



The impact of the Confidential Inquiry into premature deaths of people with ID in England (CIPOLD)

Professor Pauline Heslop
University of Bristol



What I will cover

- CIPOLD
- Measuring impact
- Impact on those reviewing deaths
- Impact nationally
- New national ID mortality review



🌟 What is a Confidential Inquiry?

Key features:

- A focused review of a particular issue
- The details of each incident are critically, independently and anonymously reviewed by a team of experts
- They are “confidential” in that details of the patients/cases remain anonymous, though reports of overall findings are published
- Their overall aim is to detect areas requiring improvement and devise recommendations to resolve them

🌟 What did we do?



We reviewed :

- All known deaths of people with ID
- In a region of SW England with a general population of 1.7m
- Deaths occurred between 1st June 2010 – 31st May 2012

233 adults with ID

14 children with ID

58 comparator cases

✦ What did we find out?

- Deaths of people with ID at significantly younger ages than the general population
- A significant burden of avoidable deaths

Preventable mortality

All or most deaths from that cause could be avoided by public health interventions in the broadest sense.

21% (all)

21% (ID)

Amenable mortality:

All or most deaths from that cause could be avoided through good quality healthcare.

13% (all)

36.5% (ID)

✦ Confidential Inquiry and change

We sought to assess:

- ✓ Impact on practitioners participating in the process
- ✓ Impact of the wider adoption of recommendations arising from the Inquiry findings

🌟 Monitoring the impact of the work

Formal feedback a few weeks after involvement (practitioners, families, panel members)

National 'roadshow'

'Linked-In' web group

One year after the Inquiry, participants asked to report actions taken in response to CIPOLD

Government response and action plan, and ongoing engagement at policy level

Review of policy and associated documents

🌟 Impact on practitioners participating

- Better understanding and adherence to relevant existing legislation and guidance
- Increased awareness of multi-disciplinary colleagues and their roles – and developed improved ways of working together
- Enhanced holistic approach



✦ Impact on practitioners participating

- Improved accuracy and completeness of documentation
- A focus on joint decision-making, and less of a tendency to make decisions in isolation
- Training needs identified and met
- Recognition of gaps in our knowledge about people with ID at strategic level



✦ Impact of the adoption of recommendations - national level

- GP registers of people with ID expanded to be all age registers
- Annual health checks for people with ID now include 14-17 year olds
- Changes in the national flu immunisation plan – now more specific about targeting people with ID for immunisation
- New questions used at Care Quality Commission inspections of acute hospitals, specifically about care of people with ID

🌟 National ID mortality review programme

Key aims of the programme

- To drive improvement in the quality of health and social care service delivery for people with ID
- To help reduce premature mortality and health inequalities in this population

🌟 Key elements of the programme



- Support local areas to conduct standardised reviews of deaths of all people with ID
- Provide training and quality surveillance function
- Check that resulting action plans are followed up and improvements made to practice
- Analyse and report national data and trends, including through data linkage

Contact details

- Pauline.Heslop@bristol.ac.uk
- +44 (0) 117 331 0973
- www.bristol.ac.uk/sps/LeDeR