Haemolytic Uremic Syndrome Surveillance to Monitor Trends in Infection with Shiga Toxin-Producing *E. coli* in France

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Background

- **Haemolytic uremic syndrome (HUS)**
  - Major cause of acute renal failure in children
  - More than 90% of HUS due to Shiga toxin–producing *E. coli* (STEC) infection
- **Since 1996, paediatric HUS surveillance in France**
  - Measure HUS incidence
  - Describe HUS cases
  - Determine proportion of HUS associated with STEC
  - Detect clusters of HUS and clusters of HUS and diarrhoea
- **Case definitions**
  - HUS: laboratory confirmed haemolytic anaemia and renal insufficiency
  - STEC infection: culture, PCR or serology positive for STEC
- **System currently only tool to monitor STEC infection trends in France and never been evaluated**

Structure and operation of paediatric HUS surveillance in France
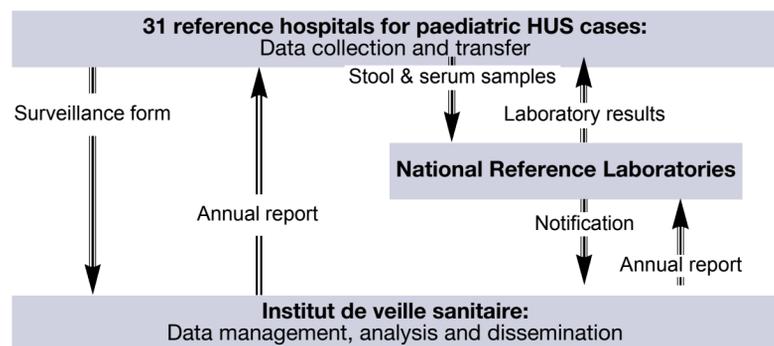
Objectives

- **To evaluate the HUS surveillance system's**
  - Performance as a tool to monitor STEC infection trends
  - Capacity to detect clusters of cases
- **In order to assess achievability of these surveillance objectives and to identify ways to improve the system**

Methods

- **Using US CDC guidelines, system's attributes selected for evaluation**
  - Data quality
  - Sensitivity
  - Representativeness
  - Timeliness
- **Data sources used in evaluation**
  - HUS surveillance database 1996-2003
  - Postal survey of 31 surveillance network hospitals
  - Postal survey of 260 other hospitals potentially receiving paediatric HUS cases in 2002-2003
- **Measures of system performance**
  - Data quality: completeness of 13 key variables in database (3 clinical, 5 laboratory and 5 epidemiological variables)
  - Sensitivity: number of cases notified by the surveillance out of total number of cases estimated in France, 2002-2003
  - Representativeness: geographical distribution of surveillance network hospitals and other hospitals receiving HUS cases
  - Timeliness: time interval between diagnosis and notification

Results

- **HUS surveillance data 1996-2003**
  - Total of 623 HUS cases recorded in surveillance database
  - Annual paediatric HUS incidence < 1/10^5 with STEC infection confirmed for 55% of the cases in France
  - Surveillance detected 15 clusters, of which common source identified for 2:
    - In 2000, 1 HUS and 10 diarrhoea cases linked to consumption of poorly grilled merguez sausages
    - In 2002, 2 HUS cases linked to contact with farm animals

Data quality based on completeness of 13 variables recorded in HUS surveillance database (N=623), 1996-2003

Variable	% of filled responses
Diarrhoea in the weeks prior to HUS	100
Date of diagnosis	100
Date of discharge from hospital	86
Haemoglobin	97
Schizocytosis	86
Blood platelets	97
Creatinine	95
Results of first serology	88
Contact with a patient with HUS	98
Contact with a household member with diarrhoea	94
Consumption of non-pasteurised dairy products	92
Consumption of minced beef	89
Contact with farm animals	89

Number of paediatric HUS cases and sensitivity of the paediatric HUS surveillance system in France, 2002-2003

| Number of paediatric HUS cases	2002	2003
A. Cases notified by the surveillance hospitals	70	90
B. Cases found exclusively in other hospitals	33	30
C. Estimated number of cases not notified	43	39
D. Estimated total number of cases in France	113	129
E. Sensitivity of paediatric HUS surveillance	**62%**	**70%**
95% confidence interval	52-71	61-77

A. Figures obtained from surveillance database.

B. Bases on survey of 260 other hospitals potentially receiving HUS cases. Cases eventually referred to surveillance hospitals (duplicates) were excluded from these figures.

C. Estimated using formula B/C=199/260, where 199 was number of hospitals responded to the survey and 260 total number of hospitals potentially receiving HUS cases in France excluding 31 surveillance hospitals.
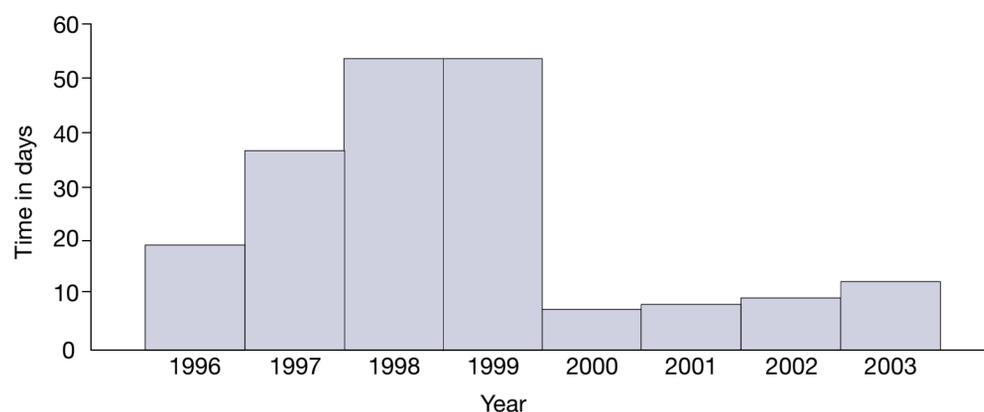
D. D = A+C

E. E = A/D

Geographical distribution of surveillance network hospitals and other hospitals potentially receiving HUS cases

Legend
- ▲ 31 network hospitals
- ● 73 hospitals with at least 1 case
- ● 126 hospitals with no cases
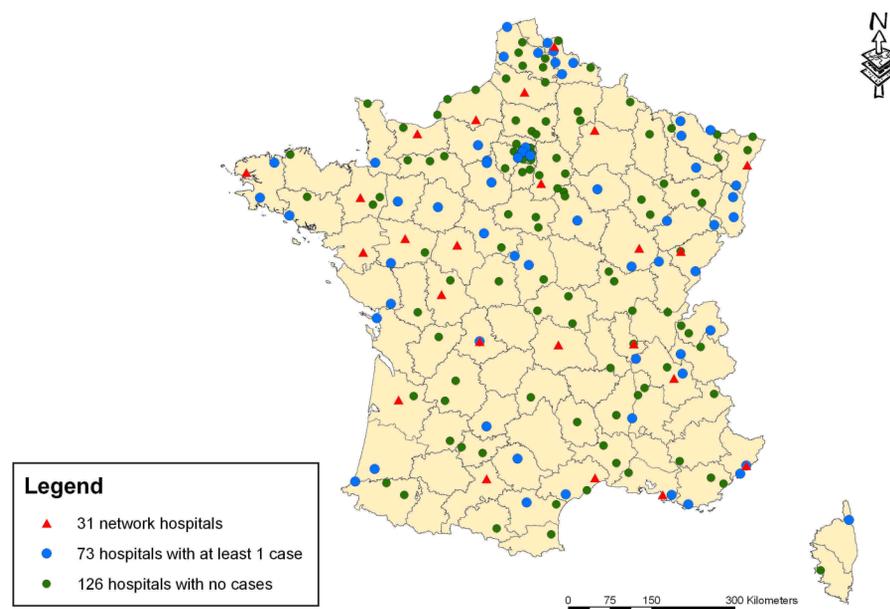
Median time interval between diagnosis and notification according to HUS surveillance database 1996-2003

Conclusion

- Paediatric HUS surveillance is a functional system to monitor STEC infection trends in France
- Surveillance data is of high quality; system's sensitivity and representativeness are appropriate for the surveillance objective of monitoring STEC infection trends
- As notification delay been shortened, the system's capacity to detect clusters of cases has improved in recent years

Recommendations

- Paediatric HUS surveillance should be continued in France
- To improve sensitivity and representativeness, the system can be expanded to other hospitals potentially receiving HUS cases
- To further improve timeliness and capacity to detect clusters of cases, an early notification procedure is recommended