BNMDR (Belgian Neuromuscular Disease Registry)

https://neurodegenerationresearch.eu/survey/bnmdr-belgian-neuromuscular-disease-registry/

Title of the register

BNMDR (Belgian Neuromuscular Disease Registry)

Name of Principal Investigator - Title

Dr

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Q1a. Please indicate below if your cohort includes or expects to include, incidence of the following conditions?

Motor neurone diseases|Spinocerebellar ataxia (SCA)|Spinal muscular atrophy (SMA)

Q2. In a single sentence, what is the stated aim of your register?

To enable epidemiological research to evaluate the importance of the diseases and the patient characteristics, to provide information to the public health authorities for planning of health care in Belgium, to promote health services for patients having a neuromuscular disease, and to improve recruitment for clinical trials.

Q2b. What distinguishes this register from other disease registers?

It collects data regarding every neuromuscular disease in Belgium.

Q3a. i) Number of publications that involve use of your register to date

3

Q3a. ii) Please give up to three examples of studies to date (PI, Institution, Title of Study)
Q3b. If data on research outputs are already available please paste the publication list/other data or provide a link to where these data are publicly available?

Batcho CS et al. How robust is ACTIVLIM for the follow-up of activity limitations in patients with neuromuscular diseases? Neuromuscul Disord. 2016 Mar;26(3):211-20. Bladen CN et al. The TREAT-NMD DMD Global Database: analysis of more than 7,000 Duchenne muscular dystrophy mutations. Hum Mutat 2015 Apr;36(4):395-402. Roy A. et al. Early stages of building a rare disease registry, methods and 2010 data from the Belgian Neuromuscular Disease Registry (BNMDR).Acta Neurol Belg. 2015 Jun;115(2):97-104.

Q3c. If no research has been done as yet, please explain in a few sentences what information (i.e. research findings) you expect will be gained from the register
Q4a. Study criteria: what is the age range of participants? Age in years: from

0

Q4a. Study criteria: what is the age range of participants? Age in years: to

until death

Q4b. Study criteria: what are the inclusion criteria?

Patient with a neuromuscular disease ; followed in one of the 7 Belgian national reference centers for neuromuscular diseases.

Q4c. Study criteria: what are the exclusion criteria?

Patients who do not meet the inclusion criteria

Q5. What is the size of the register (i.e. how many patients have been enrolled)?

1001-5000 clinical cases

Q6a. Please describe what measures are used to characterise participants

For most of diseases: Gender, date of birth, living place, diagnosis, functionnal status and reference center. Specifically for Duchenne muscular dystrophy and SMA, additional variables are collected for the TREAT-NMD registry (mutation name, feeding, scoliosis surgery, cardiac and respiratory function, steroids therapy, clinical trials, motor function, family history).

Q6b. Are there defined primary and secondary endpoints (e.g. defined health parameters)?

No

If YES, please describe
Q7a. i) Is the register of fixed duration?

No

Q7a. ii) Please enter the data collection start date

01/01/2008

Q7a. iii) Please enter the data collection end date
Q7b. Could you provide some information about the data collection for this register?

Data collection ongoing

Q8. Funding of the register - How is the register funded?

Belgian national institute for health and disability insurance (NIHDI)

Q8. Funding of the register - Is this funding expected to continue

Yes

Q8. Funding of the register - If so, for how long (months)?

Years

Q9. Could you provide information about data sweeping? - How many data sweeps have taken place?
Q9. Could you provide information about data sweeping? - When was the most recent data sweep?
Q9. Could you provide information about data sweeping? - When is the next data sweep?
Q9. Could you provide information about data sweeping? - How many more data sweeps are planned on current funding? e.g 0,1,2…..
Q9. Could you provide information about data sweeping? -How many more data sweeps are planned in total (with funding and with funding yet to be secured) e.g. 0,1,2…
Q10. Is the clinical (phenotypic) information that is held in the register from patients and other participants such as family members:

Q11. Is there a limit on the number of studies that can be based on this set of patients?

No

If YES, please give details
Q12a. Please give information on the format and availability of data stored in a database (1)

Data summarised in database

% Available
Q12a. Please give information on the format and availability of data stored in a database (2)

Database is web-based

% Available
Q12a. Please give information on the format and availability of data stored in a database (3)

Database is web-based

% Available
Q12a. Please give information on the format and availability of data stored in a database (4)

No

% Available
Q12a. Please give information on the format and availability of data stored in a database (5)

No

% Available
Please specify language used

English (French/Dutch)

Q12b. Please give information on how data is held as individual records (1)
% Available
Q12b. Please give information on how data is held as individual records (2)
% Available
Q12b. Please give information on how data is held as individual records (3)
% Available
Q12b. Please give information on how data is held as individual records (4)
% Available
Please specify language used
Q13a. Is data available to other groups?

Yes

Q13b. If data is available to other groups what is the access policy/mechanisms for access?

Access through collaboration with PI only|Access Committee mechanism|The different physicians filling in the registry are owners of the data; they all have to agree if we need to share part of the data. Ethics approval needs to be reviewed if we collaborate with external sources.

Q14. What data sharing policy is specified as a condition of use?

No policy exists

Q15a. Are tissues/samples/DNA available to other groups?

No

Q15b. i) If yes, please describe below:
Q15b. ii) In what form are tissues/samples/DNA supplied?
Q15b. iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?
Q16a. Is information on biological characteristics available to other groups?
Number of patients
% of total cohort
Q16b. If yes, is the access policy/mechanism for obtaining samples the same as that for obtaining data (Q13b above)?

Types:
Disease Registers

Member States:
Belgium

Diseases:
Motor neurone diseases, Spinal muscular atrophy (SMA), Spinocerebellar ataxia (SCA)

Years:
2016

Database Categories:
N/A

Database Tags:
N/A