

Confidential Inquiry into the Deaths of People with Learning Disabilities 2010 - 2013

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What we will talk about today.

- Why the Confidential Inquiry was set up.
- The process of the Confidential Inquiry, with a specific focus on the role of the Learning Disability Nurse.
- Some of the key findings from the first year of the Confidential Inquiry.
- What will happen in the next two years .



Why was the Confidential Inquiry set up?

- Valuing People (2001) *“increased illness and premature death is a major cause of concern...explore feasibility of establishing a Confidential Inquiry”*
- MENCAP Treat me Right (2004) Death by Indifference (2007).. *“confidential inquiry required”*
- Equal Treatment: Closing the Gap (DRC 2006) *“..not acceptable that people with LD die younger”*
- Healthcare for All (Jonathan Michael 2008) *“...highly likely that deaths occurring could be avoided “*



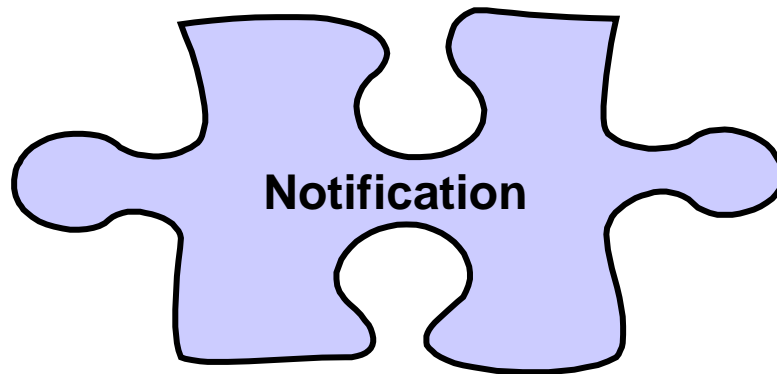
The Six Key Aims of the CI

- To detect potentially avoidable and modifiable contributory factors in the care of anyone with a learning disability over the age of 4 years, who has died
- To identify inadequate care pathways or treatment gaps
- To contribute to the evidence base of best clinical and professional practice
- To gather information to guide the commissioning of services
- To establish a usable system for reporting the deaths of people with LD that can be replicated
- To improve the standard and quality of care for people with LD and ultimately their health outcomes.



🔥 Process of the Confidential Inquiry

Step 1: Being notified of a death



- Notification of a death by anyone, by contacting the CI team at NFRC.
- Death is logged
- Checks to ensure the criteria for inclusion in the CI are met
- Start to identify all the relevant agencies and individuals that were involved in supporting the person

Case Study: Notification of James's death

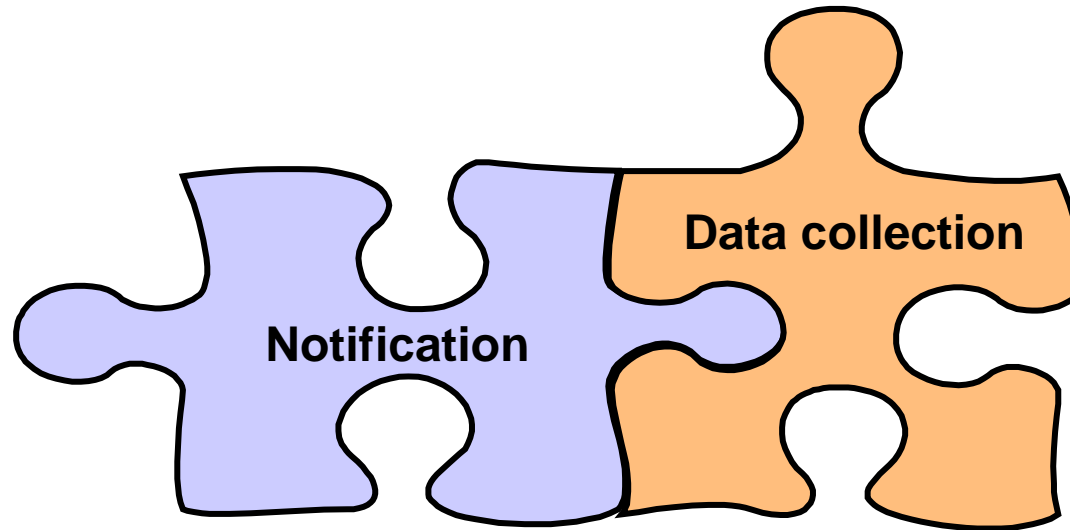
James was 26 years old when he died in hospital

- His death was reported to the CI team by:
 - the bereavement office at the hospital
 - the administrator at his local CLDT

They were able to tell the CI where James lived and who his GP was.



🔥 Step 2: The collection of core information



Core data collection forms sent to:

- GP
- Residential care home
- Hospital staff (including LD liaison nurse)
- The people at the CLDT who had worked with him

Case Study: Collection of information about James

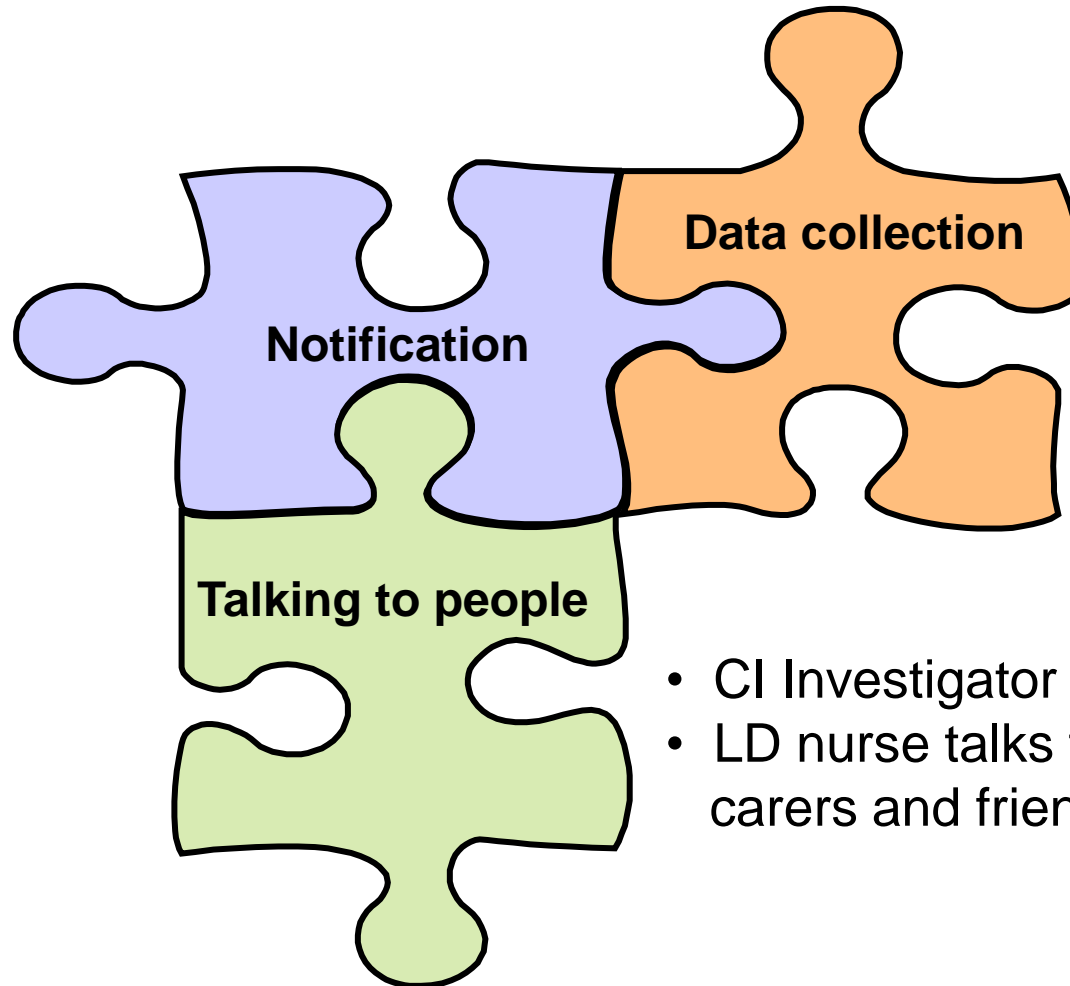
In James' case we sent out forms to his:

- GP
- Residential care home
- Staff at the hospital (including the LD liaison nurse)
- The people at the CLDT who had worked with him

The forms told us that James had severe learning disabilities. He was admitted to hospital with aspiration pneumonia and died two days after going into hospital.



🔥 Step 3: Talking to people



- CI Investigator talks to paid carers
- LD nurse talks to families, informal carers and friends

Case study: Talking to people about James

Residential care home:

- James had moved there about 5 years ago. Before that he had lived with his family.
- He used a wheel chair and had a windswept body shape.
- He was supported by the CLDT Physiotherapist

GP:

- James had a history of numerous chest infections and pneumonia.
- A best interests meeting for James agreed that James needed a PEG, but 3 months after this meeting this had still not happened.

Talking to the family

- A team of learning disability nurses are employed to talk to and support family members and close friends (including other people with learning disabilities)

The purpose of the family interview/s is to

- To allow family members to discuss the deceased
- To create a picture of the persons life
- To establish what happened when the person died
- Highlight any significant events
- Highlight good practice



Why LD Nurses?

- Good understanding of Learning Disability and related conditions.
- Respect for and experience of working with family carers/people with LD.
- Good skills in assessment/advocacy.
- Person centred approach to work
- Good communication/listening skills
- Knowledge of services/good networking.



Family Interview Process

- James family request involvement in CI.
- A nurse is allocated
- The nurse makes contact with his parents
- Arrange a time and place to meet
- Nurse talks to the investigator to understand the general picture and any specific information required.
- At visit inform parents of process and gain consent for interview/audio recording.



Family Interview process

- Information gathered using open questions
- Further visit/s arranged, if required.
- Return recording/written notes to CI office for transcription. All identifiers removed.
- Feedback family interview with investigator
- Attend local review panel (LRP)
- Feedback outcomes of LRP to the family



Role of nurse at family interview

- Clarify information about James
- Answer any questions which arise
- Listen
- Reassure
- Signpost to other services - Counselling
- Inform what will happen next
- Documents photos have been given

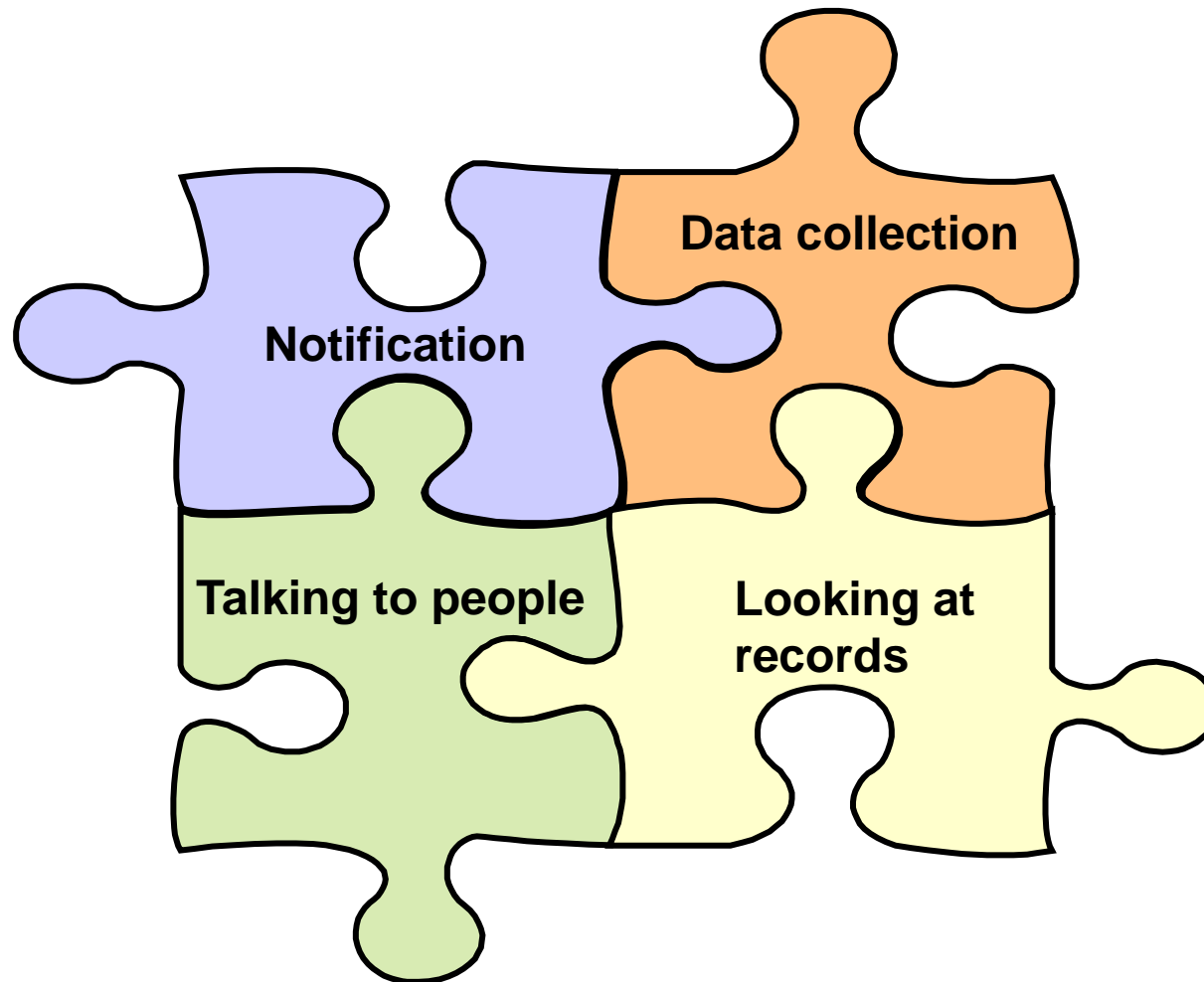


Case Study: Family feedback on James

- Welcome opportunity to talk about their son
- Guilt – could they have done anything else?
- Highlight the care James had been given
- Frustration with local mainstream services. No access to postural care in childhood.
- Support from LD Liaison Nurse was good
- Felt that James death was premature
- Feeling guilty as they were not there when he died



🔥 Step 4: Looking at records



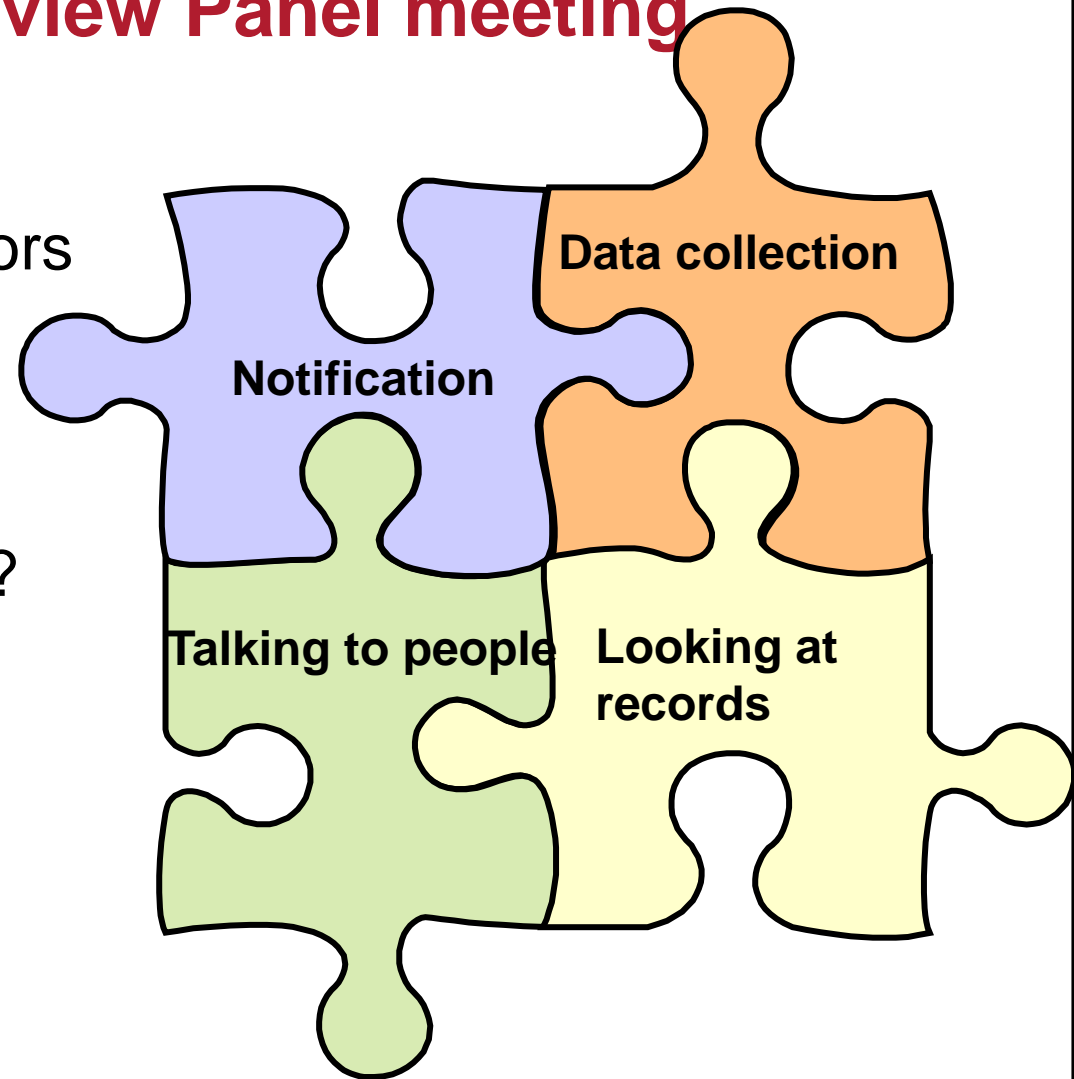
Case Study: Looking at records – what we found out about James

The CI Investigator looked at the GP practice, hospital and care home notes for James

- There was no monitoring of his fluid intake
- His weight was only occasionally recorded
- The hospital records showed someone had signed a DNAR order but there was no evidence of any discussion with the people who knew James well
- No information from the care home appeared to have been sent to the hospital with James when he was admitted

🔥 Step 5: The Local Review Panel meeting

- Potentially modifiable factors in relation to the death
- Was the death expected?
- Was the death premature?
- Good practice
- Learning points
- Recommendations



Case Study: James's Local Review Panel meeting

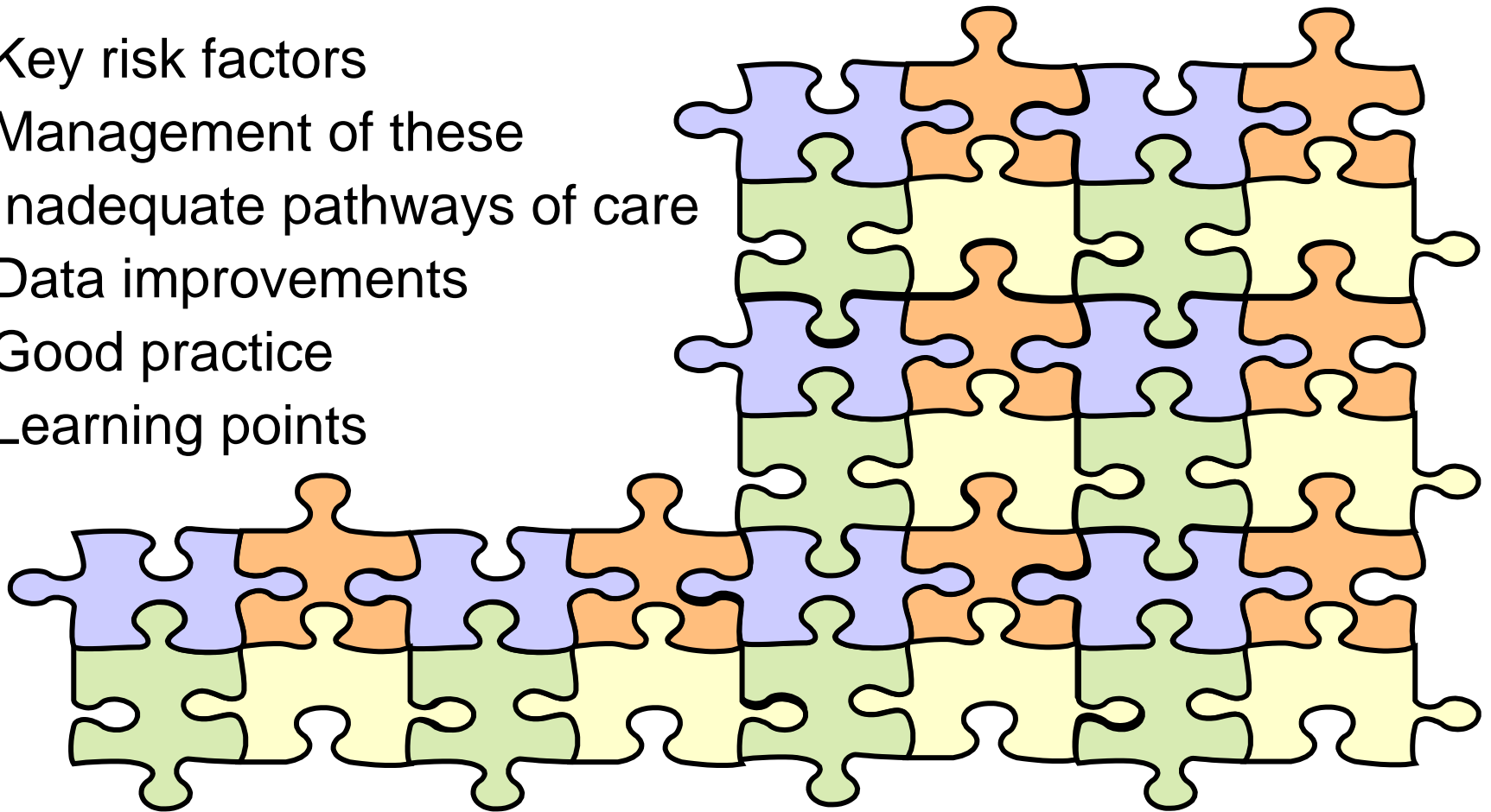
The LRP meeting was held at the GP surgery. It was attended by: Manager of care home, GP, Speech and Language Therapist, Physiotherapist. No-one from the hospital attended

Panel concluded that

- **James's death was expected but his death was premature**
- **Good practice noted(Best Interest Meeting, Hosp LD Liaison Nurse)**
- **There were potentially modifiable factors associated with his death**
- **Some learning points were highlighted (postural support in children)**
- **Some recommendations were made (monitoring those on waiting lists, DNAR recording)**

🔥 Step 6: Overview Panel

- Key risk factors
- Management of these
- Inadequate pathways of care
- Data improvements
- Good practice
- Learning points



The Overview Panel that considered James's death

- Multidisciplinary team
- The Panel agreed with the findings of the Investigation and the Local Review Panel meeting
- In addition, the Panel thought that it would have been good if there had been advance care planning for James
- This would have identified the support he needed in hospital and would have provided an opportunity for a discussion about James' DNAR status

Outcomes from Year One

Number of deaths reported	118
Number of cases completed	57
Number of current (open) investigations	61
Number of nurse team requests	31



Update on progress

	Bristol (430,000)	Glos (600,000)	South Glos (258,000)	North Somerset (207,000)	Bath and NE Somerset (180,000)
Number of deaths	43	36	11	15	13
Average age at death	61 (4-92)	54.5 (23-84)	64 (52-94)	69 (57-83)	40 (12-80)
Number of referrals per death	2.0	2.0	1.9	1.6	1.6



Some findings from preliminary analysis

- A large proportion of people were either underweight or overweight/obese
- A third of people had lived in a long-term institution in the past, usually for many years
- Just under a half of people had severe or profound learning disabilities, and a third had mild or mild/moderate learning disabilities
- Most received support 24 hours a day provided by a paid carer or family member(s)
- Age was not found to be a factor in whether the death was considered to be premature or not.



What's next?

- CI to continue until March 2013
- Matched comparator group of deaths from the general population to be introduced.
- Individual feedback to safeguarding leads.
- Increase focus on communication with minority ethnic groups
- Results from all investigations to be collated, analysed and a report for DoH



Confidential Inquiry into the deaths of people with learning disabilities

For further information:

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Website: www.bris.ac.uk/cipold/

