PLSD
The Prospective Lynch Syndromes Database

November 27th, 2023

Dear all,

Thanks for your interest to contribute to the Prospective Lynch Syndromes Database (PLSD) (htttp://plsd.eu).

We kindly ask you to complete the attached minimum data set.

Reporting format is Excel 97-2003 workbook. One table in each tab as indicated.

The more data included in PLSD, the more precise and sophisticated reports we can make. For the purpose we ask all having contributed to update their contributions, and welcome new contributors.

Short note on why update/new information is asked for:

- Info on immunotherapy when considering survival needs no explanation.
- Time since last colonoscopy combined with stages of CRCs diagnosed, is the best surrogate we can do in the absence of an RTC to consider effect of colonoscopy.
- We are for the InSiGHT or EHTG 2024 meetings preparing an abstract on relation between adenomas and CRC based on the information filed so far. We ask for information from those having not so far contributed populated tables C and C2 to test the validity of these results in a new, independent series.

For your information, our five latest reports are as follows:

https://pubmed.ncbi.nlm.nih.gov/37821984/

https://pubmed.ncbi.nlm.nih.gov/37181409/

https://pubmed.ncbi.nlm.nih.gov/36182917/

https://pubmed.ncbi.nlm.nih.gov/34478667/

https://pubmed.ncbi.nlm.nih.gov/34203177/

Updating your contribution:

Please contribute a complete new set of all the tables. We will archive your old set of tables, but from receipt of new set onwards only use the new set. We are happy to copy you, your data currently included in the PLSD if asked, which you may edit for update and return, or – better – do so and add all new carriers identified and followed-up after first contribution.

Format for PTNID is critical – see instructions.

We ask those having not done so, if possible, to populate Tables A2, B1, C, C1 and E. This to be part of further addressing more questions and approved in our last PLSD business meeting 2023 (Vilnius, Lithuania).

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New contributors

Completion of table (tab) A, B and D is mandatory and sufficient to join.

Table A may have no missing data in any record. Table B is to include all cancers diagnosed before, at or after first planned and carried out colonoscopy.

Important information:

- All filed cases meeting the criteria must be reported, meaning from start of your activity onwards, while you may select to (right) sensor last inclusion date in your local database when convenient: This to ensure complete records for those included and to avoid incomplete data – all case included have to have at least one year follow-up and all fields in tables A, B and D must be populated. If a case in your registry has incomplete information, you may skip it (the PLSD analytic algorithms will skip it anyway). Only carriers of variants class 4 or 5 in the InSiGHT variant database are to be reported: if you think you have pathogenic variants not listed in the InSiGHT database, pls give report all information you have on the case(s) and we will help to get them scored, our you may yourself report to the InSiGHT database to get them included and scored. Variants not listed in the InSiGHT database as class 4/5, will not be included in the PLSD.
- If you are not able to contribute within deadline, pls indicate when you may be able to contribute.
- When the germline pathogenic variant was detected in each single case is **not** of interest.
- Inclusion is age at first prospectively planned and carried out colonoscopy (which in former days was based on family history, not genetic testing – the genetic causative variant may have been detected later). Last observation is age of last update whatever method was used for that update.

Do not hesitate to ask if you have any questions.

Looking forward to your response latest **February 27th, 2024**.

Sincerely,

Mev Dominguez-Valentin, PhD

Principal Investigator of the PLSD