Fostering population-based cohort data discovery: The Maelstrom Research cataloguing toolkit

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Abstract

Background

The lack of accessible and structured documentation creates major barriers for investigators interested in understanding, properly interpreting and analyzing cohort data and biological samples. Providing the scientific community with open information is essential to optimize usage of these resources. A cataloguing toolkit is proposed by Maelstrom Research to answer these needs and support the creation of comprehensive and user-friendly study- and network-specific web-based metadata catalogues.

Methods

Development of the Maelstrom Research cataloguing toolkit was initiated in 2004. It was supported by the exploration of existing catalogues and standards, and guided by input from partner initiatives having used or pilot tested incremental versions of the toolkit.

Results

The cataloguing toolkit is built upon two main components: a metadata model and a suite of open-source software applications. The model sets out specific fields to describe study profiles; characteristics of the subpopulations of participants; timing and design of data collection events; and datasets/variables collected at each data collection event. It also includes the possibility to annotate variables with different classification schemes. When combined, the model and software support implementation of study and variable catalogues and provide a powerful search engine to facilitate data discovery.

Conclusions

The Maelstrom Research cataloguing toolkit already serves several national and international initiatives and the suite of software is available to new initiatives through the Maelstrom Research website. With the support of new and existing partners, we hope to ensure regular improvements of the toolkit.
Introduction

In the last decades, millions of citizens across the world contributed time, information and biological specimens to population-based cohorts, which in turn led to major scientific progress and to a better understanding of the relation between numerous risk factors and health outcomes. However, many cohort databases remain under-exploited. To address this issue and speed up discovery, it is essential to offer timely access to cohort data and samples[1–3]. Providing the scientific community with open information about existing research data is an important step toward optimizing usage of these unique scientific resources. However, even for well-known cohorts, specific information on samples and data collected is often either not publicly available or in a format that does not allow to easily understand study design and content. The lack of accessible and structured documentation thus creates major barriers for investigators interested in understanding, properly interpreting and analyzing longitudinal study data[1].

A number of study-specific or network catalogues have been developed over the years to promote discoverability of data and samples. The majority have been developed to answer the data documentation needs of individual studies[4–6]. However, the number of research networks co-analyzing data across studies has considerably increased in the past decade, leading to the implementation of central portals to document groups of studies[7–9]. The objectives of these catalogues vary, and they differ in the level of details they provide on the studies, variables and samples collected. But to truly unleash innovative research agendas and leverage usage of existing data, such catalogues need to be comprehensive and user friendly enough to easily estimate whether data: (1) is accessible to external researchers, (2) might serve to answer specific research questions (e.g. level of physical activity measured with a specific scale), and, when relevant, (3) is similar enough to enable co-analysis across multiple studies. Such criteria have been promoted in scientific data management and stewardship guidelines such as the recently published FAIR principles[3]. An additional feature particularly useful is the access to summary statistics on study subjects, such as the number of participants presenting specific characteristics (e.g. diseases or exposures).

Open source and commercial software have been developed to support the creation of data and metadata portals[10–14]. Such software offers solutions for describing datasets and finding relevant data through searching and browsing features. However, most software applications are not specifically designed for answering the practical requirements of cohorts and networks of cohorts. Therefore, individual research initiatives often need to adapt existing software or develop in-house solutions[15,16]. But developing a metadata portal is resource intensive and as generic solutions are rarely used, interoperability across partner initiatives is limited. If we are to foster a more open approach to research and optimize data discovery, we should provide access to interoperable, flexible and cost-effective software solutions to support cataloguing of longitudinal cohort data.

The present paper describes the approach and software developed by the Maelstrom Research team to answer the need for a general and customizable solution to support the creation of comprehensive and user-friendly study- and network-specific catalogues used to leverage epidemiological research making use of cohort data.

Methods

Development of the Maelstrom Research cataloguing toolkit was initiated in 2004[17]. It was guided by the exploration of existing catalogues and the feedback gathered at workshops addressing the needs of partner initiatives and working sessions evaluating incremental versions of the toolkit pilot-tested by our partners.
Exploring existing resources

Informal literature and Internet searches supplemented by references from key informants allowed identifying existing epidemiological study catalogues. The searches were undertaken in Ovid (Embase, Health and Psychosocial Instruments, Ovid Healthstar, Ovid MEDLINE(R) Versions, PsycINFO, Social Work Abstracts, NASW Clinical Register), PubMed, Web of Science, Scopus, ScienceDirect databases and Google search engine using a range of keywords including “metadata registry, metadata catalogue, metadata repository, metadata standard, metadata model, health databases, cohort, population-based studies, software”. Properties of all relevant catalogues were explored, with a focus on cohort-specific metadata repositories. As such, the search targeted catalogues which included cohorts or longitudinal population-based studies; documented multiple cohorts; included at least a minimal description of the cohort designs; and were accessible online (with or without protected access). Catalogues already making use of the Maelstrom Research toolkit were excluded.

A total of 126 catalogues were identified, 20 of which corresponded to the profile described above. Some of the catalogues identified in the search were excluded because they did not document epidemiological cohorts (e.g. eleMap[18] is a catalogue of phenotypes, DataOne[19] is a catalogue of environmental data), only documented individual cohorts as opposed to groups of cohorts (e.g. MIDUS[20,21]), or already used the Maelstrom Research toolkit (e.g. BioSHaRE[22,23], IALSA[24], MINDMAP[25,26]). Exploration of the catalogues’ content was achieved by a research assistant to document the framework used to describe the cohort profile, specific fields used to document information, software applications used, and study and variable search models. The information was then validated by the coordinator responsible for catalogue development. Information was retrieved by accessing and browsing the online catalogues and when relevant, discussing with individuals managing these catalogues.

Developing and piloting the toolkit

Development of the Maelstrom Research cataloguing toolkit was achieved in collaboration with investigators and researchers making use of cohort data, as well as with international experts with various backgrounds (e.g. epidemiologists, computer scientists, statisticians, ethicists, data librarians). Using an iterative review and consensus approach, a subgroup of epidemiologists and computer scientists established guiding principles to develop maturing versions of the toolkit. The following prerequisite guided development: the toolkit had to serve the needs of both, individual studies and study networks. For individual cohorts, a cost-effective solution to disseminate information and leverage use of available data was sought. For study networks, the toolkit had to allow assessing the compatibility of data across studies and documenting harmonized datasets. It needed to also include a complementary variable classification index to facilitate variable search. In addition, the metadata model was required to be compatible with existing standards (e.g. Data Documentation Initiative (DDI)[27]), whenever possible. It was also deemed essential to provide a simple and flexible tool allowing the documentation of studies and variables dictionaries with varying levels of completeness and diverse data formats (e.g. SAS, SPSS, STATA). Finally, the toolkit needed to be accessible to all and thus, offer free, open-source and customizable software applications. To ensure short-term applicability, development was guided by the specific needs of Maelstrom Research’s partner projects. Since 2004, maturing versions of the toolkit were produced and tested by these projects (Table 1). Throughout, comments and suggestions from investigators of these initiatives were integrated in a central repository. At least once a year, the most pressing or crucial demands for improvements were selected and the toolkit was, and still is customized to answer these requests. Improved versions of the toolkit are therefore regularly generated and tested by users.
Results

Table 2 shows existing cohort-specific catalogues identified by key informants or through Internet searches. These 20 catalogues include study descriptions, but the scope, conceptual model and completeness of the metadata fields used vary extensively. Seven (35%) of the catalogues provide a list of variables collected by studies and 2 (10%) serve as portals to access individual participants data. Only 3 (15%) annotate variables with classification schemes to facilitate the search. The potential to search information through text mining or study and variable properties depends on the structure of the metadata fields and is often limited in scope. Online or downloadable outputs (e.g. Excel tables, PDF documents) also vary, but they include: lists of studies with related properties, visualization tools outlining study characteristics (e.g. maps, tables including number of participants); list of variables and related properties; descriptive statistics (means, distribution) from participant data; and tables allowing to explore harmonization potential across studies.

Maelstrom Research cataloguing toolkit

The Maelstrom Research cataloguing toolkit was built upon two main components: a metadata model and a suite of open-source software applications. Used together these
Table 2. Characteristics of the cohort catalogues surveyed.

| Initiative [ref]                                                                 | Design                           | Country         | Online access to variables | Potential to search by                                                                 |
|---------------------------------------------------------------------------------|----------------------------------|-----------------|----------------------------|----------------------------------------------------------------------------------------|
| Biological and BioMolecular resources Research Infrastructure (BBMRI) [47]      | Various databases                | Europe          | None                       | Study properties Text in study description                                              |
| Biomarker for Cardiovascular Risk Assessment in Europe (BiomarCaRE) [48]        | Cohorts and clinical trials      | International   | None                       | -                                                                                      |
| Birthcohorts.net [49]                                                          | Cohorts                          | International   | None                       | Study properties Text in study description Categories of information collected         |
| B.R.I.D.G.E. TO DATA [50]                                                        | Various study designs            | International   | None                       | Study properties Categories of information collected                                   |
| Cancer Epidemiology Descriptive Cohort Database (CEDCD) [51]                    | Cohorts                          | International   | None                       | Study properties Categories of information collected                                   |
| Cohort and Longitudinal Studies Enhancement Resources (CLOSER) [52]             | Cohorts                          | United Kingdom  | Metadata only              | Study properties Categories of information collected                                   |
| Centre for Longitudinal Studies (CLS) [53]                                      | Cohorts                          | United Kingdom  | Metadata only              | Text in variable label Categories of information collected                              |
| The Global Alzheimer's Association Interactive Network (GAIN) [54]              | Cohorts                          | International   | Metadata only              | Study properties Categories of information collected                                   |
| The Gateway to Global Aging Data [55]                                           | Cohorts                          | International   | Metadata only              | Study properties Categories of information collected                                   |
| Inter-university Consortium for Political and Social Research (ICPSR) [56]      | Various study designs            | International   | Metadata only              | Study properties Categories of information collected                                   |
| EU Joint Programme—Neurodegenerative Disease Research Global Cohort Portal (JPND) [57] | Cohorts                          | International   | None                       | Study properties Categories of information collected                                   |
| Maternal, Infant, Child & Youth Research Network (MICYRN) [15]                  | Various study designs            | Canada          | None                       | Text in study description Categories of information collected                          |
| Medical Research Council Research Data Gateway [58]                             | Cohorts                          | United Kingdom  | None                       | Study properties Categories of information collected                                   |
| National Archive of Computerized Data on Aging (NACDA) [59]                    | Various study designs            | International   | Metadata and data          | Study properties Categories of information collected                                   |
| ONTOFORCE [60]                                                                 | Various databases                | International   | None                       | Study properties Categories of information collected                                   |

(Continued)
components enable the creation of web-based searchable and customizable study and variable catalogues.

Fig 1 presents the conceptual model underlying the study-specific metadata fields. The model sets out specific fields to document: study outline; profiles of the subpopulations of participants; timing of data collection events (or participant follow-ups); and datasets/variables collected at each data collection event. It also includes the possibility to annotate variables with different classification schemes. Detailed information on the model and fields is provided in supporting information (S1 File).

The study outline includes the name, logo and website of the study, the list of investigators and contact persons, the objectives, timeline, and number of participants recruited and participants providing biological samples. It also provides information on access to data and samples. For each subpopulation of participants, information related to the recruitment of participants and selection criteria is included. Finally, documentation of each data collection event includes a general description, start and end dates, data sources and type of information collected.

Lists of variables collected at each data collection event can also be added. The dataset metadata fields include the name and a brief description of the dataset content. The variable metadata fields include the variable name and label, and if applicable, the code and label of each variable category. Additional variable-level metadata fields can also be documented, such as the specific question used to collect the data, or measurement units. Finally, variables can be annotated using various classification schemes. One such classification has been developed by our team to specifically serve the needs of toolkit users. The Maelstrom Research classification essentially allows categorizing all information collected by a study and is composed of 18 domains and 135 subdomains: Socio-demographic and economic characteristics (14 subdomains); Lifestyle and behaviours (14 subdomains); Birth, pregnancy and reproductive health history (5 subdomains); Perception of health, quality of life, development and functional limitations (6 subdomains); Diseases (20 subdomains; ICD-10); Symptoms and signs (9 subdomains; ICD-10); Medication and supplements (3 subdomains); Non-pharmacological interventions (7 subdomains); Health and community care services utilization (4 subdomains); Death (3 subdomains); Physical measures and assessments (11 subdomains); Laboratory measures (9 subdomains); Cognition, personality and psychological measures and assessments (4 subdomains); Life events, life plans, beliefs and values (4 subdomains); Preschool, school and work life (4 subdomains); Social environment and relationships (5 subdomains); Physical environment (7 subdomains); Administrative information (6 subdomains). A complete list of the

Table 2. (Continued)

| Initiative [ref]                      | Design                      | Country            | Online access to variables | Potential to search by                                      |
|--------------------------------------|-----------------------------|--------------------|----------------------------|-------------------------------------------------------------|
| Portail Épidémiologie France[61]     | Various study designs       | France             | None                       | Study properties: Text in study description; Categories of information collected |
| RAND Survey Metadata Repository[62]  | Various study designs       | International      | None                       | -                                                          |
| Registry of Research Data Repositories (re3data.org)[63] | Various databases           | International      | None                       | Study properties: Text in study description                  |
| Swedish National Data Service (SND)[64] | Various databases           | Sweden             | None                       | Study properties: Text in study description                  |
| UK Data service[65]                 | Various study designs       | United Kingdom     | Metadata and data           | Study properties: Text in study description; Text in variable label |

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Any epidemiological study (e.g. cohort, case control, cross sectional, etc.) conducted to better understand the distribution and determinants of health and disease.

A set of individuals sharing the same selection criteria for enrolment in a study. A study can have one or more populations.

Group of information composed of variables that can be considered as a unit and linked to a specific data collection event.

Definite collection of information on one or more population(s) over a specific period of time (e.g. baseline, follow-up 1, follow-up 2).

Information that was collected, measured, or constructed within a study protocol.

Attribute assigned to a variable to add information or facilitate metadata browsing.

Two interoperable open source software applications were developed to provide study managers with easy-to-use tools to implement the conceptual model described above and create fully operational web-based metadata platforms[68]. First, Opal[69] is a software application used to store and manage both variable metadata (i.e. data dictionaries and codebooks) and individual participant data. Opal, used conjointly with 'R'[70], allows users to import, validate, derive, analyze and export data and metadata. It allows upload of various data formats including CSV, SPSS, and SAS and can store data and metadata on an unlimited number of variables, which can be uniformly annotated using controlled lists of terms such as the variable classification described above. Secondly, the Mica[69] application makes use of this metadata to create
web-based catalogues of one or more studies. Features include a user-friendly set of tools to manage and publish information on studies as prescribed by the Maelstrom Research conceptual model and metadata fields. Mica also supports management of demands for access to data. Opal and Mica software architecture and detailed functionalities have been described elsewhere [69].

Once metadata is published on a Mica-powered web portal, a powerful search engine allows users to identify studies and variables of interest and explore the potential to harmonize and co-analyze data across datasets. The search interface allows identifying studies based on study properties described in the metadata fields (e.g. number of participants, age range of the participants). It also enables identification of specific variables of interest by searching variable properties and text mining variable labels. Finally, domains and subdomains of the classification, or additional variables annotations (e.g. annotation of the measures or scales collected) can be used to extract variables of interest and generate comparison tables facilitating exploration of the harmonization potential across cohorts, subpopulations and data collection events (Table 3). All search results lead to specific entity pages describing the study network (where relevant), cohort, dataset and/or variable.

**Use case: The Maelstrom Research catalogue**

In collaboration with partner networks, the Maelstrom Research team deployed the metadata cataloguing toolkit to create the Maelstrom Research catalogue (www.maelstrom-research.

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### Table 3. Example of an interactive table comparing variables collected across subpopulations and data collection events of two birth cohorts for selected domains and subdomains of interest.

| Study                          | Socio-demographic and economic characteristics | Lifestyle and behaviours | Diseases (ICD-10) |
|--------------------------------|------------------------------------------------|--------------------------|-------------------|
|                                | Education (Number of variables) | Income, possessions, and benefits (Number of variables) | Tobacco (Number of variables) | Alcohol (Number of variables) | Pregnancy, childbirth and the puerperium (O00-O9A) (Number of variables) |
| All Our Babies and All Our Families (AOB/F) [66] | | | | | |
| **Mothers**                     | | | | | |
| 24 weeks gestation              | 4 | 8 | 5 | 14 | 0 |
| 36 weeks gestation              | 0 | 3 | 7 | 9 | 0 |
| 4 months postpartum             | 0 | 6 | 5 | 4 | 0 |
| 1 year postpartum               | 0 | 8 | 5 | 4 | 0 |
| 3 years postpartum              | 1 | 2 | 5 | 4 | 0 |
| **Children**                    | | | | | |
| 1 year postpartum               | 0 | 2 | 0 | 0 | 0 |
| Alberta Pregnancy Outcomes and Nutrition (APrON) [67] | | | | | |
| **Mothers**                     | | | | | |
| First trimester                 | 1 | 1 | 15 | 15 | 49 |
| Second trimester                | 0 | 0 | 7 | 5 | 35 |
| Third trimester                 | 0 | 7 | 6 | 6 | 29 |
| 12 weeks postpartum             | 0 | 0 | 6 | 6 | 34 |
| 24 weeks postpartum             | 0 | 0 | 2 | 2 | 0 |
| 12 months postpartum            | 0 | 0 | 3 | 3 | 0 |
| **Partners**                    | | | | | |
| Second trimester                | 1 | 0 | 4 | 3 | 0 |
| 12 weeks postpartum             | 0 | 0 | 3 | 2 | 0 |
| **Children**                    | | | | | |
| 12 weeks postpartum             | 0 | 0 | 0 | 0 | 1 |

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The catalogue currently includes 14 international networks, comprising more than 180 studies (mostly cohorts) from across the world, totalling more than 6,240,000 participants. Full data dictionaries are available for 102 of these studies, representing a total of over 760,000 annotated variables. New content is regularly added to the catalogue, increasing the number of studies and variables that can be searched within and across networks.

To ensure quality and standardization of the metadata documented across networks, standard operating procedures were implemented. Using information found in peer-reviewed journals or on institutional websites, the study outline is documented using Mica and validated by study investigators. Where possible, data dictionaries or codebooks are obtained, completed for missing information (e.g. missing labels) and formatted to be uploaded in Opal. Variables are then manually classified by domains and subdomains and validated with the help of an in-house automated classifier based on a machine learning method. When completed, study and variable-specific metadata are made publicly available on the Maelstrom Research website. For more information about the Maelstrom cataloguing procedures and rules, please refer to the supporting information (S2 File).

### Discussion

The Maelstrom Research cataloguing toolkit already serves the metadata dissemination needs of a number of international initiatives (Table 1). It distinguishes itself from network-specific catalogues and software solutions currently offered to the scientific community. Firstly, it is developed as an open source and generic tool to be used by a broad range of initiatives. Researchers can download the software to develop their own catalogue and make use (or not) of the metadata fields and variable classification proposed. Secondly, the suite of software applications can also be used in conjunction with 'R' to clean, manage, process, harmonize and analyze data. Therefore, the suite of software can also be used as a global solution for cohorts, allowing them to store and manage data as well as disseminate it to the scientific community. Thirdly, the tools offer the possibility to search studies and variables properties and annotations using many criteria and generate a broad range of search outputs. As the software is open source, these features can be customized to answer the needs of a given network. Finally, the toolkit was developed to serve the needs of study consortia and includes user-friendly features to easily estimate harmonization potential across studies, subpopulations and data collection events and document harmonized datasets generated across studies. The approach and software functionalities facilitating data harmonization and co-analysis have been previously published[69,72].

Even when using highly-performing tools, development of study and variable catalogues is challenging. The quality of a catalogue directly depends on the quality and comprehensiveness of the study-specific information documented. But, maintaining and providing access to understandable and comprehensive documentation to external users can be challenging for cohort investigators, and require resources not always available, particularly for the very small or long-established studies. In addition, the technical work required to build and maintain a catalogue is particularly demanding. For example, gathering comprehensive—and comparable—information on study designs necessitates the implementation of rigorous procedures and working in close collaboration with study investigators. Manual classification of variables is also a long and a tedious process prone to human error. Moreover, the information collected needs to be regularly revised to update metadata with new data collections. These challenges, among others, can lead to the creation of catalogues with partial or disparate information across studies, documenting limited subsets of variables (e.g. only information collected at baseline) or including only studies with data dictionaries available in a specific language or
format. However, to truly optimize usage of available data and leverage scientific discovery, implementation of high quality metadata catalogues is essential. It is thus important to establish rigorous standard operating procedures when developing a catalogue, obtain sufficient financial support to implement and maintain it overtime, and where possible, ensure compatibility with other existing catalogues.

The toolkit developed by Maelstrom Research is certainly a useful resource, but it will need to keep evolving to properly respond to the increasing demand generated by its users. Incremental versions of the toolkit are regularly generated. However, it is essential to extend our community of developers and improve compatibility with complementary resources such as software aimed at assessing data quality, or efficient text mining resources supporting automated exploration of the harmonization potential across datasets.

We hope more initiatives will make use of the toolkit and allow this unique tool to achieve its full potential. In addition, through the Maelstrom Research catalogue we hope to offer the scientific community a central repository to document networks and member studies, and thus facilitate search for information across observational cohort studies worldwide.

Supporting information
S1 File. Study- and variable-specific metadata fields. (DOCX)
S2 File. Procedures used to catalogue studies on the Maelstrom Research website. (DOCX)

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References
1. Wellcome Trust. Enhancing Discoverability of Public Health and Epidemiology Research Data [Internet]. London, UK; 2017 [cited 2017 Nov 9]. Available from: https://wellcome.ac.uk/sites/default/files/enhancing-discoverability-of-public-health-and-epidemiology-research-data-phrdf-jul14.pdf
2. Roger VL, Boerwinkle E, Crapo JD, Douglas PS, Epstein JA, Granger CB, et al. Strategic Transformation of Population Studies: Recommendations of the Working Group on Epidemiology and Population Sciences. From The National Heart, Lung, and Blood Advisory Council and Board of External Experts. Am J Epidemiol. 2015 Mar 15; 363–8. https://doi.org/10.1093/aje/kvw011 PMID: 25743324

3. Wilkinson MD, Dumontier M, Aalbersberg IJ, Appleton G, Axton M, Baak A, et al. The FAIR Guiding Principles for scientific data management and stewardship. Sci Data. 2016 Mar 15; 3:160018. https://doi.org/10.1038/sdata.2016.18 PMID: 26978244

4. Collins R. What makes UK Biobank special? The Lancet. 2012 Mar 31; 379(9822):1173–4.

5. Kirkland SA, Griffith LE, Menec V, Wister A, Payette H, Wolfson C, et al. Mining a Unique Canadian Resource: The Canadian Longitudinal Study on Aging. Can J Aging Rev Can Vieil. 2015 Sep; 34(3):366–77.

6. Scholten S, Smidt N, Swertz MA, Bakker SJ, Dotinga A, Vonk JM, et al. Cohort Profile: LifeLines, a three-generation cohort study and biobank. Int J Epidemiol. 2015 Aug 1; 44(4):1172–80. https://doi.org/10.1093/ije/dyu229 PMID: 25502107

7. Mayrhofer MT, Holub P, Wutte A, Litton J-E. BBMRI-ERIC: the novel gateway to biobanks. Bundesgesundheitsblatt—Gesundheitsforschung—Gesundheitsschutz. 2016 Mar 1; 59(3):379–84. https://doi.org/10.1007/s00103-015-2301-8 PMID: 26860601

8. Larsen PS, Kamper-Jørgensen M, Adamson A, Barros H, Bonde JP, Brescianini S, et al. Pregnancy and Birth Cohort Resources in Europe: a Large Opportunity for Aetiological Child Health Research. Paediatr Perinat Epidemiol. 2013 Jul 1; 27(4):393–414. https://doi.org/10.1111/ppe.12060 PMID: 23772942

9. Minicuci N, Naidoo N, Chatterji S, Kowal P. Data Resource Profile: Cross-national and cross-study sociodemographic and health-related harmonized domains from SAGE plus ELISA, HRS and SHARE (SAGE+, Wave 1). Int J Epidemiol. 2016 Oct; 45(5):1403–1403j. https://doi.org/10.1093/ije/dyw181 PMID: 27794522

10. Nesstar—Publish Data on the Web [Internet]. [cited 2017 Nov 30]. Available from: http://www.nesstar.com/

11. Pang C, van Enckevort D, de Haan M, Kelpin F, Jetten J, Hendriksen D, et al. MOLGENIS/connect: a system for semi-automatic integration of heterogeneous phenotype data with applications in biobanks. Bioinformatics. 2016 Jul 15; 32(14):2176–83. https://doi.org/10.1093/bioinformatics/btw155 PMID: 27153686

12. ckan [Internet]. [cited 2017 Nov 30]. Available from: https://ckan.org/

13. Microdata Cataloging Tool (NADA) | IHSN [Internet]. [cited 2017 Nov 30]. Available from: http://www.ihsn.org/software/nada

14. Crosas M. The Dataverse Network: An Open-source Application for Sharing, Discovering and Preserving Data. -Lib Mag. 2011; 17:1–2.

15. Maternal Infant Child Youth Research Network [Internet]. [cited 2017 Oct 3]. Available from: http://micym.ca/

16. GRIP Groupe de recherche sur l’inadaptation psychosociale chez l’enfant [Internet]. [cited 2017 Dec 4]. Available from: http://www.gripinfo.ca/Grip/Public/www/

17. Knoppers BM, Fortier I, Legault D, Burton P. The Public Population Project in Genomics (P3G): a proof of concept? Eur J Hum Genet. 2008 Jun; 16(6):664–5. https://doi.org/10.1038/ejhg.2008.55 PMID: 18382478

18. eMERGE data dictionary [Internet]. [cited 2018 Jun 11]. Available from: https://victr.vanderbilt.edu/eleMAP/index.php

19. DataONE [Internet]. [cited 2018 Jun 11]. Available from: https://www.dataone.org/

20. MIDUS—Midlife in the United States, A National Longitudinal Study of Health and Well-being [Internet]. [cited 2017 Oct 3]. Available from: http://midus.wisc.edu/

21. Radler BT. The Midlife in the United States (MIDUS) Series: A National Longitudinal Study of Health and Well-being. Open Health Data [Internet]. 2014; 2(1). Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4280664/ https://doi.org/10.5334/ohd.ai PMID: 25558376

22. BioShARe [Internet]. [cited 2017 Oct 3]. Available from: http://www.bioshare.eu/

23. Doiron D, Burton P, Marcon Y, Gaye A, Wolfenbuttel BH, Perola M, et al. Data harmonization and federated analysis of population-based studies: the BioShARe project. Emerg Themes Epidemiol. 2013; 10(1):12. https://doi.org/10.1186/1742-7622-10-12 PMID: 24257327

24. ALSA—Integrative Analysis of Longitudinal Studies of Aging and Dementia | Maelstrom research [Internet]. [cited 2017 Oct 3]. Available from: https://www.maelstrom-research.org/mica/network/alsal
25. Mindmap cities—promoting mental well-being and healthy ageing in cities [Internet]. [cited 2017 Oct 27]. Available from: http://www.mindmap-cities.eu/

26. Beenackers MA, Doiron D, Fortier I, Noordzij JM, Reinhard E, Courtin E, et al. MINDMAP: establishing an integrated database infrastructure for research in ageing, mental well-being, and the urban environment. BMC Public Health. 2018 Jan 19; 18:158. https://doi.org/10.1186/s12889-018-5031-7 PMID: 29351781

27. Vardigan M, Heus P, Thomas W. Data Documentation Initiative: Toward a Standard for the Social Sciences. Int J Digit Curation. 2008 Aug 6; 3(1):107–13.

28. Canadian Longitudinal Study on Aging | Canadian Longitudinal Study on Aging [Internet]. [cited 2017 Oct 26]. Available from: https://www.clsa-elcv.ca/

29. Raina PS, Wolfson C, Kirkland SA, Griffith LE, Oremus M, Patterson C, et al. The Canadian Longitudinal Study on Aging (CLSA)*. Can J Aging Rev Can Vieil. 2009 Sep; 28(3):221–9.

30. Institut de Medicina Predictiva i Personalitzada del Càncer—IM PPC [Internet]. [cited 2017 Oct 6]. Available from: http://www.imppc.org/

31. Plateforme d’harmonisation Québec-Europe [Internet]. [cited 2017 Oct 27]. Available from: https://phqe.maelstrom-research.org/

32. bbmri-lpc | BBMRI-Large Prospective Cohorts [Internet]. [cited 2017 Oct 6]. Available from: http://www.bbmri-lpc.org/

33. Canadian Partnership for Tomorrow Project—[Internet]. [cited 2017 Oct 27]. Available from: http://www.partnershipfortomorrow.ca/

34. Dummer TJB, Awadalla P, Boileau C, Craig C, Fortier I, Goel V, et al. The Canadian Partnership for Tomorrow Project: a pan-Canadian platform for research on chronic disease prevention. CMAJ. 2018 Jun 11; 190(23):E710–7. https://doi.org/10.1503/cmaj.170292 PMID: 29891475

35. InterConnect: global data for diabetes and obesity research [Internet]. InterConnect. [cited 2017 Oct 27]. Available from: http://www.interconnect-diabetes.eu/

36. SPIRIT—Sino-Quebec Perinatal Initiative in Research and Information Technology | Maelstrom research [Internet]. [cited 2017 Aug 17]. Available from: https://www.maelstrom-research.org/mica/network/spirit/

37. ATHLOS—Ageing Trajectories of Health: Longitudinal Opportunities and Synergies | Maelstrom research [Internet]. [cited 2017 Oct 3]. Available from: https://www.maelstrom-research.org/mica/network/athlos

38. CHPT—Cross-cohort Harmonization Project for Tomorrow | Maelstrom research [Internet]. [cited 2017 Aug 17]. Available from: https://www.maelstrom-research.org/mica/network/chpt

39. Cohort Metadata Repository | Cohort Metadata Repository [Internet]. [cited 2017 Oct 27]. Available from: https://cmr.nci.nih.gov/

40. Harvey C, Lynch S, Rogers S, Winn D. The National Cancer Institute (NCI) consortium of cohorts. Cancer Res. 2008 May 1; 68(9 Supplement):3865–3865.

41. Constances | Améliorer la santé de demain [Internet]. [cited 2017 Oct 6]. Available from: http://www.constances.fr/

42. Zins M, Bonenfant S, Carton M, Coeuret-Pellicer M, Guéguen A, Gourmelen J, et al. The CONSTANCES cohort: an open epidemiological laboratory. BMC Public Health. 2010 Aug 12; 10:479. https://doi.org/10.1186/1471-2458-10-479 PMID: 20704723

43. Intro to NeuroDevNet | NeuroDevNet [Internet]. [cited 2017 Oct 6]. Available from: http://www.neurodevnet.ca/

44. Goldowitz D, McArthur D. The NeuroDevNet vision. Semin Pediatr Neurol. 2011 Mar; 18(1):2–4. https://doi.org/10.1016/j.spen.2011.02.007 PMID: 21575833

45. ReACH—Research Advancement through Cohort Cataloguing and Harmonization | Maelstrom research [Internet]. [cited 2017 Aug 17]. Available from: https://www.maelstrom-research.org/mica/network/reach

46. Swedish Cohort Consortium [Internet]. [cited 2017 Aug 17]. Available from: http://cohorts.se/

47. BBMRI-ERIC: Gateway for Health—Biobanking and BioMolecular resources Research Infrastructure [Internet]. [cited 2017 Oct 27]. Available from: http://www.bbmri-eric.eu/

48. BiomarCaRE [Internet]. [cited 2017 Oct 3]. Available from: http://www.biomarcare.eu/

49. Birthcohorts | [Internet]. [cited 2017 Oct 3]. Available from: http://www.birthcohorts.net/

50. bridgedata | Your connection to healthcare database worldwide® [Internet]. [cited 2017 Oct 27]. Available from: https://www.bridgedata.org/
51. Cancer Epidemiology Descriptive Cohort Database (CEDCD) [Internet]. [cited 2017 Oct 3]. Available from: https://cedcd.nci.nih.gov/

52. CLOSER [Internet]. CLOSER. [cited 2017 Oct 3]. Available from: http://www.closer.ac.uk/

53. Centre for Longitudinal Studies—CLS—Home of the 1958 National Child Development Study, the 1970 [Internet]. [cited 2017 Oct 3]. Available from: http://www.cls.ioe.ac.uk/

54. The Global Alzheimer’s Association Interactive Network [Internet]. [cited 2017 Oct 3]. Available from: http://www.gaain.org/

55. Gateway to Global Aging Data [Internet]. [cited 2017 Oct 3]. Available from: https://g2aging.org/

56. ICPSR [Internet]. [cited 2017 Oct 27]. Available from: https://www.icpsr.umich.edu/icpsrweb/

57. JPND | Neurodegenerative Disease Research [Internet]. [cited 2017 Oct 3]. Available from: http://www.neurodegenerationresearch.eu/

58. Medical Research Council MRC. MRC Research Data Gateway [Internet]. 2016 [cited 2017 Oct 27]. Available from: https://www.mrc.ac.uk/research/facilities-and-resources-for-researchers/mrc-research-data-gateway/

59. NACDA [Internet]. [cited 2017 Oct 3]. Available from: http://www.icpsr.umich.edu/icpsrweb/NACDA/

60. ONTOFORCE | Everybody a data scientist [Internet]. ONTOFORCE. Available from: https://www.ontoforce.com/

61. Portail Epidemiologie—France | Health Databases [Internet]. [cited 2017 Oct 3]. Available from: https://epidemiologie-france.aviesan.fr/

62. RAND Labor and Population Public-Use Databases [Internet]. [cited 2017 Oct 3]. Available from: https://www.rand.org/labor/data.html

63. re3data.org [Internet]. [cited 2017 Oct 3]. Available from: http://www.re3data.org/

64. Swedish National Data Service | Swedish National Data Service [Internet]. [cited 2017 Oct 3]. Available from: https://snd.gu.se/en

65. UK Data Service Home [Internet]. [cited 2017 Oct 3]. Available from: https://www.ukdataservice.ac.uk/

66. Gracie SK, Lyon AW, Kehler HL, Pennell CE, Dolan SM, McNeil DA, et al. All Our Babies Cohort Study: recruitment of a cohort to predict women at risk of preterm birth through the examination of gene expression profiles and the environment. BMC Pregnancy Childbirth. 2010 Dec 30; 10:87. https://doi.org/10.1186/1471-2393-10-87 PMID: 21192811

67. Kaplan BJ, Giesbrecht GF, Leung BMY, Field CJ, Dewey D, Bell RC, et al. The Alberta Pregnancy Outcomes and Nutrition (APrON) cohort study: rationale and methods. Matern Child Nutr. 2012 Jul 17; 10(1):44–60. https://doi.org/10.1111/j.1740-8709.2012.00433.x PMID: 22805165

68. OBiBa [Internet]. [cited 2017 Oct 27]. Available from: http://www.obiba.org/

69. Doiron D, Marcon Y, Fortier I, Burton P, Ferretti V. Software Application Profile: Opal and Mica: open-source software solutions for epidemiological data management, harmonization and dissemination. Int J Epidemiol. 2017 Oct 1; 46(5):1372–8. https://doi.org/10.1093/ije/dyx180 PMID: 29025122

70. Khan AM. R-software: A Newer Tool in Epidemiological Data Analysis. Indian J Community Med Off Publ Indian Assoc Prev Soc Med. 2013; 38(1):56–8.

71. Maelstrom research [Internet]. [cited 2017 Nov 28]. Available from: https://www.maelstrom-research.org/

72. Fortier I, Raina P, Van den Heuvel ER, Griffith LE, Craig C, Saliba M, et al. Maelstrom Research guidelines for rigorous retrospective data harmonization. Int J Epidemiol. 2017 Feb; 46(1):103–5. https://doi.org/10.1093/ije/dyw075 PMID: 27272186