The Cambridge cohort of open spina bifida-README.docx was generated on 2021-05-19 by Prof Pippa Oakeshott

1. Title of Dataset: The Cambridge cohort of open spina bifida

The dataset comprises nine reviews of 117 consecutive infants (50 male) born in 1963-1971 with open spina bifida and treated unselectively within 48 hours of birth at Addenbrooke’s Hospital, Cambridge, UK. The earlier reviews were conducted at home and school at the mean ages of 4 and 9 years and included clinical examination. Later reviews were based mainly on questionnaires (completed by patients and/or carers) and clinical records. (Please see table below.) The Office for National Statistics provided information on deaths to August 2017. The cohort is unique in having information from detailed neurological examination at birth and 99% follow up to the mean age of 50 years.

2. Author Information

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3. Date of data collection: 1971 to 2017

|  |  |  |  |
| --- | --- | --- | --- |
| Review number | Year conducted | Mean age  of cohort | Publication (s) reporting this review |
| 1 | 1971 | 4 | BMJ 1973 (1) and Lancet 1973 (2) |
| 2 | 1976 | 9 | DMCN 1981 (3) |
| 3 | 1985 | 18 | DMCN 1990 (4) |
| 4 | 1992 | 25 | DMCN 1995 (5) |
| 5 | 1997 | 30 | BJGP 2003 (6) and JNNP 1999 (12) |
| 6 | 2002 | 35 | BMJ 2003 (7) |
| 7 | 2007 | 40 | DMCN 2010 (8) |
| 8 | 2012 | 45 | DMCN 2015 (9) |
| 9 | 2017 | 50 | DMCN 2019 (10) |

4. Geographic location of data collection:

All subjects were assessed and treated at birth at Addenbrooke’s Hospital, Cambridge. They were followed up from this site and later from St George’s, University of London.

5. Information about funding sources that supported the collection of the data:

Medical Research Council, East Anglian Regional Health Authority, Association for Spina Bifida and Hydrocephalus, Newlife Foundation for Disabled Children.

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Selected publications that cite or use the data:

**Nine reviews of the cohort**1-10

(1) Hunt GM, Lewin L, Gleave J, Gairdner D. Predictive factors in open myelomeningocele with special reference to sensory level. *BMJ* 1973; 4:187-201.

(2) Hunt GM. Implications of the treatment of myelomeningocele for the child and his family. *Lancet* 1973; 2:1308-1310. (This adds further details to reference 1.)

(3) Hunt GM. Spina bifida: implications for 100 children at school. *Dev Med Child Neurol* 1981; 23:160-172.

(4) Hunt GM. Open spina bifida: outcome for a complete cohort treated unselectively and followed into adulthood. *Dev Med Child Neurol* 1990; 32:108-118.

(5) Hunt GM, Poulton A. Open spina bifida: a complete cohort reviewed 25 years after closure. *Dev Med Child Neurol* 1995; 37:19-29.

(6) Oakeshott P, Hunt GM. Long term outcome in open spina bifida. *Br J Gen Pract* 2003; 53:632-636.

(7) Hunt GM, Oakeshott P. Outcome in people with spina bifida at age 35: prospective community based cohort study. *BMJ* 2003; 326:1365-1366.

(8) Oakeshott P, Hunt GM, Poulton A, Reid F. Expectation of life and unexpected death in open spina bifida: a 40 year complete, non-selective, longitudinal cohort study. *Dev Med Child Neurol* 2010; 52:749-753.

(9) Oakeshott P, Reid F, Poulton A, Markus H, Whitaker RH, Hunt GM. Neurological Deficit at Birth Predicts Survival to the Mid-40s and Urological Deaths in Open Spina Bifida: A Complete Prospective Cohort Study. *Dev Med Child Neurol* 2015; 57:634-638.

(10) Oakeshott P, Poulton A, Hunt GM, Reid F. Walking and living independently with spina bifida: a 50-year prospective cohort study. *Dev Med Child Neurol* 2019; 61(10):1202-1207.

**Additional important related publications:** 11;12

(11) Withycombe J, Whitaker R, Hunt GM. Intermittent catheterisation in the management of children with neuropathic bladder. *Lancet* 1978; 2:981-983.

(12) Hunt GM, Oakeshott P, Kerry S. Link between the CSF shunt and achievement in adults with spina bifida. *J Neurol Neurosurg Psychiatry* 1999; 67:591-595.

6. Recommended citation for this dataset

Oakeshott, P., Reid, F. (2021) The Cambridge cohort of open spina bifida. Figshare. DOI 10.24376/rd.sgul.14438780. Available at <https://doi.org/10.24376/rd.sgul.14438780>

DATA & FILE OVERVIEW

The data package contains the following files

File List:

1. 2021-Oakeshott-Cambridge cohort of open spina bifida.csv – This CSV file contains the full Cambridge cohort of open spina bifida database in an open file format
2. 2021-Oakeshott-Cambridge cohort of open spina bifida-Variables.xlsm – This excel file contains the full variable list for the Cambridge cohort of open spina bifida database
3. 2021-Oakeshott-Cambridge cohort of open spina bifida.sav – This SAV file contains the full Cambridge cohort of open spina bifida database in SPSS with the full variable list included
4. 2021-Oakeshott-Cambridge cohort of open spina bifida-README.docx – This file contains a description of The Cambridge cohort of open spina bifida data package

VARIABLE LIST

A full variable list has been provided in the data package. Please refer to the file: 2021-Oakeshott-Cambridge cohort of open spina bifida-Variables.xlsm

The variables are mainly in the order in which they were assessed, starting from the assessment of sensory level at birth.

If the variable is 1 then it is present. If blank then either it is not present or the patient was no longer alive at this review.

ADDITIONAL DATA

Additional related data collected that was not included in the current data package:

Dates of birth of cases (who were all born in 1963-1971) are available from the investigators, subject to appropriate approvals.

Are there multiple versions of the dataset?

Yes. Another version of this database with date of birth of cases included is available from the investigators, subject to appropriate approvals.