



Palliative care for people with intellectual disabilities in England: How much happens, how much is needed?

Gyles Glover – gyles.glover@phe.gov.uk, Julia Verne (Presenting) – julia.verne@phe.gov.uk
Learning Disabilities Observatory, Public Health England

INTRODUCTION

Providing any sort of clinical care for people with intellectual disabilities (ID) raises key challenges in relation to communication, understanding and consent. These are outlined below. Palliative care involves important choices both about treatment strategies and about the current success, for example of pain management.

Staff facing these challenges should have adequate training and resources. To understand the scale of this task it is essential to know how many people with ID are likely to receive palliative care in any given period.

This study used a national collection of data from general practitioner (GP) case notes in almost all parts of England to establish the rates of receiving palliative for people with and without identified ID, by age-group, gender and health administrative area (Clinical Commissioning Group or CCG) of GP registration.(NHS Digital 2016)

Key challenges

- Communication: People with severe or profound ID may have little or no spoken language. Some communicate to a limited extent by signing. Those with mild to moderate ID are likely to have limited complex or technical vocabulary.
- Understanding: People with severe or profound ID are likely to understand little or nothing about terminal illnesses or conditions but they will understand pain or discomfort. Those with mild to moderate are likely to understanding dying, illnesses and treatment. The complexity of treatment

choices may be harder but many are likely to be able make choices if helped carefully but may need well prepared information.

- Consent: English law requires that a persons capacity to consent, for example to treatments, is reviewed in relation to each specific decision. Staff must try as hard as is realistic to help them understand so they can make their own choice.

METHODS

Automated data collection from GP record systems by the NHS statistics agency NHS Digital using the system for collection of GP statistical and payment data (the General Practice Extraction service – GPES).

Definitions of ID and palliative care followed those designed for a national quality incentive payment system, the Quality and Outcomes Framework (QOF).

Practice level data were collated and aggregated to CCG level by NHS Digital. A data file of results at this level is publicly available.

All NHS practices were invited but not required to participate. Technical and ethical approval was obtained from the Independent Advisory Group overseeing GPES.

Data processing was done in Microsoft Access and Excel. Confidence intervals for rates used Wilson's method for proportions, as numerators were subsets of denominators. Age adjusted comparisons used indirectly standardised prevalence ratios (SPRs) with national general population rates as reference and using Byar confidence intervals for observed case numbers. (Eayres, 2008)

RESULTS

Data were obtained from 49.9% of 7,889 general practices covering 28.96 million patients, 50.9% of the national total. 27,351 (4.4 per 1000) were recorded as having ID. The proportion of practices covered varied between CCG areas with 50% of practices or more reporting in 57% of CCGs and 25% or more in 72%. No data were obtained from 19% of CCGs. The greatest amount of data loss was because the second largest information system company asked an unrealistically and unaffordably high price for processing the data.

Table 1 shows crude rates (per 1000 pop.) of receiving palliative care as recorded by GP, age/sex standardised prevalence ratios (SPRs) comparing rates in people with and without ID and the numbers of cases identified (95% confidence intervals in brackets). The final row shows the anticipated annual number of people likely to receive palliative care in 250k total population.

Figure 1 shows the age profile of cases with and without ID. 11% of those with ID receiving

Table 1. See text for description

	With ID	Without ID
Crude rates	5.51 (5.11 to 5.94)	2.99 (2.97 to 3.01)
SPR	3.34 (3.10 to 3.60)	0.99 (0.99 to 1.00)
Numbers	702	86,330
Expected deaths in 250k total population	6	745

palliative care were aged under 18, 37% were aged 65 or older. Comparable figures for those without ID were 1% and 79%.

Figure 2 shows the variation in rates between CCG areas for people with and without ID; standardised prevalence ratios were used to allow for population age/sex differences. The range of SPRs between areas for people with ID was much greater than for those without. Due to small expected numbers no statistically significantly low figures were observed in this group.

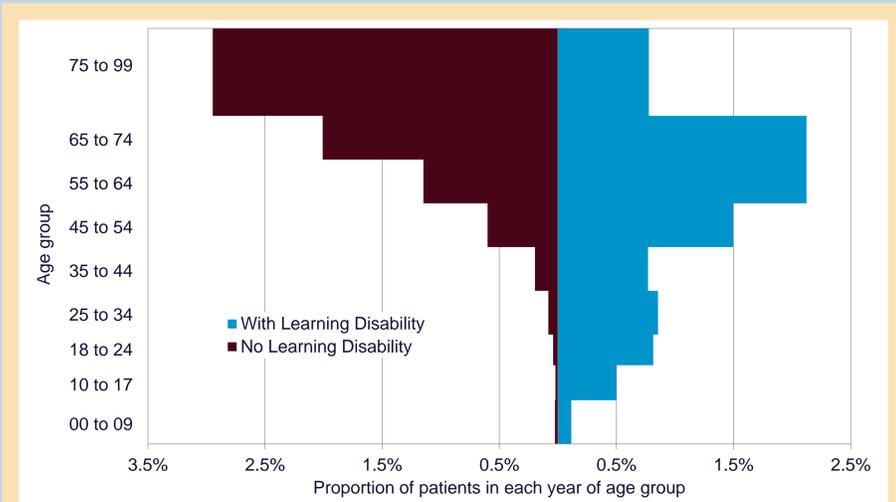


Figure 1. Age profile of cases with and without ID. Histograms show average proportion of patients in each year of age group.

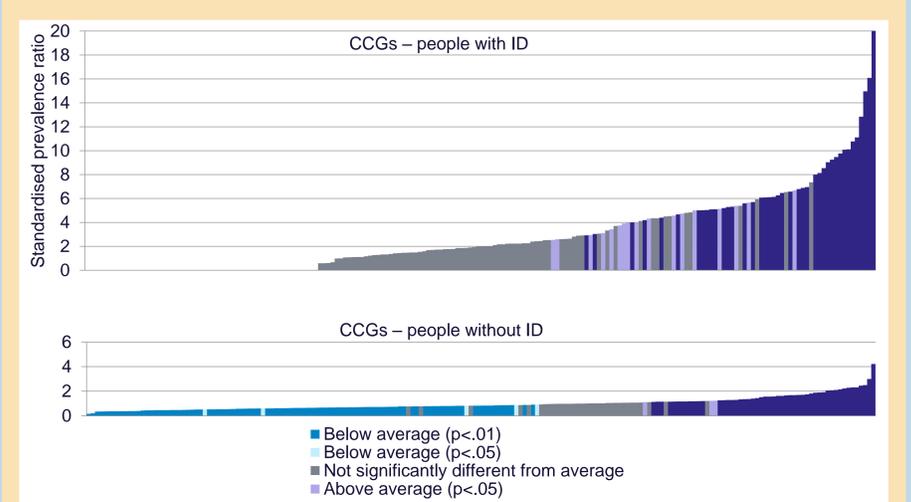


Figure 2. Variations in prevalence of palliative care between clinical commissioning group (CCG) areas. One column for each, ordered by standardised prevalence ratio. Shading shows significance of difference from national average

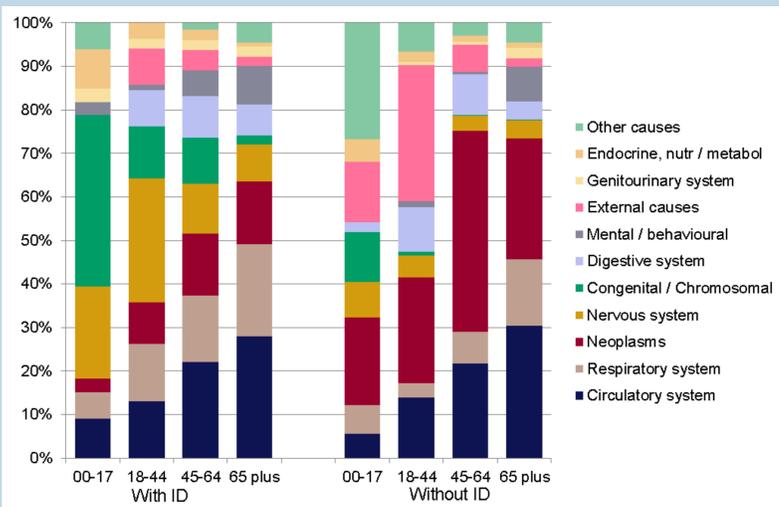


Figure 3. Causes of death

DISCUSSION

GP case notes probably provide the most comprehensive picture of people receiving palliative care in England. The rates of people with ID receiving palliative care are higher than those for people without ID. Comparison to crude mortality rates reported by Glover et al (2017) indicate that these numbers represent just over half of those with ID and just under one third of those without ID who die each year. The same study suggests that the profile of causes of death is likely to be different with fewer dying of malignant neoplasms and more dying from congenital and chromosomal and from neurological disorders.

The large variation between areas suggests that the extent to which the end of life care needs are recognised and provided for probably differs considerably between areas, possibly as a result of the work of local champions. If this is right it suggests that overall there is greater need among people with ID than these data for met need indicate.

CONCLUSIONS

- People with ID receive palliative care from GPs at higher rates and much younger ages than people without ID.
- The cause of death (figure 3) for people with ID are different from those without.
- Rates vary substantially between areas suggesting extensive unmet need in some places.
- These findings indicate that local service planners need to ensure that at least some palliative care professional sin all areas are appropriately trained and resources to work with people with ID.

REFERENCES

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CONFLICTS OF INTEREST - NONE

ACKNOWLEDGEMENTS

For more information on the Learning Disability Observatory: <http://www.improvinghealthandlives.org.uk/>