Public Health England

Public Health England: Progress report

Gyles Glover
Learning Disabilities Health Intelligence Network

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What the LD Intelligence Network is doing

- Searching for evidence of what works.
  - Systematic review
  - Effectiveness of interventions
  - For conditions associated with excess mortality
  - In people with LD
- Working on how to get proper mortality monitoring

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Getting better data for the whole country

Chapter summary

The key recommendations from the CIPOLD review of deaths are:

1 Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.

2 Reasonable adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.

3 NICE Guidelines to take into account multi-morbidity.

4 A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.

5 Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions.

6 Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.

7 People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.

8 Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services.

9 Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.

10 Mental Capacity Act advice to be easily available 24 hours a day.

11 The definition of Serious Medical Treatment and what this means in practice to be clarified.

12 Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.

13 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England.

14 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change.

15 All decisions that a person with learning disabilities is to receive palliative care only to be [illegible] and the person referred to a specialist palliative care team.

16 Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.

17 Systems to be put in place to ensure that local learning disability mortality data is analysed and published on [illegible] Strategy.

18 A National Learning Disability Mortality Review Body to be established.

108 Confidential Inquiry into premature deaths of people with learning disabilities

of the Mental Capacity Act and the person referred to a specialist palliative care team.

16 Improved systems to be put in place nationally for the collection of standardised mortality data about people with learning disabilities.

17 Systems to be put in place to ensure that local learning disability mortality data is

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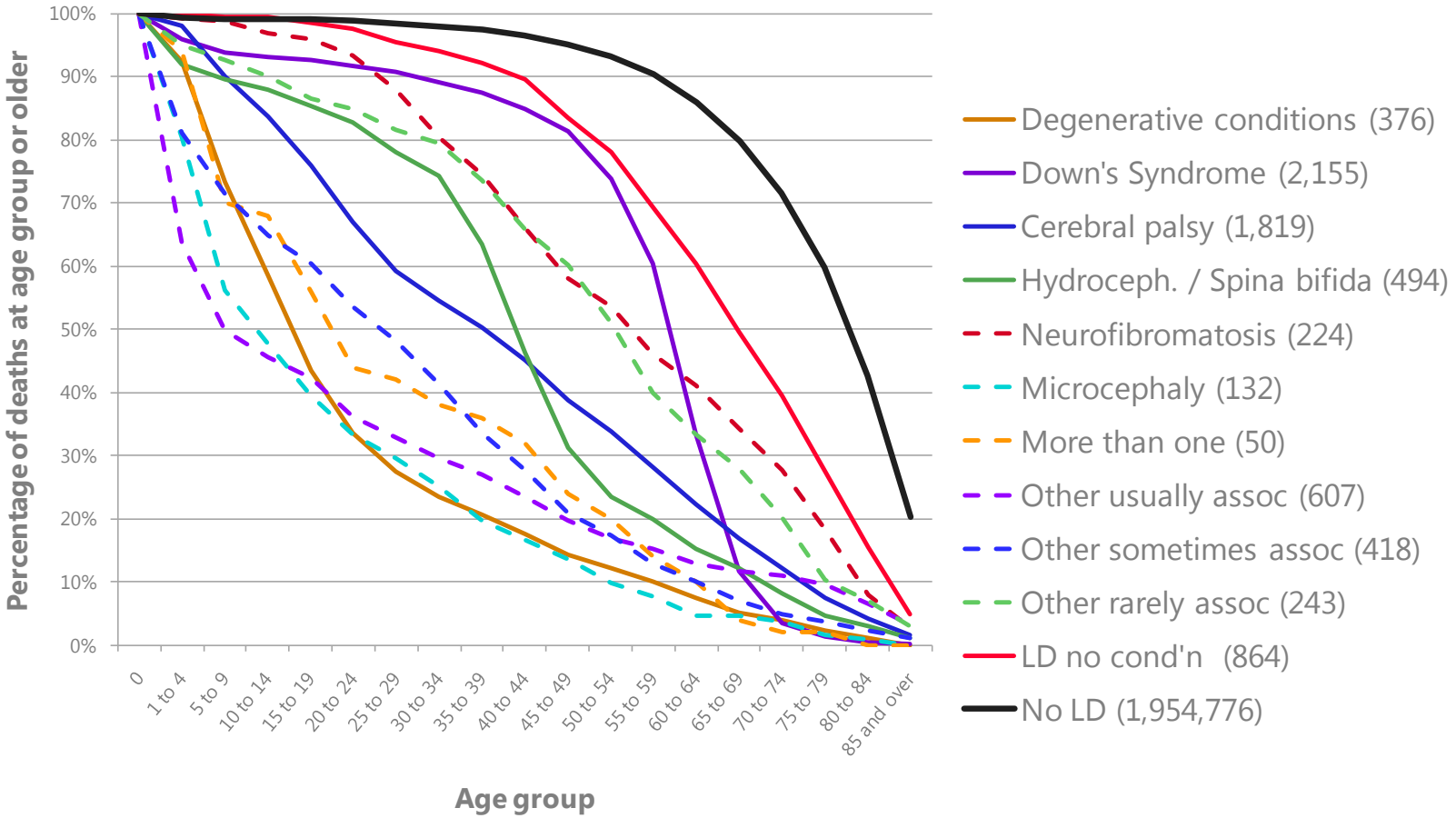
National data can show important trends

Profile of ages at death



National death certification data – 5 years

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The Challenge

- Death certificates alone not enough
  - Most don't identify the person as having a LD
  - NOT bad recording – the certificate doesn't ask
  - Need to identify all death certificates where deceased had a LD
  - Also need to know population to which they relate
  - Need to allow for different age / sex pattern for people with LD
  - Comparison to mortality in local area

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GP learning disability registers

- Should include all adults known to GPs to have LD
- Regularly maintained
- Used for DES Health Checks
- Identify population numbers for registers (206,132 is latest total)
- Identify all deaths where deceased is on register

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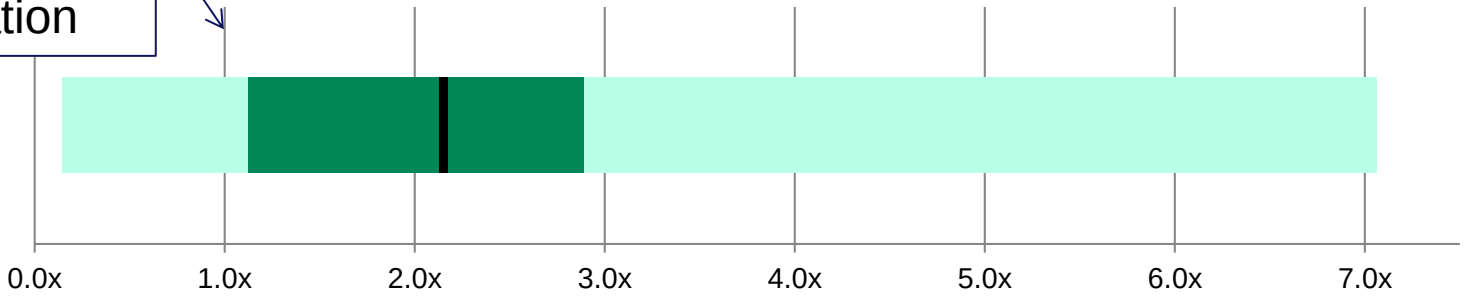
2013 Self Assessment Framework Local SMR estimates

1.0x means same as general population

Range of estimates of adult SMR
66 local PB areas with usable data - 37% of population, JHSCSAF 2013



Local areas asked:

- Numbers with LD by broad age bands
- Numbers of deaths of people with LD – same age bands
- Compared with population and mortality statistics for same areas

Median: 2.2x

Inter-quartile range: 1.1– 2.9

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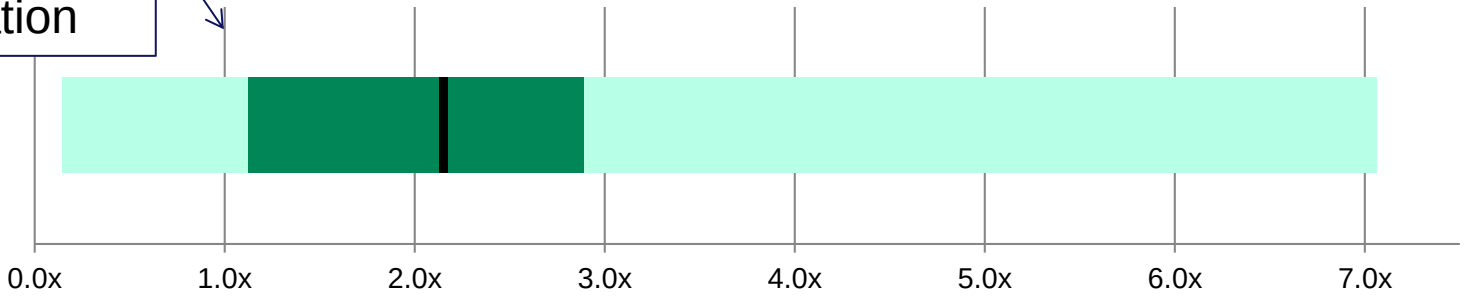

Deaths of people with LD compared with expected from local age/specific death rates

Problems with this:

- Lot of work locally
- More than half country couldn't do it
- Low values probably mean missing mortality data – so how accurate are the rest?

Median: 2.2x

Inter-quartile range: 1.1– 2.9

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Planned solution

- National collection of data from GP practice records
- System already exists (used for GP bonus payments)
- Linkage to Death certificates by Health and Social Care Information System
- Analysis should allow
  - All-causes SMR for most local authorities
  - Cause specific – regions or national

hscic Health & Social Care Information Centre

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When?

- Complex technically and for Information Governance
- Date uncertain. Possibly late 2014

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