPORT A CASE PLEASE RECORD
PATIENT DETAILS IN YOUR BLUE APSU FOLDER
FOR LATER REFERENCE

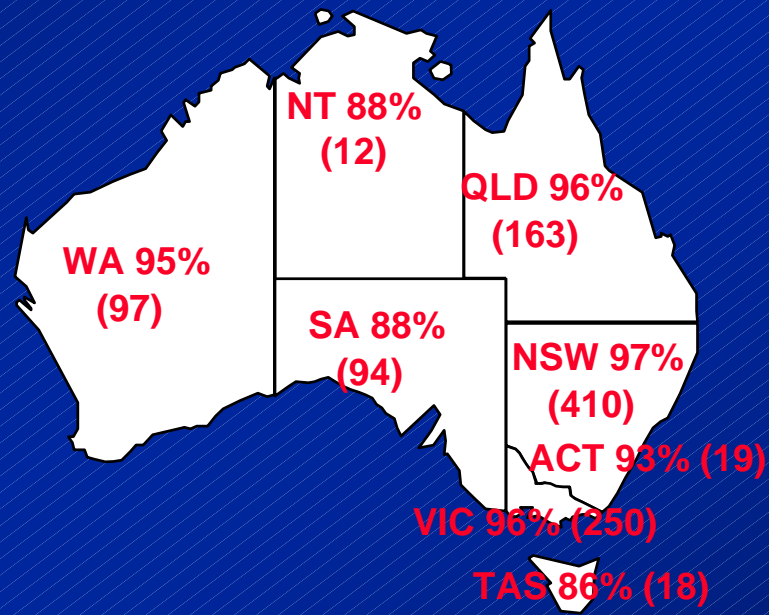
APSU Contributors, 2002



Annual return rate of monthly cards 1993-2002



Annual return rate distribution 2002



APSU Studies

- Infectious diseases
- Vaccine-preventable diseases
- Other preventable disorders
- Genetic disorders
- Birth defects
- Accidents and injuries
- Psychological disorders

>19 completed; 12 current

>150 investigators; > 100 publications

Collaborators

- National Centre in HIV Epidemiology and Clinical Research
- National Centre for Disease Control, DHFS
- National Enteric Pathogens Surveillance Lab, Melbourne
- National Centre for Immunisation Research
- National Perinatal Statistics Unit
- NSW Birth Defects Register
- Tropical Public Health Unit, Cairns
- SWS Area Health Authority
- International PSUs
- Australian Polio Expert Cttee
- AIHW
- Epidemiology Branch NSW Health Department
- WHO
- Telethon Institute for Child Health Research, WA
- ANZ Paediatric Nephrology Ass
- Australian Society of Clinical Immunology and Allergy
- Victorian Infectious Diseases Reference Laboratory
- CHARGE Association
- Rett Syndrome Association
- Centre for Prevention Psychological Problems in Children
- Oz Food Net

Australian paediatricians

International Network of Paediatric Surveillance Units

INQPSU



- 14 countries
- 56 million children < 15y
- ~10,000 paediatricians
- >200 studies

Why is the APSU needed ?

- uncommon disorders have huge impact
- *national data*
 - Low population, rare diseases, inand outpatients
 - Barriers include state/territory health, isolation
- *means* of standardised data collection
- mechanism for rapid surveillance
- mechanism for collaborative research
- enables participation of paediatricians
- educational resource
- information to guide practice, prevention, health resources
- catalyst for research

Acknowledgments

- Australian paediatricians
- Study investigators
- APSU Board & Scientific Review Panel
- Division of Paediatrics, RACP
- Dept Health and Ageing