Research Topic: Reproductive Health Registries, hRHR Project
Date: August 2012

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Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012
Potential Compulsory registries in Norway:¹

- The Medical Birth Registry
- The Cause of Death Register
- The National Insurance Scheme (disabilities, ICD codes)
- The Norwegian Population Database (demography)
- The National Education Database (education, mother and father; proxy for social class)
- The Norwegian Tax Administration’s register (income)
- The National Employment Service’s register (employment status)
- The Register of Social Services (social benefits)
- The Central Criminal and Police Information Register

Is it necessary to obtain consent before processing personal data, or are alternatives available even when obtaining consent would not be impracticable or inappropriate?

It is probably necessary to get consent when it is not impracticable or inappropriate.

Does the Data Protection Legislation cover the deceased?

No

Who is able to indirectly identify the data subject?

Anybody

### Legislation, regulation and guidelines

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Registry Act (2001)*</td>
<td>• Series of regulations:</td>
<td>Not currently available on lovdata in English</td>
</tr>
<tr>
<td></td>
<td>o Cause of death registry;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Medical Birth Registry;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Cancer registry;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Prescription Registry;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Norwegian Patient Registry etc</td>
<td></td>
</tr>
<tr>
<td>Personal Health Data Filing System Act (2001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>It seems likely that this is the same as the Health Registry Act.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Available from the following websites:</td>
</tr>
<tr>
<td>The Health Personnel Act 1999</td>
<td>• With amendments 2002</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• § 1 Objective of this Act</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o The objective of this Act is to contribute to safety for patients and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>quality within the health service as well as trust in both health</td>
<td></td>
</tr>
<tr>
<td></td>
<td>personnel and the health service.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Unofficial English translation available here-</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th><strong>§ 2</strong> Scope of this Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>o This Act applies to health personnel and facilities where health care is being provided.</td>
</tr>
<tr>
<td>o The King stipulates regulations relating to the application of this Act to Svalbard and Jan Mayen and may lay down special provisions out of regard for the local conditions. To the extent determined by the King in regulations, this Act shall apply to persons onboard Norwegian ships engaged in foreign trade, to Norwegian civil aircraft in international traffic and to installations and vessels at work on the Norwegian continental shelf and within Norwegian rescue area.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>§ 21</strong> General rule relating to the duty of confidentiality</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Health personnel shall prevent others from gaining access to or knowledge of information relating to people's health or medical condition or other personal information that they get to know in their capacity as health personnel.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>§ 22</strong> Consent to give information</th>
</tr>
</thead>
<tbody>
<tr>
<td>o The duty of confidentiality pursuant to section 21 is not to prevent information from being made known to the person that the information directly relates to, or to others, to the extent to which the person who is entitled to confidentiality gives his consent thereto.</td>
</tr>
<tr>
<td>o For persons below 16 years of age, the provisions of the Patients Rights Act section 4-4 and section...</td>
</tr>
<tr>
<td><strong>Therapeutic Biobank Act (2003)</strong></td>
</tr>
<tr>
<td>------------------------------------</td>
</tr>
<tr>
<td><strong>Research Ethics Law (2006)</strong></td>
</tr>
<tr>
<td><strong>Data Registers Act 1978</strong></td>
</tr>
<tr>
<td></td>
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<tr>
<td><strong>EU Directive 95/46/EC</strong></td>
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<tr>
<td><strong>Statistics Act (1989)</strong></td>
</tr>
<tr>
<td><strong>Personal Data Act (2001)</strong></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Personal Data Regulations</strong></td>
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</tbody>
</table>

3-4 second paragraph, shall apply correspondingly for consent granted in accordance with the first paragraph.

- For persons over 16 years of age, who are incapable of considering the question of consent for reasons as mentioned in the Patients Rights Act section 3-3 second paragraph, their next of kin may grant consent pursuant to the first paragraph.

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social welfare professionals who are not subject to official authorisation shall be exempt from the obligation to obtain a licence pursuant to section 33, first paragraph, of the Personal Data Act.

- Exemption from the licensing obligation shall only apply if the personal data are processed in connection with:
  - a) treatment and follow-up of individual patients, or
  - b) preparation of statistics.


- **Section 7-26. Processing of patient records by healthcare personnel subject to public authorisation or holding a licence**

  - The processing of patient/client data by officially authorized health professionals and health professionals who have been granted a licence, cf. sections 48 and 49 of the Act of 2 July 1999 No. 64 on health care personnel shall be exempt from the obligation to obtain a licence pursuant to section 33, first paragraph, of the Personal Data Act.

  - Exemption from the licensing obligation shall only apply if the personal data are processed in connection with:
    - a) treatment and follow-up of individual

[Please note: this link still works, but you must copy it into your browser, as I have had trouble when trying to access it from this Word file].

[http://www.datatilsynet.no/Global/english/Personal_Data_Regulations_20100215.pdf](http://www.datatilsynet.no/Global/english/Personal_Data_Regulations_20100215.pdf)
patients,
  - b) work as an appointed expert, or
  - c) preparation of statistics.


- **Section 7-27. Research projects**
  - Personal data processing in connection with a research project shall be exempt from the obligation to obtain a licence pursuant to section 33, first paragraph, of the Personal Data Act. Exemption from the licensing obligation shall only apply if all the conditions set out in points a)-e) are satisfied:
    - a) first-time contact is established on the basis of publicly available information or through a person who is professionally responsible at the enterprise where the respondent is registered, or the respondent personally contacts the project manager or the latter's representative,
    - b) the respondent has consented to all parts of the study. If the respondent is a minor or a person adjudicated incompetent, another person with authority to give consent on behalf of the respondent may give such consent,
| **Health Research Act (2009)** | - Regulates all Norwegian health care research.  
- Its aim is to regulate medical research by one law and allow for only one review of projects.  
- It delegates this task to Regional Committee for Medical Research Ethics (REK). REK is governed by a separate statute, not available in English.  
- Information from European Network of Research Ethics Committees - [http://www.eurecnet.org/information/norway.html](http://www.eurecnet.org/information/norway.html)  

**Note:** having difficulty finding the exact name of this law, but will be able to in future. | - Norway does not allow anonymous donor insemination.  
- It allows donor insemination, but does not allow “in vitro fertilization (IVF) with donated sperm or oocytes”\(^2\).  
- European Society of Human Reproduction and Embryology provides useful information on this, with an overview of European national legislation on donor anonymity. See:  

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\(2\) Claudia Lampic, Agneta Skoog Svanberg, and Gunilla Sydsjö 'Attitudes towards gamete donation among IVF doctors in the Nordic countries—are they in line with national legislation?' *J Assist Reprod Genet.* **26(5)**, 231 (May, 2009).
<table>
<thead>
<tr>
<th>Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivery of data from central personal health data filing systems</td>
</tr>
<tr>
<td>• § 2-7. The right of the child to information about a sperm donor</td>
</tr>
<tr>
<td>• A person born in consequence of Assisted Reproduction with the use of donor sperm has the right to identifying information on the sperm donor at the age of 18 years. A donor register shall assist the child in this matter.</td>
</tr>
<tr>
<td>• Also, regulates use of human cells for research purposes.³</td>
</tr>
<tr>
<td>³ For more information please refer to <a href="http://tidsskriftet.no/article/2228394/en_GB/#fotnote21">http://tidsskriftet.no/article/2228394/en_GB/#fotnote21</a></td>
</tr>
<tr>
<td>• 2.1 specifies who can access such data-</td>
</tr>
<tr>
<td>o Researchers, or others, may receive access to data from these personal health data filing systems in accordance with their guidelines. Access to data for a research project implies that the project manager is affiliated to an institution with the expertise that is deemed necessary for the realization of the project. The project manager must also have the qualifications stated by the act on medical and health research (the Health Research Act).</td>
</tr>
<tr>
<td>o Person-identifiable data is only delivered to the project manager after permission is granted from The Norwegian Data Inspectorate (dispensation from confidentiality agreements) and from The</td>
</tr>
</tbody>
</table>
| Guidelines accessible in English- [http://www.fhi.no/dav/4db1cb039e.pdf](http://www.fhi.no/dav/4db1cb039e.pdf) [link is not working at present, will check again].
| Guidelines for access to data and biological samples from the Norwegian Mother and Child Cohort Study (MoBa) | • The purpose of the MoBa Conditions is to provide the framework for access to and use of MoBa data and BM, which will facilitate high-quality research based on MoBa.  
• The following types of data are available:  
  o MoBa questionnaire data: Access requires approval from the MoBa SMG.  
  o MBRN data for MoBa participants: Access requires approval from the MoBa SMG.  
  o MoBa ultrasound data: Access requires approval from the MoBa SMG.  
  o Data collected or generated by MoBa Sub-studies: For ongoing Sub-studies, access requires approval from the PI or steering committee of the Sub-study of interest. For finalized Sub-studies, the data are governed in the same manner as other MoBa data, and access requires approval from the MoBa SMG only.  
• Content of the database is described in detail in the MoBa Study Protocol. | Guidelines available in English here- [http://www.fhi.no/dokumenter/652b02730a.pdf](http://www.fhi.no/dokumenter/652b02730a.pdf)  
Previously, I accessed them here- [http://www.fhi.no/dokumenter/d990f068be.pdf](http://www.fhi.no/dokumenter/d990f068be.pdf)  
[Note: I have these Guidelines in a PDF but the link, which is also still on the current website is not working]  
MoBa Study Protocol available in English at- [http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15.3137:1:0:0:::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15.3137:1:0:0:::0:0)  
[Note: this link takes you to a page which has the Protocol, as well as other relevant documents on data access]. |
| Guidelines for access to data from central personal health data filing systems | • 5 types of data:  
  o Statistical;  
  o Anonymous on an individual level; | Available in English at: [http://www.fhi.no/dokumenter/4db1cb039e.pdf](http://www.fhi.no/dokumenter/4db1cb039e.pdf) |

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2.1- • Granted to researchers and others in accordance with these guidelines. • It is expected that research projects will be led by project managers who are connected with institutions that have the necessary skills for the realization of the project. • Project managers must also have qualifications in accordance with the Health Research Act. • Person-identifiable data will only be accessible after permission has been granted by the Norwegian Data Inspectorate and the Norwegian Directorate of Health.

2.2- • Applications for data access should be sent to the Department for Project Support (SIPS) at datatilgang@fhi.no.

2.4- • There are no formal permissions required for access to statistical data (tables) or anonymous data from one central personal health data filing system, or data from linking two or more such registers. This also applies for access to de-identified data. [I suspect “implies” should read “applies”].
“Anyone who is interested in utilizing the research possibilities may apply for access to the CONOR data. All contracts will be signed by Norwegian Institute of Public Health (data distributor on behalf of CONOR) and by the institution receiving data. The applicant must therefore be connected to an institution with the competence to carry the research project to term. Inexperienced researchers must have an advisor connected to such an institution. All data deliveries will be regarded as partial projects of CONOR. Each partial project must have a manager who bears the professional responsibility.”

Application process:
- An electronic application process will be implemented in the near future.
- At present, all applications should be emailed to conor@fhi.no

Data delivery:
- Will be tailored to the specific project
- Data will be in de-identified form.

Guidelines for access to data from the Norwegian Prescription Database

Access to data, who can access it?4
- Researchers may receive data in the form of tables or by individual record (using pseudonyms) for health monitoring or research for an explicitly declared

4 Please see NIPH, *Extraction of data from the NorPD - Access and Guidelines*, available at: [http://www.fhi.no/eway/default.aspx?pid=238&trg=Area_5954&MainLeft_5812=5954:0:&Area_5954=5825:67758::0:5955:1:::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=Area_5954&MainLeft_5812=5954:0:&Area_5954=5825:67758::0:5955:1:::0:0)
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| Purpose, within the NorPD’s regulations. Research projects must be evaluated as legitimate and justifiable (from an ethical perspective). Health personnel, students and others can receive data for use within the NorPD’s regulations.  
• As of 1st January 2007, the cost for receiving additional information from the NorPD is 815 Norwegian kroner per hour’s work, with a minimum price of 1 630 Norwegian kroner, excluding VAT, according to the guidelines.  

| Access to biological materials  
• requires completion of Application for access to data and biological samples from The Norwegian Institute of Public Health (S601BE)  
| [http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0:0:0::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0:0:0::0:0) |
### Institutional Bodies

<table>
<thead>
<tr>
<th>Name of organisation:</th>
<th>Key points:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Data Inspectorate     | - Established in 1980.  
- Functions of the Data Inspectorate, to:  
  - keep a systematic, public record of all processing that is reported or for which a licence has been granted  
  - deal with applications for licences, receive notifications and assess whether orders shall be made in cases where this is authorized by law  
  - verify that statutes and regulations which apply to the processing of personal data are complied with, and that errors or deficiencies are rectified  
  - keep itself informed of and provide information on general national and international developments in the processing of personal data and on the problems related to such processing  
  - identify risks to protection of privacy, and provide advice on ways of avoiding or limiting such risks  
  - provide advice and guidance in matters relating to protection of privacy and the protection of personal data to persons who are planning to process personal data or develop systems for such processing, including assistance in drawing up codes of conduct for various sectors  
  - on request or on its own initiative give its opinion on matters relating to the processing of personal data | Main website- [http://www.datatilsynet.no/English/](http://www.datatilsynet.no/English/)  
Further information from- [http://www.privireal.org/content/dp/norway.php](http://www.privireal.org/content/dp/norway.php) |
| The Schengen Information | “The objective of the Schengen cooperation is to...” | [http://www.datatilsynet.no/English/The-](http://www.datatilsynet.no/English/The-) |
| **System (SIS)** | realise the free movement of persons by abolishing checks of persons at the borders between the member states.  
- Any member state can enter information in the SIS on persons who are wanted or searched for together with a request that a specific action be taken if the person is found. Each member state is responsible for its national section of the SIS. In addition to this, there is a joint central function in Strasbourg, the technical support function, which shall ensure that all the different national sections contain identical information. The SIS has been in operation since 1995. Norway has been a part of the Schengen area since March 2001.” | Schengen-Information-System-SIS/  

| **Norwegian Prescription Database (2004) (NorPD)** | Established in 2004  
- aim of the NorPD is to collect and process data on prescribed drug use in humans and animals.  
- Researchers can request table data and individual data (by pseudonym) from NorPD for health monitoring or research, in accordance with NorPD’s Aims – see related documents for Aims and Guidelines.  
- Publishes annual report, which is based on data from the previous 5 year period  
- They also publish a report on drug consumption  
- Governed by Regulation § 1-8  
- Aim is to collect and process data on drug consumption by humans and animals to: | Overview-  
http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4440:1:0:0::0:0  
Main website-  
http://www.norpd.no/  
- this also provides a summary of the applicable regulations at  
http://www.norpd.no/Regulations.aspx  
[please note this is the correct web address, but when you click on it from this document it is not working for some reason, so please copy into your browser] |
<table>
<thead>
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<th>Research Topic: Reproductive Health Registries</th>
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</tr>
</tbody>
</table>

- **Map usage in Norway and monitor trends**
- **Be a resource for research in order to see positive and negative effects of drug consumption**
- **Give health authorities a statistical base for quality control of drug use and for steering and planning**
- **Give prescribers a basis for internal control and quality improvements.**

- Use and delivery of data from the NorPD is evaluated according to the agreed aim. The NorPD only contains information directly or indirectly resulting from prescriptions or requisitions. Information about the patient or prescriber will be protected with a pseudonym.

### Norwegian Registration Authority for Health Personnel (SAFH)

- In pursuance of the Health Personnel Act
- This body has the authority to give authorisation and licences to health care personnel lies in SAFH.

http://www.safh.no/english/index.html

### The Norwegian Institute of Public Health (NIPH)

- Responsible for the following registries and statistical collections: (10 out of the 15 registers that exist)
  - The Medical Birth Registry
  - Cause of Death Registry
  - Norwegian Immunisation Registry
  - Food Allergy Register
  - Norhealth (key statistics)
  - Norwegian Cardiovascular Disease Registry
  - Norwegian Prescription Database

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainLeft_5853&MainArea_5834=5853:0:15,2825:1:0:0:::0:0

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainLeft_5853&MainArea_5834=5853:0:15,2825:1:0:0:::0:0

Modernising national health registries:

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainLeft_5853&MainArea_5834=5853:0:15,2825:1:0:0:::0:0


Drug consumption report available at-

(available in English and Norwegian in 1 document)

http://www.legemiddelforbruk.no/english/

Regulation available at-

http://www.fhi.no/eway/default.aspx?pid=238&trg=Area_5954&MainLeft_5812=5954:0:&Area_5954=5825:67758::0:5955:1:::0:0

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainLeft_5853&MainArea_5834=5853:0:15,2825:1:0:0:::0:0
## Register of Pregnancy Termination
- Surveillance System for Antimicrobial Drug Resistance (NORM)
- Surveillance System for Communicable Diseases (MSIS)

The Ministry of Health and Care Services has established the National Health Registry project to co-ordinate and modernise the national clinical registries and the mandatory national health registries.

The purpose of the project is to improve the use of data for research, health surveillance, prevention and quality assurance of healthcare.

In 2011, the Norwegian government approved a national strategy for health registries for the period 2010-2020.

## The Department for Research Data
- responsible for processing applications, plus delivering data from existing health registers and health studies.
- The department also offers legal advice to ensure that laws and rules are followed concerning the use of the data, while strictly protecting the privacy and other rights for participants in the studies.
- A Data Protection Officer is employed at the NIPH with the approval of the Norwegian Data Inspectorate.

Norwegian Mother and Child Cohort Study (MoBa)
- ongoing pregnancy cohort study, aiming to include 100,000 pregnancies by 2008.

Main website:
[http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5853:0:15,3894:1:0::0:0&MainLeft_5853=5825:52966::1:5857:1:::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5853:0:15,3894:1:0::0:0&MainLeft_5853=5825:52966::1:5857:1:::0:0)
- The study is based on questionnaires to the mother and father, with biological specimens being collected from mother, father and child.
- The main purpose of the study is to find causes of serious diseases in mothers and children.
- Approximately 100 subprojects with specific research questions have been proposed.
- The questions cover environmental factors, such as medication, nutrition, infection and work exposure. Genetic factors and the interplay between genes and the environment will be studied.
- Blood samples from as many fathers as possible will also be collected, enabling association studies between genes and diseases.

**How can data be accessed?**
- Researchers who are applying for statistical data do not need licences and can simply fill out a form and apply for statistical data in the form of ready-made tables.
- Research data requires an application for a licence. Researchers are responsible for acquiring all necessary licences. This could be a licence from the Norwegian Data Inspectorate, exemption from confidentiality from the Norwegian Directorate of Health or approval from the Regional Committee for Medical Research Ethics (REK).
- Biological samples- Approval is required from the REK. A licence must be sought from the [here](http://www.fhi.no/eway/default.aspx?pid=23&trg=MainArea_5811&MMainArea_5811=5903:0:15,3046:1:0:0:::0:0):0::0:0

Forms for applications for accessing data available [here](http://www.fhi.no/eway/default.aspx?pid=23&trg=MainArea_5811&MMainArea_5811=5903:0:15,4278:1:0:0:0:0&MainLeft_5903=5954:0:15,4278:1:0:0:0:0).
| **Regional Committee for Medical Research Ethics (REK).** | • Administratively REK is organized under the medical faculties at the four large universities in Norway. So:  
  o REK North under the University of Tromsø,  
  o REK Mid under the University of Trondheim,  
  o REK West under the University of Bergen,  
  o and REK South-East under the University of Oslo.  
• Decisions by REK can be appealed to NEM.  
• REK reviews issues of privacy, secrecy and establishment of biobanks. The only exception is clinical trials that also need permission from the Medicinal Health Authority. | Main website in Norwegian- [http://helseforskning.etikkom.no/ikbViewer/page/forside?lan=2](http://helseforskning.etikkom.no/ikbViewer/page/forside?lan=2)  
Also, in English- [http://helseforskning.etikkom.no/ikbViewer/page/forside?_ikbLanguageCode=us](http://helseforskning.etikkom.no/ikbViewer/page/forside?_ikbLanguageCode=us) |
|---|---|---|
| **The National Committee for Medical and Health Research Ethics (NEM)** | • NEM is an advisory and appeal body for the seven regional committees for medical research ethics.  
• If you are to do medical or health research in Norway, or Norwegian scientists within this field doing research abroad, you must apply to the regional committees for medical research ethics (REK). | Main website in English- [http://www.etikkom.no/en/In-English/About-us--key-information/](http://www.etikkom.no/en/In-English/About-us--key-information/) |
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Date: August 16th 2012

| • Several areas of special concern: |
| o Biotechnology and genetic engineering – |
| o information technology, privacy, safety and security issues |
| o risk and safety |
| o environment, sustainability and resource allocation. |

| Cohort of Norway, (CONOR) data from several regional health studies |
| Collection of health data and blood samples from several health surveys. |
| The first of these surveys was conducted in Tromsø in 1994-9. |
| The most recent survey was carried out in Nord-Trøndelag (HUNT 3), concluding in 2008. |
| All data will be anonymised and blood samples which are made available to researchers will have only be identified by a serial number. |
| Researchers may gain access to the data stored in CONOR by submitting an application to the Department of Research Data. |
| The Guidelines specify who is eligible to apply for access- |
| o “Anyone who is interested in utilizing the research possibilities may apply for access to the CONOR data. All contracts will be signed by Norwegian Institute of Public Health (data distributor on behalf of CONOR) and by the institution receiving data. The applicant must therefore be connected to an institution with |

http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15.4220:1:0::0:0

[Note: Guidelines regarding access to data stored in CONOR are also available here].
the competence to carry the research project to term. Inexperienced researchers must have an advisor connected to such an institution. All data deliveries will be regarded as partial projects of CONOR. Each partial project must have a manager who bears the professional responsibility. A contract will give the right to use one or more specific scientific approaches for a limited period (see point 7).”

- Additional approval must be sought where researchers intend to link information from CONOR with other registers.

**Child Growth Study**
- This is the Norwegian part of the European Childhood Obesity Surveillance Initiative (COSI).
- “The aim of COSI is to routinely measure overweight and obesity among primary school children in about 20 countries for a long-term, inter-country comparison within Europe.”
- The first Norwegian study was conducted in 2008 and the second in 2010. It is intended that studies will be conducted every two years.

**The Norwegian Directorate of Health**
- Has a Code of Conduct for Information Security, which is applicable to the healthcare, care and social services sector. [An updated version of the Code was available at](http://www.helsedirektoratet.no/publikasjoner/norm-for-informasjonssikkerhet/Publikasjoner/code-of-conduct-for-information-security.pdf).

Norwegian version of the website - [http://www.helsedirektoratet.no/Sider/SidenFinnesIkke.aspx](http://www.helsedirektoratet.no/Sider/SidenFinnesIkke.aspx)

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5 Available at: [http://www.helsedirektoratet.no/publikasjoner/norm-for-informasjonssikkerhet/Publikasjoner/code-of-conduct-for-information-security.pdf](http://www.helsedirektoratet.no/publikasjoner/norm-for-informasjonssikkerhet/Publikasjoner/code-of-conduct-for-information-security.pdf)
| released in 2011, but the version available on the website is from 2010]. |
|---|---|---|
| • The Code enables interoperability for organisations which comply with it. | • It has also produced guidelines to assist with compliance with the Code. | • It also provides factsheets on a variety of topics, including:\(^6\) |
| | | o Access control; |
| | | o Use of data processor; |
| | | o Agreements and authorisations relating to research; |
| | | o Information security for research projects; |
| | | o And patient access to incident registers. |

\(^6\) All factsheets available at: [http://www.helsedirektoratet.no/english/topics/code-of-conduct/fact-sheets/Sider/default.aspx](http://www.helsedirektoratet.no/english/topics/code-of-conduct/fact-sheets/Sider/default.aspx)

Research Topic: Reproductive Health Registries

Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX
Researchers who want to access data or other biological material from health registers, biobanks and projects administered by the Norwegian Institute of Public Health (NIPH) must apply according to defined rules, submitting the appropriate application form together with licences and approval as needed.” NIPH's website provides all the relevant guidelines.\(^7\)

Depending on the project, researchers will need to gain a licence from either the Norwegian Data Inspectorate, or exemption from the Norwegian Directorate of Health or approval from the Regional Committee for Medical Research Ethics (REK).

<table>
<thead>
<tr>
<th>Register</th>
<th>Functions and relevant information</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harmonized Reproductive Health Registries (hRHR) project</td>
<td>the aim is “to develop a harmonized WHO framework for the development, management, use, evaluation and accountability of reproductive health registries to support progress towards the UN's Millennium Development Goals (MDG) 4 and 5.”</td>
<td><a href="http://www.fhi.no/eway/default.aspx?pid=238&amp;trg=MainArea_5811&amp;MainArea_5811=5903:0:15,4278:1:0:0::0:0">http://www.fhi.no/eway/default.aspx?pid=238&amp;trg=MainArea_5811&amp;MainArea_5811=5903:0:15,4278:1:0:0::0:0</a></td>
</tr>
</tbody>
</table>
| Cancer Registry (1952) | • Governed by the Institute of Population-based Cancer Research, was established in 1951.  
• It is one of the oldest national cancer registries in the world.  
• This, combined with the unique personal identification number used in Norway, makes the Cancer Registry's data suitable, also internationally; by establishing new knowledge through research and spreading information on cancer.  
• The Cancer Registry is part of South-Eastern Norway | [http://www.kreftregisteret.no/en/](http://www.kreftregisteret.no/en/)  

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\(^7\) Please see NIPH, *Access to data*, available at: [http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0:0::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0:0::0:0)
<table>
<thead>
<tr>
<th>Regional Health Authority and is organized as an independent institution under Oslo University Hospital Trust, with its own board.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• All medical doctors in the country are instructed by law to notify new cancer cases to us. Cancer must be notified in case of cancer suspicion, even without a verified cancer diagnosis, and also if cancer is first diagnosed by autopsy. In case of doubt, a notification must be sent.</td>
</tr>
<tr>
<td>• Responsible for national screening programmes</td>
</tr>
<tr>
<td>The Health Personnel Register</td>
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<tr>
<td></td>
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<tr>
<td>Register of Pregnancy Termination</td>
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<tr>
<td>Norwegian Cardiovascular disease registry (2012)</td>
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</table>

Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012
<table>
<thead>
<tr>
<th>Research Topic: Reproductive Health Registries</th>
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</thead>
<tbody>
<tr>
<td>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</td>
</tr>
<tr>
<td>Date: August 16th 2012</td>
</tr>
</tbody>
</table>

| Cause of Death Registry | • Individual electronic data since 1951  
|                        | • All deaths are reported by doctors who are required to complete a death certificate.  
|                        | • Death certificates are collected by the Cause of Death Registry for coding of information based on an international system and determines the cause of death to be used in the cause of death statistics (underlying cause of death).  
|                        | • The register allows us to follow developments in mortality e.g. for heart attacks, cancer, accidents and suicide.  
|                        | • The Section for Health Statistics at Statistics Norway is the Data Processor (Databehandler) for the Cause of Death Registry.  
|                        | • And the Norwegian Institute of Public Health is the Data Controller (Behandlingsansvarlig).  |

| Medical Birth Registry (1967) (MBRN) | • Established in 1967.  
|                                      | • The Norwegian Institute of Public Health manages the MBRN, and is the registry and data controller.  
|                                      | • Governed by MBRN-regulations  
|                                      | • All maternity units in Norway must notify births to the MBRN. This is done electronically.  
|                                      | • The notification form includes the name and personal identity number of the child and parents, as well as |

http://www.fhi.no/eeway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5160:1:0:0::0:0

http://www.fhi.no/eeway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5895:0:15,3320:1:0:0::0:0

MBRN-regulations- available only in Norwegian at-

http://www.lovdata.no/cgi-
<table>
<thead>
<tr>
<th>Information:</th>
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<tbody>
<tr>
<td>- about maternal health before and during pregnancy,</td>
</tr>
<tr>
<td>- any complications during pregnancy or birth,</td>
</tr>
<tr>
<td>- This includes information about:</td>
</tr>
<tr>
<td>Medicine used in-</td>
</tr>
<tr>
<td>- pregnancy,</td>
</tr>
<tr>
<td>- labour interventions,</td>
</tr>
<tr>
<td>- birth complications,</td>
</tr>
<tr>
<td>- maternal complications after birth,</td>
</tr>
<tr>
<td>- whether the baby is born alive,</td>
</tr>
<tr>
<td>- any diagnoses in the child or evidence of congenital abnormalities.</td>
</tr>
</tbody>
</table>

**Data access:**

- “The department will contribute to making data and information easily accessible, and has a service unit extracting data files from the MBRN for researchers and other interested parties.”
- Researchers who are interested in using this data should make an application to the service unit.

**eMBRN**

- begun in 2010
- Purpose is to-
  - develop and implement new versions of electronic maternity, child and abortion notifications where pre-coded information can be used.
  - The project will also develop MBRN’s internal IT system for receipt and quality assurance of relevant work processes.

Data access guidelines and information are available at: [http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0::0::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0::0::0:0)
| Norwegian Patient Registry (hospital discharge registry 2008) Under PolSys Data on the Political System | • Publishes annual reports in Norwegian.  
• There are many laws applicable to this register.  
http://www.nsd.uib.no/polsys/data/en/forvaltning/enhet/37606 |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>PolSys Data on the Political System</td>
<td>• contains information about institutions, persons and resources in (mainly) the Norwegian political and civil [8] Laws</td>
</tr>
</tbody>
</table>

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8 Laws

- Lov om transplantasjon, sykehusobduksjon og avgivelse av lik m.m.
- Lov om vern mot tobakksskader
- Lov om svangerskapsavbrudd
- Lov om sterilisering
- Lov om helsetjenesten i kommunene
- Lov om tannhelsetjenesten
- Lov om omsetning av alkoholholdig drikk m.v. (alkoholloven)
- Lov om sosiale tjenester m.v. (sosialtjenesteloven)
- Lov om framstilling og bruk av genmodifiserte organismer m.m. (genteknologiloven)
- Lov om vern mot smittsomme sykdommer
- Lov om medisinsk utstyr
- Lov om spesialisthelsetjenesten m.m.
- Lov om etablering og gjennomføring av psykisk helsevern (psykisk helsevernloven).
- Lov om pasientrettigheter (pasientrettighetsloven)
- Lov om helsepersonell m.v. (helsepersonelloven)
- Lov om strålevern og bruk av stråling
- Lov om helsemessig og sosial beredskap
- Lov om helseregister og behandling av helseopplysninger (helseregisterloven).
- Lov om erstatning ved pasientskader mv. (pasientskadeloven).
- Lov om biobanker (biobankloven)
- Lov om alternativ behandling av sykdom mv.
- Lov om introduksjonsordning for nyankomne innvandrere (introduksjonsloven)
- Lov om humanmedisinsk bruk av bioteknologi m.m. (bioteknologiloven).

| Norwegian Twin Registry (NTR) | • This project started in 2008.  
• The aim is “to create a national and international scientific resource that brings together and builds upon data, biobank material and competence from all three Norwegian twin panels. It will be population-based and include health history information of approximately 14 000 twin pairs.”  
• Guidelines on data access are not yet available in English, and researchers are encouraged to contact NTR if they are interested in accessing data.  
• However, the website summarises the guidelines as follows:  
  o Researchers who have an interest in using data for research purposes can apply for access to data. Any delivery of data will be considered as a sub-project in NTR.  
  o The applicant has to be affiliated with an institution with competence in conducting research projects that is willing to be responsible for a sub-project. Inexperienced researchers must have a scientific supervisor belonging to such an institution. All sub-projects must have a principal investigator with scientific responsibility for the project.  
• For each sub-project, a contract will be written between the Norwegian Institute of Public Health and the relevant institution. A contract gives the right to study one or more research questions for a defined | http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5031:1:0:0::0:0 |
limited period of time.
**UK**

**Institutional Bodies**

<table>
<thead>
<tr>
<th>Regulatory body:</th>
<th>Functions and relevant information:</th>
<th>Websites:</th>
</tr>
</thead>
</table>
| Maternal Mortality-Centre for Maternal and Child Enquiries (CMACE) | • This produces a report every 3 years (and this article draws its numbers from that report). The overall maternal death rate for the Enquiry is calculated from the number of deaths assessed as being due to Direct and Indirect causes.  
• Publishes reports on:  
  o Child Death  
  o Maternal Death  
  o Perinatal Mortality | [http://www.patient.co.uk/doctor/Maternal-Mortality.htm#ref2](http://www.patient.co.uk/doctor/Maternal-Mortality.htm#ref2)  
| Infant mortality-Office for National Statistics | • Publishes birth cohort tables, which present data on infant deaths that have been linked to their corresponding birth record. These birth cohort tables relate to deaths among infants born in a given calendar year.  
| Information Communications Office (ICO) | • Responsible for administering:  
  o the Data Protection Act  
| Human Fertilisation and Embryology Authority (HFEA) | (EC Directive) Regulations 2003  
• Freedom of Information Act  
• The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004  
• The Freedom of Information (Removal and Relaxation of Statutory Prohibitions on Disclosure of Information) Order 2004  
• The Environmental Information Regulations 2004  
• The INSPIRE Regulations 2009  
• From 2010 has had power to issue fines and penalties |  
|  |  |  
• Is responsible for the HFEA Register.  
• Publishes annual reports.  
• Main functions are to:  
  o license and monitor clinics carrying out in vitro fertilisation (IVF) and donor insemination  
  o license and monitor establishments undertaking human embryo research  
  o maintain a register of licences held by clinics, research establishments and storage centres  
  o regulate storage of gametes (eggs and sperm) and embryos  
  o implement the requirements of the European Union Tissue and Cells Directive (EUTCD) to | http://www.hfea.gov.uk/135.html  
Useful document explaining the role of the HFEA. Available for download at-  
http://www.hfea.gov.uk/docs/About_the_HFEA.pdf  
Most recent report is Human Fertilisation and Embryology Authority Annual Report and Accounts 2010/11.  
This is available for download at-  
http://www.hfea.gov.uk/docs/2011-07-
relicense IVF clinics and to license Intrauterine Insemination (IUI), Gamete Intrafallopian Transfer (GIFT) and other services.

- Provides summaries of national statistics on:
  - fertility problems and treatments including in vitro fertilisation (IVF),
  - intra-cytoplasmic sperm injection (ICSI),
  - pre-implantation genetic diagnosis (PGD)
- and natural cycles.

**Ethics and Confidentiality Committee of the National Information Governance Board (NIGB)**

- Dr Kaye is one of the members of the Committee.
- Will consider applications for access to data for research purposes from the HFEA Register.
- Established in accordance with section 251 of the NHS Act 2006.
- Section 251 of the NHS Act 2006 (originally enacted under Section 60 of the Health and Social Care Act 2001), allows the common law duty of confidentiality to be set aside in specific circumstances where anonymised information is not sufficient and where patient consent is not practicable.

**General Registrar Office**

- Responsible for birth and death registrations

**Health Protection Agency (HPA)**

- Responsible for Genitourinary Medicine Clinic Activity Dataset (GUMCAD)
- It collects data on sexually transmitted infections diagnosed in England in genitourinary medicine (GUM)

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Research Topic: Reproductive Health Registries
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX
clinics (also called STI clinics) and other settings.

- It publishes tables and reports of data online.
- How can GUMCAD data be accessed?
  - GUMCAD and HIV Data Sharing Policies

4.1.1. The GUMCAD data custodian at CfI is responsible for ensuring that patient-level GUMCAD data are held, managed and accessed at the Colindale site in line with Caldicott principles and according to these guidelines.

4.1.2. Regional GUMCAD data custodians are responsible for ensuring that patient-level GUMCAD data for their region are managed and accessed in line with Caldicott principles and according to these guidelines.

4.1.3. The GUMCAD data custodian at CfI is responsible for ensuring that high-level aggregated data are appropriately anonymised prior to publication on the HPA website or in national reports.

4.1.4. Regional GUMCAD data custodians are responsible for ensuring that high-level aggregated data are appropriately anonymised prior to publication on regional websites or in regional reports.

All-Party Parliamentary Group on Sexual and Reproductive Health in the UK (APPG)

- Main aim is “to raise awareness in parliament of the needs of women seeking abortion and the importance of improving all aspects of the sexual health of women and men in the UK.”
- Has joint support from the British Association for Sexual Health and HIV

And main website:
<table>
<thead>
<tr>
<th>Organization</th>
<th>Description</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual Health and HIV, the FPA, and the Faculty of Sexual and Reproductive Healthcare.</td>
<td>• It conducts inquiries and produces reports on key issues in sexual health.</td>
<td><a href="http://www.fpa.org.uk/campaignsandadvocacy/advocacy-and-lobbying/all-party-groups-on-sexual-health/appg-uk">http://www.fpa.org.uk/campaignsandadvocacy/advocacy-and-lobbying/all-party-groups-on-sexual-health/appg-uk</a></td>
</tr>
<tr>
<td>The Family Planning Association UK (FPA)</td>
<td>• Aims to educate and inform people about sexual and reproductive health.</td>
<td><a href="http://www.fpa.org.uk">http://www.fpa.org.uk</a></td>
</tr>
</tbody>
</table>

Fact sheets on matters of sexual health available at: [http://www.fpa.org.uk/professionals/factsheets](http://www.fpa.org.uk/professionals/factsheets)
# Registers

<table>
<thead>
<tr>
<th>Name of register:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
<tbody>
<tr>
<td>HFEA Register</td>
<td>• governed by the HFEA</td>
<td><a href="http://www.hfea.gov.uk/5447.html">http://www.hfea.gov.uk/5447.html</a></td>
</tr>
<tr>
<td></td>
<td>• collects data on:</td>
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</tr>
<tr>
<td></td>
<td>o IVF/ICSI</td>
<td></td>
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<tr>
<td></td>
<td>o donor treatments and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o the storage of embryos, eggs and sperm.</td>
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<tr>
<td></td>
<td>• The Register records information on donors and on any children conceived as a result of their donation.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• It provides a record of all births as a result of assisted reproduction from licensed UK fertility clinics from 1 August 1991 – the date the HFEA was set up – and onwards.</td>
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<tr>
<td></td>
<td>Since 2005, the Register now collects the following information regarding donors:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• their physical description (height, weight, eye and hair colour) if provided by the donor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• the year and country of their birth</td>
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<tr>
<td></td>
<td>• their ethnicity</td>
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<tr>
<td></td>
<td>• whether they had any children, how many and their gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• their marital status</td>
<td></td>
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<tr>
<td></td>
<td>• their medical history</td>
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<tr>
<td></td>
<td>• a goodwill message to any potential children, if provided by the donor</td>
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</tr>
<tr>
<td></td>
<td>• identifying information (the donor’s name, date of birth, etc.)</td>
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<tr>
<td>What data be accessed?</td>
<td></td>
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<tr>
<td>----------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Can be accessed for research purposes</td>
<td></td>
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</tr>
<tr>
<td>• Donor-conceived offspring can access information regarding their biological parents.</td>
<td></td>
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</tr>
<tr>
<td>• Donor-conceived people who are conceived after 1 April 2005 can:</td>
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<tr>
<td><strong>at 16 years old</strong> apply to the HFEA to receive the non-identifying information that their donor provided (all information given by the donor except for their name and last-known address).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>And when they reach 18 years old, they can apply to the HFEA to find the information their donor provided, including identifying information.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anonymised data?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• The HFEA will be publishing an anonymised version of our Register.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• This will contain a large proportion of all the register data going back to 1991, with the patient identifiers (for example date and place of birth, names, address, place of treatment) removed.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>UK Donor Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Voluntary register,</td>
</tr>
<tr>
<td>• It allows people conceived through donated sperm, and / or eggs, their donors and half-siblings to exchange information and where desired to contact</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
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<tr>
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<tbody>
<tr>
<td></td>
<td>The register is specifically for anyone over the age of 18 who was conceived using donated sperm or eggs, or who donated, in the UK, before the Human Fertilisation and Embryology Act came into force in August 1991.</td>
</tr>
<tr>
<td></td>
<td>The register is available throughout the UK.</td>
</tr>
<tr>
<td></td>
<td>Has funding from Department of Health</td>
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<td></td>
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</tbody>
</table>
### Legislation

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Health and Social Care Act 2012 | • “Establishes an independent NHS Board to allocate resources and provide commissioning guidance  
• increases GPs’ powers to commission services on behalf of their patients  
• strengthens the role of the Care Quality Commission  
• develops Monitor, the body that currently regulates NHS foundation trusts, into an economic regulator to oversee aspects of access and competition in the NHS  
• cuts the number of health bodies to help meet the Government’s commitment to cut NHS administration costs by a third, including abolishing Primary Care Trusts and Strategic Health Authorities.” | Available in full at-  
Further information and explanatory notes available at-  
http://services.parliament.uk/bills/2010-12/healthandsocialcare.html  
| Human Fertilisation and Embryology Act 2008 | • Administered by the Human Fertilisation and Embryology Authority (HFEA) | http://www.legislation.gov.uk/ukpga/2008/2/2/contents  
Also, useful to look at the HFEA’s website http://www.hfea.gov.uk/134.html |
| Human Fertilisation and Embryology Act 1990- this is amended and replaced by the 2008 Act | | |
| Abortion Act 1967  
The Abortion Regulations 1991 | | |
|---|---|
| The Human Fertilisation and Embryology (Disclosure of Information for Research Purposes) Regulations 2010 | Came into force on 6 April 2010. With the exception of information relating to donor conception and to patients who have opted out, the HFEA can disclose such data which was entered on the Register prior to October 2009, for research purposes, with the following safeguards:  
- Only recognised research institutions may apply for access to Register data.  
- Applicants must demonstrate how their research will be in the public interest, and why it cannot be carried out on non-identifying information  
- Applicants must have research ethics committee approval for their proposed projects prior to submission to the HFEA  
- Researchers will be bound by the same confidentiality restrictions as the HFEA and licensed clinics. |
### India Regulatory Bodies and Projects

<table>
<thead>
<tr>
<th>Regulatory body or project:</th>
<th>Functions and relevant information:</th>
<th>Websites:</th>
</tr>
</thead>
</table>
| Institute for Reproductive Health (IRH) in India, project of Georgetown University | • FAM project aims to increase access to and expand the range of family planning options in India.  
• Started in 2001 and is ongoing | |
| National Family Health Surveys (NFHS) | • Primary aim is to provide reliable data on population and health indicators. | [http://hetv.org/india/nfhs/anfhs.html](http://hetv.org/india/nfhs/anfhs.html) |
| The Medical Council of India | • Established in 1934 under the National Medical Council Act. This was repealed and replaced by a new enactment in 1956. This Act was most recently amended in 2001.  
• The Council’s aim is to establish and maintain uniform standards in higher education in medicine and also ensure the recognition of Indian medical qualifications. | [http://www.mciindia.org/AboutMCI/Introduction.aspx](http://www.mciindia.org/AboutMCI/Introduction.aspx)  
The website also contains copies of all applicable legislation, regulations and rules. |
<p>| Humanitarian Technology Challenge | • | <a href="http://ieeehtc.org">http://ieeehtc.org</a> |</p>
<table>
<thead>
<tr>
<th>Institution</th>
<th>Details</th>
</tr>
</thead>
</table>
| Post-Graduate Institute of Medical Education and Research (PGIMER) | - PGIMER is in the process of computerising all its patient records. [9]  
| The Indian Council of Medical Research (ICMR) | - Originally established in 1911 as the Indian Research Fund Association, from 1949 it became the ICMR.  
- Its research priorities include research into:  
  o Fertility control;  
  o Maternal and child health;  
  o And control of nutritional disorders. |
| National Institute of Malaria Research (NIMR) | - Is an institute of the ICMR  
- Runs the Malaria Parasite Bank, which collects samples of human malaria parasites |
| Commission for Protection of Rights of the Child (NCPCR) | - Established in 2007 in accordance with the Commission for Protection of Child Rights Act, 2005.  
- Its “mandate is to ensure that all Laws, Policies, Programmes, and Administrative Mechanisms are in consonance with the Child Rights perspective as enshrined in the Constitution of India and also the UN Convention on the Rights of the Child. The Child is defined as a person in the 0 to 18 years age group.”  
- The Commission carries out a wide range of activities, including work in the areas of Child Health and Nutrition and Children with HIV/AIDS.  
- The NCPCR has issued a series of policy documents and guidelines, including a policy document on the rights of children. |


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children infected or affected by HIV/AIDS and Guidelines on nutrition.

- It has also carried out public hearings on matters including, HIV/AIDS.
- So far, NCPCR has established or has issued notice for the establishment of 15 state commissions:
  - Assam State Commission for Protection of Child Rights;
  - Bihar State Commission for Protection of Child Rights;
  - Chhattisgarh Commission for Protection of Child Rights;
  - Delhi Commission for Protection of Child Rights (DCPCR);
  - Goa Commission for Protection of Child Rights (GCPCR);
  - Jharkhand – should be formed soon, as in 2011 the Jharkhand Department of Social Welfare Women and Child Development issued a notification establishing rules for a Jharkhand Commission for the Protection of Child Rights;¹⁰
  - Karnataka Commission for Protection of Child Rights (KCPCR);
  - Madhya Pradesh State Commission for Protection of Child Rights (MPSCPCR);
  - Maharashtra Commission for Protection of Child Rights (MCPCR);
  - Orissa State Commission for Protection of Child Rights


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### Punjab- Soon to be constituted in accordance with the notification issued in 2011, Notification No. 5/1/2006-1SS/916:
- Notification No. F/DWCD/ICDS/Uni-Cons/09-10/11919 and Notification no- F(WCD/ICDS/Uni-Cons/ICDS/09-10/26112;

### Rajasthan State Commission for Protection of Child Rights (RSCPCR)
- Notification No. G.O. (Ms) No. 202;

### Sikkim Commission for Protection of Child Rights (SCPCR)

### Tamil Nadu Commission for Protection of Child Rights (TNCPCR)
- Notification No. F(DWCD/ICDS/Uni-Cons/ICDS/09-10/26112;

### Uttrakhand Commission for Protection of Child Rights (UCPCR)

Several Working Groups have also been created including:
- The Working Group on Female Feticide and Infanticide;

<table>
<thead>
<tr>
<th>Family Planning Association India</th>
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</thead>
<tbody>
<tr>
<td>• Established in 1949.</td>
</tr>
<tr>
<td>• It seeks to strengthen “a voluntary and non-government commitment to promote sexual and reproductive health and rights including family planning. It supports the rights of individuals to reproductive choices, including legal and safe abortion; works towards reducing the spread and the</td>
</tr>
</tbody>
</table>

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11 Available at: [http://www.ncpcr.gov.in/StateCommissions/Notification-%20PSCPCR.pdf](http://www.ncpcr.gov.in/StateCommissions/Notification-%20PSCPCR.pdf)


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impact of STIs/HIV/AIDS and increasing access to gender sensitive SRH information, education and services to all especially the young and marginalized and eliminating violence, discrimination, and abuse.”

- It works with NGOs and the Government.
- Its key areas of interest are:
  - Population Stabilisation
  - Prevention of Unsafe Abortion and Sex Selective Abortions
  - Reduction in Infant Mortality Rate
  - Reduction in Maternal Mortality Rate
  - Reduction in Reproductive Morbidity of Men and Women
  - Reduction in Sexually Transmitted Infections including HIV
  - Gender Equity and Gender Equality
  - Meeting the SRH Needs of Youth

- Its collaborating partners are:
  - National Integrated Medical Association (NIMA)
  - Federation of Indian Chambers of Commerce & Industry (FICCI)
  - Packard Foundation
  - Planned Parenthood Federation of America, University of Rochester, USA
  - Japan Trust Fund
  - UNFPA
  - West Wind Foundation
  - Ford Foundation
  - Government of India
<table>
<thead>
<tr>
<th>Research Topic: Reproductive Health Registries</th>
<th>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</th>
<th>Date: August 16th 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ministry of Health and Family Welfare (MOHFW)</td>
<td>• Consists of 4 departments:</td>
<td><a href="http://mohfw.nic.in">http://mohfw.nic.in</a></td>
</tr>
<tr>
<td></td>
<td>o State AIDS Cell</td>
<td></td>
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<td></td>
<td>o FHI (Family Health International)</td>
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<td></td>
<td>o CORT (Centre for Operations Research and Training)</td>
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<td>o Humanas</td>
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<td></td>
<td>o Avert Society</td>
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<td></td>
<td><a href="http://www.mohfw.nic.in/NRHM/RCH/Inde">http://www.mohfw.nic.in/NRHM/RCH/Inde</a></td>
<td></td>
</tr>
<tr>
<td>Reproductive and Child Health Programme II</td>
<td>•</td>
<td><a href="http://www.mohfw.nic.in">http://www.mohfw.nic.in</a></td>
</tr>
<tr>
<td>Reproductive Health Programme, (project of the</td>
<td>• Is an international, nonprofit, NGO “that seeks to improve</td>
<td><a href="http://www.popcouncil.org/what/hivaids.asp">http://www.popcouncil.org/what/hivaids.asp</a></td>
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<td>Population Council)</td>
<td>the well-being and reproductive health of current and</td>
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<td>future generations around the world and to help achieve</td>
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<td>a humane, equitable, and sustainable balance between</td>
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<td>people and resources.”</td>
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<td></td>
<td>• It conducts research and runs programmes in many</td>
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<td></td>
<td>countries,</td>
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<tr>
<td>Norway-India Partnership Initiative (NIPI)</td>
<td>• This initiative began in 2006 to support an existing</td>
<td><a href="http://www.unops.org/english/whatwedo/UN%EF%BF%BDOPSinaction/Pages/norway-india-partnership-initiative.aspx">http://www.unops.org/english/whatwedo/UN�OPSinaction/Pages/norway-india-partnership-initiative.aspx</a></td>
</tr>
<tr>
<td></td>
<td>National Rural Health Mission (NRHM).</td>
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<td></td>
<td>The project was set to run until 2011, and focussed on 5</td>
<td><a href="http://www.norad.no/en/tools-and-publications/publications/publication?key=157459">http://www.norad.no/en/tools-and-publications/publications/publication?key=157459</a></td>
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<td>states:</td>
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<td>o Bihar;</td>
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<td>o Rajasthan;</td>
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<tr>
<td>Research Topic: Reproductive Health Registries</td>
<td>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</td>
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<td>---------------------------------------------</td>
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</table>

### Janani Suraksha Yojana (JSY)
- Is a national “scheme aimed at reducing maternal and infant mortality rates and increasing institutional deliveries in below poverty line (BPL) families. The JSY, which falls under the overall umbrella of National Rural Health Mission (External website that opens in a new window), covers all pregnant women belonging to households below the poverty line, above 19 years of age and up to two live births.”
- The scheme began in 2003 and made cash available to pregnant women to assist them in obtaining antenatal services and institutional care. This modified the National Maternity Benefit Scheme (NMBS), which was focussed on improving diet.

A summary of the NMBS Scheme is available at-
http://planningcommission.nic.in/reports/sereport/ser/maker/mak_cht5c.pdf

For more information please refer to-


### National Rural Health Mission (NRHM)
- the project was intended to improve healthcare delivery to vulnerable populations with a focus on women living below the poverty line.
- Its key target was to reduce “maternal mortality to fewer than 100 per 100,000 live births by 2012.”
- However, evaluations by a wide variety of organisations

http://mohfw.nic.in/NRHM.htm
show that a large number of women still have no access to fair, affordable and reliable maternal healthcare.

- One problem is that the composite index, which was meant to be developed and then used to allocate resources, has not been developed.
- Also, the National Maternity Benefit Scheme (NMBS) has been closed and the central government has requested the return of funds granted under the NMBS scheme.
- The actions of the central government here are in contradiction to a Supreme Court order in 2007 which "clarified that nutritional benefits guaranteed under the NMBS and the cash incentives provided under the JYS are independent of each other; pregnant women are entitled to both."\(^{14}\)

| Janani-Shishu Suraksha Karyakaram (JSSK) (project of MOHFW as part of the NRHM) | • Aims to provide free and cashless service to all pregnant women and also care for sick newborns in Government health institutions.
| Repository on Maternal Child Health | • “virtual guide to Child Health and related Maternal Health information relevant to Public Health in India. It is a one-stop access to efficiently search, organize and share latest information.” | [Human Rights Law Network (HRLN)](http://www.hrln.org/hrln/) |
| Human Rights Law Network (HRLN) | • has launched many legal cases seeking accountability for “maternal health violations”. |  


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### Registers

<table>
<thead>
<tr>
<th>Name of register</th>
<th>Functions and information</th>
<th>Website</th>
</tr>
</thead>
</table>
| National Transplant Register     | • Project of the Indian Society of Organ Transplantation.  
• The aim is to collect transplant related data on a national basis.  
• This register is to be developed in phases. It is currently in the first stage of development and this will focus on collecting data related to kidney and liver transplant.  
• “The data will be stored in a secure server and can be accessed by any registered member of ISOT. The information submitted will be treated as highly confidential. So the members will be able to see the data of their hospital. Only collated data will be available for viewing.” | [http://www.transplantindia.com/index.asp](http://www.transplantindia.com/index.asp) |
| Clinical Trials Registry India (CTRI) | • Established in 2007  
• It is a “free and online public record system for registration of clinical trials being conducted in India.”  
• Registration was initially voluntary, but in 2009 the Drugs Controller General (India) (DCGI) has made registration mandatory.  
• Provides guidance and has produced the Good Clinical Practice Guidelines (GCP) | Central Drugs Standards Control Organisation (CDSCO)- [http://www.cdsco.nic.in](http://www.cdsco.nic.in) |
| Duchenne muscular dystrophy (DMD) registries | • 2 DMD registries are in the process of being established. | Please follow the link which provides contact details of the project leaders-[http://www.treat-nmd.eu/registry/335/](http://www.treat-nmd.eu/registry/335/) |
| Birth Defects Registry of India | • | http://www.fcrf.org.in/bdri_abus.asp |
### State Registers and Projects

“At the state level, the Vital Statistics Division of the Directorate of Health deals with cause of death statistics. Cause of death reports originate from lay reporters in rural areas and medical attendants in urban areas. The reports reach the State Vital Statistics office through the primary health centre, in case of rural areas, and the municipal health office for urban areas. Tabulation is usually done at the state level but the statistics are published by the RGI.”

<table>
<thead>
<tr>
<th>Name of register or project</th>
<th>Functions and information</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Births and Death Register, Gujurat</td>
<td>&quot;Registration of Births/deaths Act, 1969 is operative in Gujarat state since 1-4-1970. Rules under section 3 of the Act were implemented since 18-4-1973. Registration general India reviewed the procedure of total registration of statistical works of Birth/deaths and to modify various rules applied Gujarat registration of birth and deaths (revision) rules were published in gazette dated 22-1-2004 and come into force. Registration of births/death are made accordingly.&quot;</td>
<td><a href="http://valsaddp.gujarat.gov.in/valsad/english/shakhao/statistic-branch/birth_death.htm">valsaddp.gujarat.gov.in/valsad/english/shakhao/statistic-branch/birth_death.htm</a></td>
</tr>
<tr>
<td>Tamil Nadu Maternal Death Audit reporting system</td>
<td>This was established in 2000. The system requires that all maternal deaths must be reported within 24 hours of their occurrence, directly to the Commissioner of Maternal and Child Health and Family Welfare.</td>
<td><a href="http://cbhi-hsprod.nic.in/listdetails.asp?roid=22">cbhi-hsprod.nic.in/listdetails.asp?roid=22</a> <a href="http://mohfw.nic.in/NRHM/State%20Files/tamil%20nadu%20maternal%20death%20audit%20reporting%20system.pdf">mohfw.nic.in/NRHM/State%20Files/tamil%20nadu%20maternal%20death%20audit%20reporting%20system.pdf</a></td>
</tr>
</tbody>
</table>

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15 Institute of Health Systems, A brief overview of the cause of death reporting systems in India, available at: [http://www.ihsnet.org.in/BurdenOfDisease/CauseofDeath.htm#A%20brief%20overview%20of%20the%20cause%20of%20death%20reporting%20systems%20in%20India](http://www.ihsnet.org.in/BurdenOfDisease/CauseofDeath.htm#A%20brief%20overview%20of%20the%20cause%20of%20death%20reporting%20systems%20in%20India)

16 For more information please see the following:
| Health Department of M.C.D. (Delhi) | Registers vital events in Delhi.  
Governed by the Registration of Births & Deaths Act 1969 (RBD Act) and Delhi State Rules for Registration of Births & Deaths 1999.  
Has a scheme, OLIR for the online registration of births and deaths | [milnadu.htm](http://111.93.47.72/rbd/)  
For information on OLIR, see-[http://111.93.47.72/rbd/detail.php?&var=aWQ9NiZwYXJhbXM9aWQ](http://111.93.47.72/rbd/detail.php?&var=aWQ9NiZwYXJhbXM9aWQ) |
|-----------------|-----------------------------------------------|----------------------------------------------------------------------------------|
| Goa Department of Health Services, Offices of the Registrar of Births, Deaths and Marriages | Governed by the Registration of Births & Deaths Act 1969 (RBD Act)  
"In Goa, the District Magistrate and Collectors have been designated as “District Registrar of births and deaths” the Sub-Divisional Magistrates/Block Development Officers have been designated as Additional Registrar for birth.”  
"In addition, the commissioner of Panaji Municipal Corporation/ secretary of Municipal Council/ secretary of Village Panchayat and incharges of State/District/Sub-Divisional Hospitals have also been notified as “Registrar of births and deaths”.”  
The different bodies in the state for birth registration are:  
- Corporation of the City of Panaji  
- Municipal Council  
- Village Panchayat  

17 Please see [http://www.goa.gov.in/howdoi/birthcertificate.html](http://www.goa.gov.in/howdoi/birthcertificate.html)
<table>
<thead>
<tr>
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<th>Date: August 16th 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reproductive Child Health Service in Urban Slum, Assam</td>
<td>“The urban health intervention in Guwahati, Assam, involves contracting a trust hospital - Marwari Maternity Hospital (MMH) to provide services in eight low-income municipal wards of the city, having a total population of 2 – 2.5 lakh. The state government pays the MMH for providing outreach and referral services, in the identified areas. In addition, vaccines and contraceptives are provided free to MMH. MMH is covering 14 outreach sites in these areas. It is mainly providing RCH services but the outreach team includes a doctor and they can also treat simple ailments or refer patients to the hospital.”</td>
<td><a href="http://hsprodindia.nic.in/listdetails.asp?roid=29">http://hsprodindia.nic.in/listdetails.asp?roid=29</a></td>
</tr>
</tbody>
</table>
### Legislation and policy

#### Federal legislation and policy

<table>
<thead>
<tr>
<th>Legislation and guidelines etc:</th>
<th>Key points:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Registration of Births & Deaths Act, 1969 | • The Act requires all births to be registered within 21 days of their occurrence.  
• However, there is still relatively low adherence to its provisions.  
• Each state is meant to have its own register. | [http://cr.lsgkerala.gov.in/Docs/RBD%20Act.pdf](http://cr.lsgkerala.gov.in/Docs/RBD%20Act.pdf) |
| ICMR Ethical Guidelines For Biomedical Research on Human Participants | | [http://icmr.nic.in/ethical_guidelines.pdf](http://icmr.nic.in/ethical_guidelines.pdf) |
| • Guidelines for Management of Stomach Cancer  
• Guidelines for Management of Cervix Cancer  
• Guidelines for Management of Buccal Mucosa Cancer | | |
| ICMR Draft Assisted Reproductive Technology (Regulation) Bill - 2010 | | |
| Draft Assisted Reproductive Technology (Regulation) Rules - 2010 | | |
| National Guidelines for Accreditation, | | Available at: |
| Supervision & Regulation of ART Clinics in India | [http://icmr.nic.in/art/art_clinics.htm](http://icmr.nic.in/art/art_clinics.htm) |
| Right to Information Act 2005 (RTI) | • |
| Manual on the Right to Information Act | • Gives information relevant to the NCPCR in compliance with the RTI Act and RTI Rules. [http://www.ncpcr.gov.in/Acts/MANUAL%20ON%20RIGHT%20TO%20INFORMATION%20ACT.pdf](http://www.ncpcr.gov.in/Acts/MANUAL%20ON%20RIGHT%20TO%20INFORMATION%20ACT.pdf) |
| Drugs & Cosmetics Act 1940 (23 of 1940) and Rules made under the Act | • Covers a wide variety of drugs. • Blood is classed as a “drug” for the purposes of the Act and consequently blood banks are regulated by the Act and rules issued under it. Available at- [http://cdsco.nic.in/html/GCP1.html](http://cdsco.nic.in/html/GCP1.html) For more information on blood banks please see- [http://cdsco.nic.in/html/guideline.htm](http://cdsco.nic.in/html/guideline.htm) |
| Drugs & Cosmetics Amendment Act 2008 | • |
| The Commission for Protection of Rights of the Child enactments- | • Established the Commission for Protection of Rights of the Child (NCPCR) • Rule 17(e) and (d) mandates that the Commission: o Ensures that the work of the Commission is directly informed by the views of children in order to reflect their priorities and [http://www.ncpcr.gov.in](http://www.ncpcr.gov.in) |

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<table>
<thead>
<tr>
<th>Law</th>
<th>Description</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Transplantation of Human Organs Act</td>
<td>•</td>
<td>Available at- <a href="http://www.transplantindia.com/tho_act/thobill1cont.asp">http://www.transplantindia.com/tho_act/thobill1cont.asp</a></td>
</tr>
<tr>
<td>1994 (Central Act 42 of 1994)</td>
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<tr>
<td>The Medical Termination of Pregnancy Act</td>
<td>• Specifies circumstances under which medical abortions can legally be carried</td>
<td></td>
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<tr>
<td>1971</td>
<td>out.</td>
<td></td>
</tr>
<tr>
<td>The Medical Termination of Pregnancy</td>
<td>• Makes some minor amendments.</td>
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</table>


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### Amendment Act 2002
- Most notably: section 4 specifies that abortions must take place in hospitals.

### Medical Termination of Pregnancy Regulations, 2003
- Require an Admissions Register to be kept, recording the admission of all women who have terminations. These records are to be kept for 5 years.
- Personal information recorded on the Register is not to be disclosed to anyone.

### Medical Termination of Pregnancy Rules, 2003
- 

### Notification on Medical Termination of Pregnancy (Amendment) Act
- This simply states when the Medical Termination of Pregnancy (Amendment) Act, 2002 shall come into force.

#### Legislation and guidelines etc:

<table>
<thead>
<tr>
<th>Legislation and guidelines etc:</th>
<th>Key points:</th>
<th>Website:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarat Registration of Marriages Act, 2006</td>
<td>•</td>
<td>Available at <a href="http://www.gujhealth.gov.in/Portal/Tender/1/4_Marriagesacteng.pdf">http://www.gujhealth.gov.in/Portal/Tender/1/4_Marriagesacteng.pdf</a></td>
</tr>
<tr>
<td>Reproductive Child Health, RCH II, 2005 (Orissa)</td>
<td>•</td>
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<tr>
<td>Delhi State Rules for Registration of Births &amp; Deaths 1999</td>
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Ghana

Institutional Bodies and projects

<table>
<thead>
<tr>
<th>Institutional bodies and projects:</th>
<th>Functions and relevant information:</th>
<th>Websites:</th>
</tr>
</thead>
</table>
| National Health Insurance Council and the National Health Insurance Scheme (NHIS) | • Established “under Act 650 of 2003 by the Government of Ghana to provide basic healthcare services to persons resident in the country through mutual and private health insurance schemes. The District Mutual, Private Mutual and Private Commercial Schemes are regulated by the National Health Insurance Council (NHIC).”
  • The NHIC is the regulatory body for the National Insurance Scheme.
  • Current operating legislation is the Insurance Act, 2006 (Act 724).  
  • The National Health Insurance Scheme provides 3 main types of insurance:
    ▪ The District-Wide Mutual Health Insurance Scheme.
    ▪ The Private Mutual Health Insurance Scheme.

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22 Legislation is available through the National Insurance Commission’s website, see http://www.nicgh.org/live/images/photos/downloads/Insurance_Act_724_2006.pdf

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Date: August 16th 2012
| National Insurance Commission (NIC) | • “established under Insurance Law 1989 (PNDC Law 227)”
• It currently operates under Insurance Act, 2006 (Act 724).
• Its main objective, in accordance with Act 724 I”s to ensure effective administration, supervision, regulation and control the business of Insurance in Ghana.”
• The Commission also makes recommendations to the sector Minister for policy formulation, supervision of practitioners, enforcement of compliance and public education. | [http://www.nicgh.org/live/en/](http://www.nicgh.org/live/en/) |
| The Assisted Conception Unit, (ACU) Finney Hospital and Fertility Centre | • Recently established.
| EngenderHealth runs the following programmes in Ghana: | • The R3M project focuses on assisting health care providers’ capacity to prevent unwanted pregnancies and engage men in reproductive health.
• The QHP project ran from 2004-2009 and was “funded by the U.S. Agency for International Development (USAID) to support the Ghana Health Service/Ministry of Health to ensure high quality of reproductive and child health services in Ghana. | [http://www.engenderhealth.org/our-countries/africa/ghana.php](http://www.engenderhealth.org/our-countries/africa/ghana.php) [http://www.ghanaqhp.org](http://www.ghanaqhp.org) |
• The program spanned the public and the private sectors and included: family planning, reproductive health, maternal and child health, HIV and AIDS prevention, care and treatment, malaria prevention and treatment, and infectious disease surveillance. The program focused its efforts on 30 districts located in 7 regions of Ghana plus other districts with high prevalence of HIV, and led major efforts in the development of national service delivery protocols, guidelines and training curricula for health care providers."\(^{23}\)

• QHP’s work for HIV and AIDS prevention was extended into 2010.

• QHP supports training and provision of equipment to practitioners working in family planning and reproductive health.

• As part of its work QHP has conducted several baseline surveys and has reports available on its website.\(^{24}\)

• Engender’s other activities relating to HIV and AIDS aim to:
  o Promote voluntary counselling and testing for HIV


| Ghana Community-Based Health Planning and Services (CHPS) Initiative | • This model was adopted in Ghana in 1999.  
• “CHPS is based on the successful Navrongo Community Health and Family Planning (CHFP) experimental model, which changes the focus of primary health care and family planning services from clinical care to providing high-quality services at community and doorstep locations. This national program of service delivery change is achieved by forging partnerships between health care providers and the communities they serve.” | [http://www.popcouncil.org/projects/26_CHPS.asp](http://www.popcouncil.org/projects/26_CHPS.asp)  
| Ipas Ghana, an Ipas project. | • Established in 1973 Ipas is a global NGO which works to improve access to safe abortions and abortion care, as well as ending preventable deaths and Abortion attitude transformation: A values clarification toolkit for global audiences, | [http://www.ipas.org/en/Who-We-Are.aspx](http://www.ipas.org/en/Who-We-Are.aspx) |
disabilities caused by unsafe abortions.

- “Ipas Ghana advocates for women’s access to a full range of reproductive health services, including family planning and safe abortion.” It works to reduce maternal mortality and improve maternal health.
- Ipas also provides training and information toolkits on its website.

available at
Other resources also available at

INDEPTH Network

- “INDEPTH will be an international platform of sentinel demographic sites that provides health and demographic data and research to enable developing countries to set health priorities and policies based on longitudinal evidence. INDEPTH's data and research will guide the cost effective use of tools, interventions and systems to ensure and monitor progress towards national goals.”
- Its mission is: “To harness the collective potential of the world's community-based longitudinal demographic surveillance initiatives in resource constrained countries to provide a better, empirical understanding of health and social issues, and to apply this understanding to alleviate the most severe health and social challenges.”

Main website -
iSHARE –
http://www.indepth-ishare.org
<table>
<thead>
<tr>
<th>Research Topic: Reproductive Health Registries</th>
<th>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</th>
<th>Date: August 16th 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data sharing?</td>
<td><img src="image" alt="Image" /></td>
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<tr>
<td>Has established iSHARE in order to share its data over the Internet.</td>
<td><img src="image" alt="Image" /></td>
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<tr>
<td>Data is not currently available for Ghana, but it may be in the future.</td>
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</table>

**Reducing Maternal Morbidity and Mortality (R3M) (project of the Population Council)**

- Project begun in 2006.
- It aims to reduce unwanted fertility and improve the availability of comprehensive abortion care (CAC).
- “In 2010, the Council received a two-year follow-on grant to extend R3M activities. The Council’s role in this second phase of the program centers on providing technical and financial support for improving the Ghana Health Service’s health information management system, coordinating activities of R3M partners and reporting on progress and accomplishments, renovating identified health facilities for improved provision of high-quality services, conducting small-scale operations research studies to guide program activities, and leading the development of an advocacy strategy to support program efforts. The program has successfully provided technical assistance in training midlevel providers (midwives) in the provision of CAC.”

services, supported the country’s contraceptive commodity security drive, supplied essential equipment needed for family planning and CAC services, and constructed two reproductive health Centers of Excellence to help in the further development of the country’s health providers.”

<table>
<thead>
<tr>
<th>Strengthening Evidence for Programming on Unintended Pregnancy (STEP UP) (project of the Population Council)</th>
</tr>
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<tbody>
<tr>
<td>• “The goal of the STEP UP Research Program Consortium is to improve the health of the poorest and most vulnerable, particularly women, in the developing world. The consortium supports an evidence-based approach to scaling up access to high-quality family planning and safe abortion services (where available within the context of national laws).”</td>
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<td>•</td>
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</table>

http://www.popcouncil.org/projects/325_STEPUP.asp

http://stepup.popcouncil.org
### Registers

<table>
<thead>
<tr>
<th>Name of register</th>
<th>Functions and information</th>
<th>Website</th>
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</thead>
</table>
| Births and Deaths Registry                 | • Established in 1965 under the Registration of Births and Deaths Act, 1965 (Act301).  
• It records only births, deaths and foetal deaths.  
• Its primary function is to record and provide accurate information regarding all births and deaths occurring in Ghana.  
• In accordance with Act301 “the activities of the Vital Registration System are coordinated from a national headquarters, referred to as the Central Registry Office.”  
• Ghana is divided into 10 Registration Regions and the Registry has offices in 138 districts.  
• It has also begun the process of computerising the Register, although this is an ongoing process. | http://www.bdrghana.gov.gh/            |
| Registrar General’s Department             | • Established in accordance with the Ordinance of 1950. It has been a department of the Ministry of Justice since 1961.  
• It is responsible for registering:  
• businesses,                                                                                                                                  | http://www.rgd.gov.gh                   |
| • industrial property,  
| • marriages,  
| • administration of estates,  
| • and public trustees. |
### Legislation and policy

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
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</thead>
<tbody>
<tr>
<td>Registration of Births and Deaths Act, 1965 (Act 301)</td>
<td>•</td>
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<tr>
<td>National Blood Policy for the Health Sector 2006</td>
<td>• Clause 3.1- Its aim is to &quot;ensure safety, efficacy and adequacy of blood and blood products for all patients, in all Health Institutions of the country, both public and private, making it accessible and affordable.”</td>
<td>Available at- <a href="http://www.who.int/bloodsafety/transfusion_services/GhanaNationalBloodPolicy2006.pdf">http://www.who.int/bloodsafety/ transfusion_services/GhanaNationalBloodPolicy2006.pdf</a></td>
</tr>
<tr>
<td>National Health Insurance Act 2003</td>
<td>• established the National Insurance Scheme</td>
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</table>
### Other African Nations

#### Organisations and Projects-

<table>
<thead>
<tr>
<th>Project name</th>
<th>Functions and relevant information:</th>
<th>Websites:</th>
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</table>
| STEP UP programme (project of Population Council)                            | - Works in Ghana, Kenya, Senegal, India and Bangladesh.  
- It aims “to strengthen evidence-based programming for improving access to family planning and safe abortion services and reducing unintended pregnancy in priority countries in sub-Saharan Africa” | [http://stepup.popcouncil.org/keyresearch.html](http://stepup.popcouncil.org/keyresearch.html)       |
| The Karonga Health and Demographic Surveillance System (Karonga HDSS). This is currently in the process of changing its name to the Malawi Epidemiology and Intervention Research Unit (MEIRU). | - Collaborative effort by Malawi College of Medicine and the London School of Hygiene and Tropical Medicine (LSHTM). It works closely with the Ministry of Health.  
- It began in 1979 in the Karonga province and was focused on researching the incidence and risk factors associated with leprosy. It has since expanded its research into AIDS, tuberculosis and most recently, non-communicable diseases, including hypertension, diabetes and hyperlipidaemia.  
- They have created a database with records relation to more than 300,000 individuals and “have a biorepository of over 100,000 samples and | [http://www.lshtm.ac.uk/eph/ide/research/kps/](http://www.lshtm.ac.uk/eph/ide/research/kps/) |
Research Topic: Reproductive Health Registries

Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012

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**KEMRI/CDC Research and Public Health Collaboration**

- Established in 1979 by US Centers for Disease Control and Prevention (CDC) and the Kenya Medical Research Institute (KEMRI).
- Collaborative effort by US and Kenya.
- It initially focused on malaria research, but has since expanded its endeavours and now has diverse projects throughout Kenya.
- It has established a population registration system, the Health and Demographic Surveillance System (HDSS), which monitors the health and wellbeing of a geographically defined population in the Nyanza province.


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**African Population and Health Research Center**

- One of its current projects is Demographic and health dynamics in urban Africa (DHDU): 2011-2014.
- DHDU has 4 main objectives:
  1. Strengthen the evidence base to guide policies and programs aimed at improving the wellbeing of the urban poor through conducting a unique set of cross-sectional and longitudinal surveys in informal settlements of Nairobi;
  2. Use these and related evidence to advocate and advance policy and action in meeting the health needs and wellbeing challenges of the urban population.

[http://www.aphrc.org](http://www.aphrc.org)

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<td>poor at various local, national, regional and global forums;</td>
<td>Build the research capacity of young and promising African scholars through doctoral research grants and related efforts, and</td>
</tr>
<tr>
<td>o Build the research capacity of young and promising African scholars through doctoral research grants and related efforts, and</td>
<td>o Build strategic partnerships with other urban health research institutions in sub-Saharan Africa to strengthen and consolidate the generation and use of evidence on urban reproductive health challenges across sub-Saharan Africa.</td>
</tr>
</tbody>
</table>
### Organisation and registers:

<table>
<thead>
<tr>
<th>Organisation and registers:</th>
<th>Functions and information:</th>
<th>Website:</th>
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</table>
| The Personally Controlled eHealth Record System (PCEHR) | • This is the first stage in the development of the eHealth system began this year.  
• This is an innovative development in personalised medicine, allowing people to register and have access to their personal health records online.  
• However, there has been a relatively low level of registration so far.  
• Note: it uses the term “consumer” rather than patient to refer to those who have an account on the system. | Privacy policy is available here- http://ehealth.gov.au/internet/ehealth/publishing.nsf/Content/ehealth_privacy#.UDVSxEK4Ss8  
| National Health and Medical Research Council (NHMRC) | • Responsible for issuing the Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice (ART Guidelines). | http://www.nhmrc.gov.au/ |
| AIHW National Perinatal Epidemiology and Statistics Unit (PRERU) | • Includes IHW National Perinatal Epidemiology and Statistics Unit (NPESU).  
• Established in 1979  
• It is part of the University of New South Wales | http://www.preru.unsw.edu.au/PRERUWeb.nsf/page/AIHW%20National%20Perinatal%20Epidemiology%20and%20Statistics%20Unit |

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| Research Topic: Reproductive Health Registries | It has 3 main data collections:  
• National Perinatal Data Collection  
• Australian Congenital Anomalies Monitoring System  
• Maternal Deaths Data Collection  
• Ethical approval may be required for some project utilising NPESU data. Approval can be obtained from:  
  o UNSW Ethics Committee  
  o AIHW Ethics Committee  

| National Health Information Standards and Statistics Committee (NHISSC) | Established in August 2008.  
• Its functions are to:  
  o Provide strategic advice to AHMC on issues relating to health information standards;  
  o Endorse national information standards for the health sector; and  
  o Endorse specifications for statistical collections of national health information.  
• Data Principles for the Blood Sector must comply with NHISSC requirements. The data principles used to guide the Strategy to data are currently in the process of being updated.  

| National E-Health Information Principal Committee (NEHIPC) | Its main aim “is to advise AHMAC on e-health and information strategies and to facilitate collaboration  

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between the Commonwealth, States and Territories to implement these strategies.”
- set out 4 priorities for the improved use of health information in its Strategic Plan for 2007-08 to 2012-13.

National Blood Authority (NBA)
- “Under the National Blood Agreement one of the primary policy objectives for the NBA is to undertake national information gathering, monitoring of new developments, reporting and research in relation to the Australian Blood sector.”
- Is committed to making data available to the community.
- It publishes an Annual Report, the most recent in 2010-11.

Childrens Services Data Working Group (CSDWG)
- Established in 1998
- Aims to improve national children’s services data
- It is a subgroup of the National Community Services Information Management Group (NCSIMG).
- Its membership is composed of:
  - representatives from each of the state and territory departments responsible for children’s services and education, the Australian Government departments of Family and Community Services, and Education, Science and Training, the Australian Bureau of Statistics, the Productivity Commission and the Australian Institute of Health and Welfare.”
| Australian Haemophilia Centre Directors' Organisation (AHCDO) | • Its aims are to:  
  o “To advance care and treatment of people with haemophilia in Australia;  
  o to advance the education of the medical profession and the broad range of health professionals associated with people with haemophilia in the knowledge of haemophilia and its treatment;  
  o to promote haemophilia research, and to disseminate the results of such research;  
  o to liaise with, and provide information and advice to Haemophilia Foundation Australia, Federal, State and Territory Governments, and other such bodies involved in the welfare of people with haemophilia in Australia.”  
• Members previously met under the name of Medical Advisory Panel (MAP) of the Haemophilia Foundation Australia (HFA).  
• Provides useful guidelines on a variety of matters relating to bleeding disorders. |
| Department of Epidemiology and Preventative Medicine (DEPM), Monash University | • Responsible for a wide variety of projects.  
• Its core areas of research are:  
  o Epidemiology;  
  o Biostatistics;  
  o and data management support  
• Many Australian registries are managed by DEPM’s Clinical Informatics and Data Management Unit | [http://www.ahcdo.org.au](http://www.ahcdo.org.au)  
Registry currently managed by or affiliated with DEPM and CIDMU are:

- ANZSCTS Database Project
- Australian Rheumatology Association Database
- Haemostasis Registry
- Melbourne Interventional Group
- REACH Registry
- ASCTS Database Project
- Australian Rheumatology Association Database (ARAD) Project
- Bosentan Patient Registry
- Population-based prostate cancer clinical registry
- Surveillance of workplace Based Respiratory Events (SABRE)
- Victorian Cardiac Arrest Registry
- Victoria Lung Cancer Registry
- Victorian Orthopaedic Trauma Registry
- VSTORM - Monitoring and Evaluation of the Victorian State Trauma System

Australian Institute of Health and Welfare (AIHW)

- Agency established under the Australian Institute of Health and Welfare Act.
- Aims "to provide reliable, regular and relevant information and statistics on Australia's health and welfare."
- It is "an independent statutory authority

established in 1987, governed by a management Board, and accountable to the Australian Parliament through the Health and Ageing portfolio.”

• It produces reports on key health and welfare issues.
• It collects, analyses and reports information “drawn from health services, community services and housing assistance services.”

National Maternity Data Development (NMDD) – a project of PRERU

• “project aims to develop nationally consistent and comprehensive maternity data collection in Australia that will encompass the entire range of models of maternity across all states and territories. Progressive models of maternity care and good quality maternity information are required to maintain good outcomes for mothers and babies in Australia. This project is a collaborative undertaking between the Australian Institute of Health and Welfare (AIHW) and NPESU.”
• Its projects include:
  o Maternal Mortality Project. This “aims to establish a nationally consistent maternal death reporting system, as well as publish a national report on maternal deaths in Australia 2006-2010.”


Research Topic: Reproductive Health Registries
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEx

HeLEx
Oxford

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<tr>
<th>Robinson Institute Research Centre for Reproductive Health (RCRH)</th>
<th><strong>Scope</strong></th>
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</table>
| • The Centre will advance fundamental knowledge and undertake clinical and commercial translation of research outcomes in human and animal reproduction.  
• Centre research focuses on gonadal function and gametogenesis, fertilization and embryo development, implantation and placental development, pregnancy and fetal development, female and male reproductive tract biology and reproductive health | [http://www.adelaide.edu.au/rcrh/about/aims/](http://www.adelaide.edu.au/rcrh/about/aims/) |

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contraception.
• Centre activities span the disciplines of molecular and cell biology, genetics and epigenetics, endocrinology, immunology, physiology and pathophysiology, public and population health as applied to research questions in reproductive health.

Aims
• Undertake world-class fundamental and applied research in key aspects of reproductive biology and medicine.
• Provide national and international leadership in reproductive research and innovation.
• Enhance interdisciplinary and collaborative links and engage in teaching and training to build research capacity.
• Devise research strategies to target clinical, industry and community needs.
• Ensure the Centre's future sustainability through actively sourcing research funding and recruiting first rate students and staff.
• Provide infrastructure and core facilities to optimise research outcomes.
• Facilitate commercial and clinical translation of research.

Strategic Plan 2009
The strategic plan lists specific goals and outcomes for the Centre and outlines the strategies required to achieve these and the key performance indicators.
<table>
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<tr>
<td>Date: August 16th 2012</td>
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<table>
<thead>
<tr>
<th>Conducts research in the following areas:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ovarian and Follicular Function</td>
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<tr>
<td>• Oocyte and Early Embryo Development</td>
</tr>
<tr>
<td>• Uterine Biology</td>
</tr>
<tr>
<td>• Embryo Implantation and Placental Development</td>
</tr>
<tr>
<td>• Male Reproduction</td>
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<tr>
<td>• Reproductive Immunology</td>
</tr>
<tr>
<td>• Reproductive Biotechnology</td>
</tr>
<tr>
<td>• Nutrition, Environment and Reproduction</td>
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<tr>
<td>• Early Life Programming of Fetal Development and Adult Health</td>
</tr>
<tr>
<td>• Menopause</td>
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<td>• Infectious Diseases of the Reproductive and Gestational Tissues</td>
</tr>
<tr>
<td>• Cancers of the Reproductive System</td>
</tr>
<tr>
<td>• Breast Biology and Cancer</td>
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<thead>
<tr>
<th>Australian Reproductive Health Alliance</th>
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<tbody>
<tr>
<td>• This organisation ceased its operations in September 2011.</td>
</tr>
<tr>
<td>• Its work was focussed on the advancement of “the status of women and girls by promoting public support for improved sexual and reproductive health. We do this by providing information and support to leaders, including members of parliament, in Australia and the Asia Pacific region.”</td>
</tr>
</tbody>
</table>

| National Advisory Committee on Maternal Mortality (NACMM) | • Provides oversight for Maternal Deaths Data Collection and publishes reports based on the data.  
• “A subcommittee of the NACMM reviews all maternal deaths to allocate principal and contributory causes of death and to classify the deaths as direct, indirect or incidental in a nationally consistent way.”  
• Consists of representatives of various entities including:  
o “State and Territory Maternal Mortality Committees,  
o Royal Australian and New Zealand College of Obstetricians and Gynaecologists,  
o Australian and New Zealand College of Anaesthetists,  
o Royal Australian and New Zealand College of Psychiatrists,  
o Royal College of Pathologists of Australasia,  
o Australian Commission for Safety and Quality in Health Care,  
o the Maternity Alliance, School of Public Health and Community Medicine (UNSW),  
o Australian College of Midwives, and expert clinicians.”[^33] | http://www.preru.unsw.edu.au/preruweb.nsf/page/NACMM |

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</tr>
</thead>
</table>
| (FSA)                                          | nurses, consumers and counsellors in reproductive medicine in Australia & New Zealand.  
• Each year the FSA holds a Scientific Meeting attracting experts in reproductive health from around the world to present research and discuss new technologies and treatments.” |                                                                                     |
| Australasian Maternity Outcomes Surveillance System (AMOSS) | • “national surveillance mechanism designed to study a variety of rare or serious conditions in pregnancy, childbirth and the post natal phase. Through translating the findings from these studies into reliable evidence-based practice, the aim of AMOSS is to improve the safety and quality of maternity care in Australia and New Zealand.” | http://www.amoss.com.au/ |
| Australasian Association of Cancer Registries (AACR) | • “is a collaborative body representing the eight Australian state and territory cancer registries, the New Zealand Cancer Registry and the AIHW. It was formed in 1982 to provide a formal mechanism for promoting uniformity of collection, classification and collation of cancer data.  
• The AACR collaborates with the AIHW through the National Cancer Statistics Clearing House (NCSCH), which was established at the AIHW in 1986 to co-ordinate national cancer statistics.” | http://www.aihw.gov.au/cancer/aacr/ |

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34 Australasian Maternity Outcomes Surveillance System (AMOSS),  
that makes the reporting of all cancers (other than basal and squamous cell carcinomas of the skin) mandatory. State and territory population-based cancer registries receive information on cancer diagnoses from a variety of sources such as hospitals, pathology laboratories, radiotherapy centres and registries of births, deaths and marriages. When any of these institutions deal with someone with cancer, they are required by law to notify the cancer registries.”

- These registries contain information including:
  - name and address
  - sex
  - date of birth
  - country of birth
  - whether the person is of Aboriginal or Torres Strait Islander descent
  - clinical details about the cancer
  - the notifying institution and doctor.

- All state registries send information to the National Cancer Statistics Clearing House (NCSCH)

| National Cancer Statistics Clearing House (NCSCH) | NCSCH protocol 2010 sets out its objectives and operating structure  
| **Research Topic:** Reproductive Health Registries  
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX | 1982 onwards, and compiled from state and territory cancer registry data.  
| **National Centre for Monitoring Cancer (NCMC)** | Created in 2009 to assist AIHW in improving “population-level cancer data and related evidence in Australia and meet an increasing demand for cancer information.”  
**Main aims are:**  
1. to monitor cancer rates and their impact and outcomes; and  
2. to identify and address priority gaps and deficiencies in population-level cancer and related data in order to improve the evidence base.  
| **Cancer Monitoring Advisory Group (CMAG)** | “was established to provide expert advice to the AIHW regarding the activities of the National Centre for Monitoring Cancer.”  
“It is a multidisciplinary committee whose members are familiar with the cancer data environment, current cancer-related priorities, policies and practices; and emerging issues.”  
| **ACCESS - Australia’s National Infertility Network** | National organisation representing the interests of infertile people.  
| **Flinders Reproductive Medicine (FRM)** | “one of the first fertility clinics in the world, and helped to conceive South Australia’s first IVF baby in  
1982."^37
• Offers individualised fertility treatment.

## National Registers

<table>
<thead>
<tr>
<th>Register:</th>
<th>Key points and data access:</th>
<th>Websites:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Voluntary Register of Information about Donation in Assisted Reproduction</td>
<td>“Voluntary Register provides a service for donor offspring who wish to find out about their genetic origins and donors who want to know if a child has been born as a result of their donations. The Director General of the Department of Health established the Voluntary Register for people in Western Australia.”</td>
<td><a href="http://www.voluntaryregister.health.wa.gov.au/home/">http://www.voluntaryregister.health.wa.gov.au/home/</a></td>
</tr>
</tbody>
</table>
| Australian Bleeding Disorders Registry (ABDR)                           | • It is a clinical database and business system designed for use by a variety of persons including:
  o Clinicians
  o Nurses
  o Physiotherapists
  o Social workers
  |                                                                          | Additional information on the ABDR and data access are available here-                                                                                                                                                  |                                                                                             |


Research Topic: Reproductive Health Registries

Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012
| **Australian Clinical Quality Registry** | “Australian Clinical Quality Registries build on data collected from events in daily health care and use this information to assess care provision and


- It contains information on all patients who require blood clotting therapy
- Publishes an annual report. Most recent report 2010-11.

**The process for access to de-identified data is as follows:**
- Applicants must apply for data access for research purposes by making written submissions to ABDR NBA Secretariat.
- Submissions must specify what data is required and the purposes for which it will be used.
- Requests made by external third parties will be passed to the AHCDO Executive Committee for initial approval.
- “The ABDR Steering Committee will then consider the request. If your research project requires HREC approval you must also include confirmation that this has been obtained.”
- “If the request is reasonable the ABDR Steering Committee will approve the request and it will be sent to the NBA for verification and ratification. You will be advised of the outcome in due course. If the request is unreasonable the NBA Secretariat will advise you accordingly.”
implement quality improvements where required.”

- “Clinical quality registers are a particular subset of clinical registers. The purpose of a clinical quality register is to improve the safety or quality of health care provided to patients by collecting key clinical information from individual healthcare encounters which enable risk-adjusted outcomes to be used to drive quality improvement.”
- Also provides Operating Principles and Technical Standards.

<table>
<thead>
<tr>
<th>Australian Childhood Immunisation Register (Immunisation Register)</th>
<th>It “records details of vaccinations given to children under the age of seven who live in Australia, helping Australian parents to ensure that their children grow up healthy and are fully immunised. Health professionals also use the Immunisation Register to monitor immunisation coverage levels, service delivery and disease outbreaks.”</th>
<th><a href="http://www1.hic.gov.au/general/acircirgacir">http://www1.hic.gov.au/general/acircirgacir</a></th>
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</thead>
<tbody>
<tr>
<td>Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS)</td>
<td>This programme is a collaboration of ANZSCTS and the Victorian Department of Health. It began by collecting data on cardiac surgery in Victorian hospitals and has now expanded its operations to include 19 of Australia’s 25 public hospitals and 6 private hospitals. It currently has a collection of more than 55,000 records. It has created the only database on cardiac procedures and outcomes in Australasia and data from New Zealand is going to be included soon.</td>
<td><a href="http://www.ccretherapeutics.org.au/information/currentresearch/anzscts/anzscts.html">http://www.ccretherapeutics.org.au/information/currentresearch/anzscts/anzscts.html</a></td>
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<td>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</td>
<td>Date: August 16th 2012</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Australian Organ Donor Register</th>
<th>• It publishes annual reports, the most current report is for 2011.</th>
<th><a href="http://www.humanservices.gov.au/customer/services/medicare/australian-organ-donor-register">Link</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Is the only Australian national register for organ and tissue donations.</td>
<td>• Allows people to register as donors online.</td>
<td></td>
</tr>
<tr>
<td>The Australian Twin Registry (ATR)</td>
<td>• Established in 1981.</td>
<td><a href="http://www.twins.org.au">Link</a></td>
</tr>
<tr>
<td>• Non-profit organisation which supports medical and scientific research involving twins with the aim of improve general health and wellbeing.</td>
<td>• It maintains a national register of twins and those members of their family willing to participate in research.</td>
<td></td>
</tr>
<tr>
<td>• Currently, there are more 35,000 pairs of twins on the Register, which makes it one of the largest voluntary registers in the world.</td>
<td>• Twins can join the register online.</td>
<td></td>
</tr>
<tr>
<td>• They currently have 50 studies either recruiting or collecting data.</td>
<td>• Affiliated with:</td>
<td></td>
</tr>
<tr>
<td>• Affiliated with:</td>
<td>o the Australian Multiple Birth Association (AMBA);</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Western Australian Twin Child Health Cohort (WATCH Cohort);</td>
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</tr>
<tr>
<td></td>
<td>o and the Western Australian Twin Registry (WATR).</td>
<td></td>
</tr>
<tr>
<td>• Data access:</td>
<td>o Governed by ethical principles, guidelines and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The DTA is available here-</td>
<td></td>
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</table>
|   | privacy legislation, which “allow all Australian researchers access to its service on a fair, reasonable and equitable basis.”
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</thead>
<tbody>
<tr>
<td></td>
<td>o All researchers must execute a Data Transfer Agreement (DTA) between the ATR and their research institution.</td>
</tr>
<tr>
<td></td>
<td>o Researchers are encouraged to make contact with the ATR Management to discuss their proposed research.³⁸</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organisation:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales Health Central Register</td>
<td>• Its main function is “to support information for donor conceived people, donors of sperm, eggs and embryos, parents and siblings of children who are donor conceived, those born through surrogacy arrangements and health services providing assisted reproductive technology.”</td>
<td><a href="http://www.health.nsw.gov.au/art/index.asp">http://www.health.nsw.gov.au/art/index.asp</a></td>
</tr>
</tbody>
</table>
| The New South Wales Registry of Births, Deaths and Marriages (NSW) | • registers life events of NSW citizens, including:  
  o births  
  o deaths  
  o marriages  
  o sex changes  
  • Provides “data for planning and research to the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS).”  
  • Administers 2 main pieces of legislation:  
    o *Births, Deaths and Marriages Registration Act, 1995*; and  
| New South Wales Pregnancy and newborn Services Network | • Established in 1991.  
  • “provides an interface between health care providers and NSW Health. Responsibilities include service coordination of high risk pregnancy and neonatal care, monitoring and evaluation of health services to mothers and infants; planning, policy development | http://www.psn.org.au/ |
and implementation, education and research.\textsuperscript{39}

- Aims "to improve the process and outcome of maternal and neonatal care in NSW, especially to those women and/or babies at risk of an adverse outcome, through clinical co-ordination, education and research. This is achieved through collaboration and communication with service providers."\textsuperscript{40}

- It conducts and supports research in a variety of areas including:
  - Analysing Perinatal Data
  - Implementation of Research Findings
  - Promoting and Conducting RCTs
  - Systematically Reviewing Evidence
  - Collaborative Projects

- Some of its research projects include:
  - SEA-ORCHID: Optimising Reproductive and Child Health Outcomes in Developing Countries\textsuperscript{41}

- Linked population health data: methods for dealing with discrepant records.-- "This study will examine the effect of four methods of reconciling discrepant reports from different population health datasets on


\textsuperscript{40} NSW Pregnancy and Newborn Services Network, Aim of the NSW Pregnancy and Newborn Services Network, available at http://www.psn.org.au/index.php?option=com_content&task=view&id=60&Itemid=58


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HeLEX

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The estimated prevalence of hypertensive disorders of pregnancy and on the adjusted odds ratios for known risk factors. Data is being obtained from linked, validated, birth and hospital data for 250,173 women who gave birth in a New South Wales hospital in 2000-2002.\textsuperscript{42}

| Western Australian Cancer Registry | Collects information about cancer in people diagnosed with cancer within the state.  
| Information about patients with cancer includes:  
| o name and address  
| o date of birth  
| o country of birth  
| o whether they are of Aboriginal or Torres Strait Islander descent  
| o location and type of each cancer  
| o doctor and medical service  
| Does publish reports based on data, but does not include names or identifying information in these reports.  
| “Health and medical researchers may request access to personal information in order to ask individuals if they are willing to be involved in research studies. This is only granted under strict conditions which are governed by the Department’s Human Research Ethics Committee and how to apply for access to data is available here: http://www.health.wa.gov.au/healthdata/hr/ec/index.cfm” |

\textsuperscript{42} NSW Pregnancy and Newborn Services Network, Linked population health data: methods for dealing with discrepant records, available at http://www.psn.org.au/index.php?option=com_content&task=view&id=27&Itemid=37; and an article relating to the project is available at http://www.biomedcentral.com/content/pdf/1472-6963-7-12.pdf
<table>
<thead>
<tr>
<th>Research Topic: Reproductive Health Registries</th>
<th>Reproductive Technology Council – Western Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What type of data is available to researchers?</td>
<td>• Established in accordance with Human Reproductive Technology Act 1991.</td>
</tr>
<tr>
<td>o “case counts and summary cancer statistics at various levels of detail. Standard outputs are .CSV or Excel files sent by email. Data can also be supplied on paper or disk.”</td>
<td>• Section 14 of the Act sets out its main functions.</td>
</tr>
<tr>
<td></td>
<td>• Its primary functions are:</td>
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<td></td>
<td>o formulate and review a Code of Practice to govern the use of artificial fertilisation and storage procedures carried on by licensees;</td>
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<td></td>
<td>o advise the Commissioner of Health on the suitability of applicants, and compliance of licensees with conditions of their licences;</td>
</tr>
<tr>
<td></td>
<td>o make sure that any research carried out by or on behalf of a licensee on eggs, sperm, or participants, has general or specific approval of Council;</td>
</tr>
<tr>
<td></td>
<td>o advise the Minister for Health on matters related to reproductive technology;</td>
</tr>
<tr>
<td></td>
<td>o encourage and facilitate research into the causes and prevention of all types of human infertility and on the social and public health implications of reproductive technology; and</td>
</tr>
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Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012
<table>
<thead>
<tr>
<th>Location</th>
<th>Details</th>
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</thead>
</table>
| University of Sydney, Reproductive, Maternal and Child Health | - maintains registers for births, deaths and marriages, as well as other life events.  
- There are 5 key pieces of legislation, which govern the functioning of the registers. These are:  
  - Births, Deaths and Marriages Registration Act 1996  
  - Adoption Act 1988  
  - Cremation Act 2000  
  - Sexual Reassignment Act 1988  
  - Witness Protection Act 1996  
| Births, Deaths and Marriages Registration Office (SA) | - maintains registers for births, deaths and marriages, as well as other life events.  
- There are 5 key pieces of legislation, which govern the functioning of the registers. These are:  
  - Births, Deaths and Marriages Registration Act 1996  
  - Adoption Act 1988  
  - Cremation Act 2000  
  - Sexual Reassignment Act 1988  
  - Witness Protection Act 1996  
| Australian Capital Territory Births, Deaths and Marriages (ACT) | - maintains registers for:  
  - births,  
  - deaths,  
  - marriages,  
  - changes of name,  
  - changes of sex,  
  - adoptions,  
  - deaths abroad  
- State legislation which relates to this includes: 

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|---------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------------------------|

**Research Topic:** Reproductive Health Registries

**Research conducted by:** Andelka M. Phillips, DPhil Candidate HeLEX

**Date:** August 16th 2012
<table>
<thead>
<tr>
<th>Births, Deaths and Marriages (NT)</th>
<th>events.</th>
<th><a href="http://www.childrenandfamilies.nt.gov.au/Office_of_Womens_Policy/">nt</a></th>
</tr>
</thead>
</table>
| Northern Territory Office of Women’s Policy | • Responsible for providing “gender specialist policy advice to the Minister for Women's Policy, the Northern Territory Government and public sector agencies. It has a central coordination, monitoring and reporting function regarding women's issues in the Northern Territory.”  
• Advises on issues including:  
  o Maternal health\(^{45}\)  
  o Women’s reproductive choices. | [nt](http://www.childrenandfamilies.nt.gov.au/Office_of_Womens_Policy/) |
| Victorian Registry of Births, Deaths and Marriages | • Registers:  
  o Births;  
  o Deaths;  
  o Marriages;  
  o And other vital events.  
• Also maintains 2 donor treatment registers, the Central Register and the Voluntary Register in accordance with the Assisted Reproductive Treatment Act 2008 (ART Act).  
• The Central and Voluntary Registers:  
  o “record information about the people who are connected to assisted reproductive treatment (ART), such as: | [nt](http://online.justice.vic.gov.au/CA2574F700805DE7/HomePage?ReadForm1=Home~&2=~&3=~) |

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Date: August 16th 2012

- the donor/s
- the woman who underwent treatment using donated gametes (i.e. egg or sperm) or a donated embryo, and her partner (if any)
- the donor conceived person.
  - Information held on the registers may include details such as full name, date of birth and medical history.\(^{46}\)
- Surrogacy births must be registered.
  - Commissioning parents may apply for a substitute parentage order from the County Court of Victoria.
  - Surrogacy legislation:
    - Assisted Reproductive Treatment (ART) Act 2008
    - Status of Children Act 1974
    - Births, Deaths and Marriages Registration Act 1996

<table>
<thead>
<tr>
<th>Victorian Assisted Reproductive Treatment Authority (VARTA)</th>
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<tr>
<td>•</td>
<td><a href="http://www.varta.org.au/">http://www.varta.org.au/</a></td>
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</table>

<table>
<thead>
<tr>
<th>Sands Victoria</th>
<th>“self-help support group comprised of parents who have experienced the death of a baby through miscarriage, stillbirth, or shortly after birth”.</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.sandsvic.org.au/about/">http://www.sandsvic.org.au/about/</a></td>
<td></td>
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</tbody>
</table>

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<tr>
<th>SIDS and Kids Australia</th>
<th>“dedicated to saving babies and children’s lives</th>
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</thead>
</table>

Research Topic: Reproductive Health Registries
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

<table>
<thead>
<tr>
<th>Research Topic</th>
<th>Details</th>
<th>Website</th>
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</table>
| Registry of Births, Deaths and Marriages in Western Australia | Registers:  
  - Births;  
  - Deaths;  
| Tasmanian Registry of Births, Deaths and Marriages | Registers:  
  - Births;  
  - Deaths;  
  - Marriages;  
  - Deeds of relationships;  
### Legislation

**Federal Legislation and Policy**

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
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</thead>
</table>
| Research Involving Human Embryos Act 2002 (RIHE ACT) – and amendments | • Both the RIHE and PHCR acts have been recently reviewed by an independent committee, which has published a report, known as the Heerey Report. The Australian Government is currently reviewing the recommendations made in Heerey.  
• Governs research on human embryos and allows for research to be conducted under licence where certain criteria have been met.  
• Licences are granted by the NHMRC Embryo Licensing Committee.  
• In order for a licence to be granted the Committee must be satisfied that the applicants have had their application assessed and approved by the Human Research Ethics Committee. |  |
<table>
<thead>
<tr>
<th>Prohibition of Human Cloning for Reproduction Act 2002 (PHCR Act)</th>
<th></th>
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</thead>
</table>
State Legislation and Policy

Introductory comment:

All Australian states and territories have their own legislation and regulatory bodies, which are responsible for issuing licences to all clinics which provide ART services. “When there are anomalies between the state acts and the guidelines, the state acts have precedence.”

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
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<tbody>
<tr>
<td>Research Topic: Reproductive Health Registries</td>
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<table>
<thead>
<tr>
<th>Assisted Reproductive Technology Act (2007) (NSW)</th>
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<tr>
<th>Human Tissue Regulation 2010 (NSW)</th>
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<table>
<thead>
<tr>
<th>Guideline - Human Tissue - Requirements of the Human Tissue Act 1983 in relation to research &amp; use of tissue</th>
<th>“Outlines the requirements of the Human Tissue Act 1983 and subsequent amendments in relation to research utilising human tissue: guidance for human research ethics committees. Also takes into account amendments to the Human Tissue Act which came into effect in January 2006”</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Assisted Reproductive Technology Amendment (Transitional Provisions)</th>
<th>“The Amending Regulation extends the transitional provisions for women who</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relating to Donated Gametes) Regulation 2012 (Amending Regulation)</td>
<td>have obtained donated gametes before 1 January 2010 and who have already conceived a child using those gametes before 1 January 2010 to continue to use those gametes before 1 January 2015 without the full effect of the ART Act applying.(^{47})</td>
</tr>
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### New Zealand

#### Institutional Bodies

<table>
<thead>
<tr>
<th>Institutional bodies:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Medical Council of New Zealand               | • Registers all medical doctors in NZ  
• Also, is the main regulator of the medical profession, setting standards.                                                                                            | [http://www.mcnz.org.nz](http://www.mcnz.org.nz) |
| Pacific Society for Reproductive Health      | • Registered charitable organisation in NZ.  
• It “encourages and contributes to the professional development of sexual, reproductive and neonatal health care professionals across the diversity of Pacific Island Countries. The Society also advocates for the improvement of Women’s Health in the Pacific.” | [http://www.psrh.org.nz](http://www.psrh.org.nz) |
| Medical Sciences Council of New Zealand      | • Main regulatory body for:  
  o Anaesthetists  
  o Medical laboratory scientists  
| New Zealand Multiple Birth Association       | • Provides information and support to Multiple Birth clubs and members                                                                                                                                                | [http://www.multiples.org.nz](http://www.multiples.org.nz) |
| Biological and Life                          | • “Provides advice on matters of concern to "                                                                                                                                         | [http://www.royalsociety.org.nz/orga](http://www.royalsociety.org.nz/orga) |

Research Topic: Reproductive Health Registries  
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX  
Date: August 16th 2012
### Registers and Projects

<table>
<thead>
<tr>
<th>Register: Births, Deaths and Marriages, (BMD) Department of Internal Affairs</th>
<th>Key points and data access: “Registers and maintains New Zealand birth, death, marriage, civil union and name change information and provides access to that information by issuing certificates and printouts.”</th>
<th>Websites: <a href="http://www.dia.govt.nz/Births-deaths-and-marriages">http://www.dia.govt.nz/Births-deaths-and-marriages</a></th>
</tr>
</thead>
</table>

| **Breast Cancer Patient Registers** | **Supported by New Zealand Breast Cancer Foundation** regional breast cancer registries have been created, which together form the National Breast Cancer Register database.  
**There are 4 regional registries:**  
- Auckland;  
- Waikato;  
- Christchurch;  
- And Wellington.  
**How information is collected:**  
- "The current regional registers are computerised databases where the information is entered and stored in a confidential manner. Information is fed back to each register's Executive Group before release; the group governs who can use the information/data and for what purpose."
- "Both public and private sector breast cancer patients are eligible to participate in the regional registers (must be living in the region); however, participation is voluntary and all participants are required to sign a consent form before being included in the register."
Participants are followed up each year to monitor how they are doing following their breast cancer diagnosis. All registers include patients with breast cancer and DCIS (ductal carcinoma in situ - a pre-invasive cancer)."

<table>
<thead>
<tr>
<th>Human Assisted Reproductive Technology (HART) Register</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Run by the Births, Deaths and Marriages division of the Department of Internal Affairs.</td>
</tr>
<tr>
<td>• The Register has been operating since the 22\textsuperscript{nd} of August 2005.</td>
</tr>
<tr>
<td>• Governed by Human Assisted Reproductive Technology (HART) Act 2004.</td>
</tr>
<tr>
<td>• &quot;holds information about donors, donor offspring and guardians who have been involved in fertility treatment that involves the use of donated embryos, sperm or eggs through fertility clinics.&quot;</td>
</tr>
<tr>
<td>• Access to information:</td>
</tr>
<tr>
<td>o &quot;access to information held on the register is restricted. Generally only the people named on the register can access the information, or the guardians of offspring under the age of 18.</td>
</tr>
<tr>
<td>o The Human Assisted Reproductive Technology (HART) Act restricts the release of some information,&quot;</td>
</tr>
<tr>
<td>Research Topic: Reproductive Health Registries</td>
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<td>-----------------------------------------------</td>
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<tr>
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<table>
<thead>
<tr>
<th>New Zealand Neurological Foundation Human Brain Bank, School of Medical Sciences, University of Auckland</th>
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<tbody>
<tr>
<td>• It “provides tissue for research programmes such as the pattern of cell death and chemical changes in Huntington's disease, Parkinson’s disease, Alzheimer’s disease, Epilepsy and Motor Neuron Disease. “</td>
</tr>
<tr>
<td>• The bank contains tissue received from over 300 normal and diseased human brains.</td>
</tr>
<tr>
<td>• So far the bank has collaborated with researchers in Europe, Scandinavia and Japan.</td>
</tr>
<tr>
<td>• Has ethically approved procedures in place for the collection of post-mortem healthy and diseased brains.</td>
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<tr>
<th>National Immunisation Register (NIR)</th>
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<tr>
<td>• Keeps records of children’s immunisation.</td>
</tr>
<tr>
<td>• Records are stored for the lifetime of the person plus 10 years.</td>
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<tr>
<td>• Parents can opt-out of the scheme, but they must complete an opt-out form.</td>
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<thead>
<tr>
<th>New Zealand Neuromuscular Disease Registry</th>
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<thead>
<tr>
<th>ASCIA Primary</th>
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<tbody>
<tr>
<td>• Access to the Register:</td>
</tr>
<tr>
<td><a href="http://www.immunodeficiency.org.a">http://www.immunodeficiency.org.a</a></td>
</tr>
</tbody>
</table>
| Immunodeficiency Diseases Register of Australia and New Zealand (PID) | • “Physicians or other health care workers who are responsible for patients with PID may apply for “Approved Access” to the Register. Approved access enables you to provide information on patients (subject to their consent), and to receive constantly updated summary data reports from the Register.  
• Reports include Registrations by Diagnosis, State by State updates and Immunoglobulin usage.  
• Any Physician who is aware of an unregistered patient living with a PID in Australia or New Zealand (or suspects that they might not be registered) is strongly encouraged to apply for access. Ongoing surveillance is vital to the success of this project.”  
• Application forms for approved access are available on the website.\textsuperscript{48} | u |
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<tbody>
<tr>
<td>New Zealand Birth Defects Registry (NZBDR)</td>
<td>•</td>
<td><a href="http://www.nzbdmp.ac.nz">http://www.nzbdmp.ac.nz</a></td>
</tr>
</tbody>
</table>

\textsuperscript{48} Available at: http://www.immunodeficiency.org.au/docs/Approved%20access%20agreement%20V3.pdf
### Legislation and Policy

All official legislation is available online and downloadable in PDF form.

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
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<tbody>
<tr>
<td>Status of Children Act 1969</td>
<td></td>
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<tr>
<td>Marriage Act 1955</td>
<td></td>
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<tr>
<td>Civil Unions:</td>
<td></td>
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<tr>
<td>• Civil Union Act 2004</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Civil Union (Prescribed Information, Fees, and Forms) Regulations 2005</td>
<td></td>
<td></td>
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<tr>
<td>• Civil Unions (Recognised Overseas Relationships) Regulations 2005</td>
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<tr>
<td>Research Topic: Reproductive Health Registries</td>
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<thead>
<tr>
<th>Births Deaths Marriages and Relationships Registration Act 1995</th>
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<thead>
<tr>
<th>Births, Deaths, Marriages, and Relationships Registration (Non-Disclosure Direction) Regulations 2008</th>
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<thead>
<tr>
<th>Births, Deaths, Marriages, and Relationships Registration (Prescribed Information) Regulations 1995</th>
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<tr>
<th>Privacy Act 1993</th>
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<table>
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<tr>
<th>Health Information Privacy Code 1994</th>
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</thead>
<tbody>
<tr>
<td>Amended in 2008</td>
</tr>
<tr>
<td>Available at <a href="http://privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-incl.-amendments-revised-commentary.pdf">Link</a></td>
</tr>
<tr>
<td>Research Topic</td>
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</table>
### Institutional Bodies and projects

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<thead>
<tr>
<th>Institutional bodies and projects:</th>
<th>Functions and relevant information:</th>
<th>Websites:</th>
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</thead>
</table>
| Assisted Human Reproduction Canada (AHRC) | • Established in 2007.  
• Its main aim is to improve health and safety of Canadians who are involved with ART.  
• It enforces the provisions of the Assisted Human Reproduction Act.  
• Its role has been reduced and it will be reduced further over the course of the next year. It is supposed to cease its operations by the 31st March, 2013. This is largely due to a Supreme Court ruling.49  

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Research Topic: Reproductive Health Registries

Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012
|---------------------|----------------------------------------|---------------------------------------------------------------------|--------------------------------------------------|
|                     | Nunavut Status of Women Council         | Its main objectives are:  
• “to develop public awareness of issues affecting the status of women;  
• to promote a change in attitudes within the community in order that women may enjoy equality of opportunity;  
• to encourage discussion and expression of opinion by residents of Nunavut on issues affecting the status of women;  
• to advise the Minister on issues that the Minister may refer to the Council for consideration;  
• to review policies and legislation affecting women and to report its findings to the relevant government departments or agencies;  
• to provide assistance to the Minister in promoting changes to ensure the attainment of equality of women; and  
• to provide the appropriate assistance to organizations and groups whose objectives” promote the equality of women. | http://www.qnsw.ca |
|                     | Canadian Fertility and Andrology Society |                                                      | http://www.cfas.ca |

## Registers

<table>
<thead>
<tr>
<th>Name of register:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Vital Statistics Division of Service Nova Scotia and Municipal Relations (Nova Scotia) | • Responsible for registering:  
  o births,  
  o deaths,  
  o marriages,  
  o stillbirths  
| Vital Statistics, (Service Alberta) | • Responsible for registering:  
  o births,  
  o deaths,  
  o marriages,  
  o stillbirths  
  o name changes  
  • also registers “religious organizations and clergy who perform marriages, marriage commissioner appointments and providing burial permits. The office also processes delayed registration events and amendments to event records.”  
| Vital Statistics Agency, (British Columbia) | • Maintains a research database for the current and historical records called Vital Statistics Information System (VISION).  
  • Responsible for registering:  
    o Births; | [http://www.vs.gov.bc.ca](http://www.vs.gov.bc.ca) |
<table>
<thead>
<tr>
<th>Vital Statistics Agency (Manitoba)</th>
<th></th>
<th>Vital Statistics Office (New Brunswick)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Responsible for registering:</td>
<td>• 3 main functions:</td>
<td>• 3 main functions:</td>
</tr>
<tr>
<td>o births,</td>
<td>• the collection, storage, maintenance,</td>
<td>• the collection, storage, maintenance,</td>
</tr>
<tr>
<td>o deaths,</td>
<td>and retrieval of vital events data (births,</td>
<td>and retrieval of vital events data (births,</td>
</tr>
<tr>
<td>o marriages,</td>
<td>deaths, stillbirths, and marriages);</td>
<td>deaths, stillbirths, and marriages);</td>
</tr>
<tr>
<td>o stillbirths</td>
<td>• the synthesis and analysis of vital</td>
<td>• the synthesis and analysis of vital</td>
</tr>
<tr>
<td>o name changes</td>
<td>events data; and,</td>
<td>events data; and,</td>
</tr>
<tr>
<td>• Privacy legislation governs</td>
<td>• the provision of vital events</td>
<td>• the provision of vital events</td>
</tr>
<tr>
<td>who has access to the Agency’s</td>
<td>documents for personal use (birth</td>
<td>documents for personal use (birth</td>
</tr>
<tr>
<td>records.</td>
<td>certificates, marriage licenses,</td>
<td>certificates, marriage licenses,</td>
</tr>
<tr>
<td>• Their database provides records</td>
<td>death certificates).(^{51})</td>
<td>death certificates).(^{51})</td>
</tr>
<tr>
<td>of all vital events occurring in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manitoba from 1882 to the present.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>These records are kept in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>perpetuity.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^{51}\) Vital Statistics Office, Introduction, available at [http://www.snb.ca/e/1000/1000-01/e/intro-e.asp](http://www.snb.ca/e/1000/1000-01/e/intro-e.asp)
<table>
<thead>
<tr>
<th>Research Topic: Reproductive Health Registries</th>
<th>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</th>
<th>Date: August 16th 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vital Statistics, Department of Health and Wellness (Prince Edward Island)</td>
<td>registers: o births, o deaths, o stillbirths, o adoptions, o marriages, o divorces, o and change of name</td>
<td><a href="http://www.gov.pe.ca/health/index.php3?number=1020357">http://www.gov.pe.ca/health/index.php3?number=1020357</a></td>
</tr>
<tr>
<td>Register of civil status (Quebec)</td>
<td>Responsible for registering: o Births; o Marriages;</td>
<td><a href="http://www.etatcivil.gouv.qc.ca/en/default.html">http://www.etatcivil.gouv.qc.ca/en/default.html</a></td>
</tr>
</tbody>
</table>
### Vital Statistics Registry (Saskatchewan)

- Formerly administered by the Ministry of Health, it is now part of Information Services Corporation (ISC). [ISC was formed as a corporation in 2000].
- Established in accordance with The Vital Statistics Administration Transfer Act.
- Registers all:
  - Births;
  - Deaths;
  - Marriages;
  - Stillbirths;
  - And changes of name.
- A Privacy Statement regarding access to data is available. It was developed in order to comply with:
  - The Vital Statistics Administration Transfer Act;
  - The Vital Statistics Act; 2009;
  - The Change of Name Act, 1995;
  - The Health Information Protection Act;
  - and other laws applicable to the Vital Statistics Registry.


http://www.isc.ca/VitalStats/Pages/default.aspx


All Saskatchewan law available at- http://www.qp.gov.sk.ca

| Civil unions; | Access to records is governed by the Civil Code of Quebec. | http://www.health.gov.sk.ca/Default.aspx?DN=e5fc4552-1af0-4c27-854a-0ce1226aa91f |
| and deaths. | All organizations which are governed by the Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information (R.S.Q., c. A-2.1) are obliged to publish certain information on their website. |     |
| o | | http://www.isc.ca/VitalStats/Pages/default.aspx |
| o | | All Saskatchewan law available at- http://www.qp.gov.sk.ca |

Research Topic: Reproductive Health Registries
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012
| Vital Statistics, (Yukon) | Registers:  
|-------------------------|-------------------------------------------------------------------------------------------------
|  | o births;  
|  | o deaths;  
|  | o marriages;  
|  | o and other vital events.  
**Federal Legislation and Policy**

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
</tr>
</thead>
</table>
• It prohibits certain activities under sections 5-8, including human cloning and the purchase or offering for sale of sperm or ova. | [https://www.cfas.ca/images/stories/pdf/a-13.4.pdf](https://www.cfas.ca/images/stories/pdf/a-13.4.pdf) |

**Provincial legislation and policy**

<table>
<thead>
<tr>
<th>Legislation:</th>
<th>Key points:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Alberta-  
• Freedom of Information and Protection of Privacy Act (FOIP)  
• the Personal Information Protection Act (PIPA).  
• The Health Information Act 2000 and Regulations under the Act, including: Alberta Electronic Health Record Regulation | | [All laws available at-http://www.qp.alberta.ca/570.cfm](http://www.qp.alberta.ca/570.cfm) |
| British Columbia-  
• E-Health (Personal Health Information Access and Protection of Privacy) Act | • Part 2 of the E-Health Act allows for the creation and classification of particular databases as "health information" | |

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Research Topic: Reproductive Health Registries  
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX  
Date: August 16th 2012
<table>
<thead>
<tr>
<th>Research Topic: Reproductive Health Registries</th>
<th>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</th>
<th>Date: August 16th 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manitoba-</td>
<td>All legislation available at-</td>
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<tr>
<td>- The Marriage Act,</td>
<td></td>
<td></td>
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<tr>
<td>- The Change of Name Act</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- The Public Health Act 2006(^{56})</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- The Personal Health Information Act 1997(^{57})</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- The Privacy Act 1987</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario-</td>
<td>OPHS main website-</td>
<td></td>
</tr>
<tr>
<td>- Public Health Standards (OPHS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Healthy Babies Healthy Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>banks”. It also sets out criteria for when information is permitted to be disclosed.</td>
<td>All legislation available at-</td>
<td></td>
</tr>
</tbody>
</table>

\(^{53}\) Available at [http://www.bclaws.ca/ELibraries/bclaws_new/document/ID/freeside/00_08038_01](http://www.bclaws.ca/ELibraries/bclaws_new/document/ID/freeside/00_08038_01)

\(^{54}\) Available at [http://www.bclaws.ca/ELibraries/bclaws_new/document/ID/freeside/00_96479_01](http://www.bclaws.ca/ELibraries/bclaws_new/document/ID/freeside/00_96479_01)


\(^{57}\) Available at [http://web2.gov.mb.ca/laws/statutes/ccsm/_pdf.php?cap=p33.5](http://web2.gov.mb.ca/laws/statutes/ccsm/_pdf.php?cap=p33.5)

\(^{58}\) The Act is available at [http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90h07_e.htm#](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90h07_e.htm#)
### Protocol, 2008.
- Regulated Health Professions Act
- the Nursing Act,
- the Municipal Freedom of Information and Protection of Privacy Act (MFIPPA),
- the Child and Family Services Act (CFSA),
- the Ministry of Community and Social Services Act, and the Personal Health Information Protection Act.

### substance misuse;
- And chronic disease prevention.
- OPHS are issued in accordance with the HPPA by the Minister of Health and Long Term Care. "Protocols are program and topic specific documents which provide direction on how boards of health must operationalize specific requirement(s) identified within the OPHS."

### New Brunswick-
- The Marriage Act
- The Public Health Act

### Northwest Territories-
- Vital Statistics Act

<table>
<thead>
<tr>
<th>Protocol, 2008.</th>
<th>substance misuse;</th>
<th>OPHS on Reproductive Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>• the Nursing Act,</td>
<td></td>
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<tr>
<td>• the Municipal Freedom of Information and Protection of Privacy Act (MFIPPA),</td>
<td></td>
<td></td>
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<tr>
<td>• the Child and Family Services Act (CFSA),</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• the Ministry of Community and Social Services Act, and the Personal Health Information Protection Act.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• substance misuse;</td>
<td>- And chronic disease prevention.</td>
<td></td>
</tr>
<tr>
<td>• OPHS are issued in accordance with the HPPA by the Minister of Health and Long Term Care.</td>
<td>• A Reproductive Health Guidance Document released in 2010.</td>
<td></td>
</tr>
</tbody>
</table>

### New Brunswick-
- The Marriage Act
- The Public Health Act

### Northwest Territories-
- Vital Statistics Act

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Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX
### Human Tissue Act
- Available at: [http://www.justice.gov.nt.ca/PDF/ACTS/Human_Tissue.pdf](http://www.justice.gov.nt.ca/PDF/ACTS/Human_Tissue.pdf)

### Public Health Act
- Available at: [http://www.justice.gov.nt.ca/PDF/ACTS/Public%20Health.pdf](http://www.justice.gov.nt.ca/PDF/ACTS/Public%20Health.pdf)

### Prince Edward Island
- **Vital Statistics Act**
- Available at: [http://www.gov.pe.ca/law/statutes/pdf/v-04_01.pdf?PHPSESSID=a37482661d3e6f0f84d32273b8de713e](http://www.gov.pe.ca/law/statutes/pdf/v-04_01.pdf?PHPSESSID=a37482661d3e6f0f84d32273b8de713e)

### Quebec
- Act respecting Access to documents held by public bodies and the Protection of personal information (R.S.Q., c. A-2.1)
- Regulation respecting the distribution of information and the protection of personal information
- Available at: [http://www.isc.ca/VitalStats/Pages/ActsandRegulations.aspx](http://www.isc.ca/VitalStats/Pages/ActsandRegulations.aspx)

### Saskatchewan
- Vital Statistics Act, 2009
- The Marriage Act, 1995
- Change of Name Act, 1995.
- Available at: [http://www.isc.ca/VitalStats/Pages/ActsandRegulations.aspx](http://www.isc.ca/VitalStats/Pages/ActsandRegulations.aspx)

### Yukon
- Vital Statistics Act
- Vital Statistics Regulations
- Marriage Act
- A new bill on Personal Health Information Legislation has been proposed and is currently under consideration, but has not yet passed into law. A discussion paper is available on the Yukon Health and Social Services website.
- Available at: [http://www.gov.yk.ca/legislation/tps/tps_v.html#vitalstatisticsact](http://www.gov.yk.ca/legislation/tps/tps_v.html#vitalstatisticsact)
Institutional Bodies and projects

<table>
<thead>
<tr>
<th>Institutional bodies and projects:</th>
<th>Functions and relevant information:</th>
<th>Websites:</th>
</tr>
</thead>
</table>
| Division of Reproductive Health, Centers for Disease Control and Prevention (CDC) | • monitors maternal and infant mortality, the most serious reproductive health complications.  
• In addition, attention is focused on gathering data to better understand the extent of maternal and infant morbidity, adverse behaviors during pregnancy, and long-term consequences of pregnancy.  
• Annual reports on Assisted Reproductive Technology (ART) | http://www.cdc.gov/reproductivehealth/DRH/index.htm  
Reports available at: http://www.cdc.gov/art/ARTReports.htm |
| American Society for Reproductive Medicine | • Founded in 1944.  
• Its main aim is to be a “recognized leader for multidisciplinary information, education, advocacy and standards in the field of reproductive medicine.”  
• They publish the Fertility and Sterility journal.  
• Their J. Benjamin Younger Office of Public Affairs works to promote the views of the society at the federal and state level, especially in relation to legislation in this area. | http://www.asrm.org  
http://www.asrm.org/about/ |
<p>| CPONDER, Pregnancy Risk Assessment Monitoring System (PRAMS), project of Centers for Disease Control and Prevention | • PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. | Allows state searches: <a href="http://apps.nccd.cdc.gov/cPONDER/">http://apps.nccd.cdc.gov/cPONDER/</a> |</p>
<table>
<thead>
<tr>
<th>The Maternal and Child Health Epidemiology Program (MCHEP), project of Centers for Disease Control and Prevention (CDC).</th>
<th>• “The MCHEP mission is to promote and improve the health and well-being of women, children, and families by building capacity at state, local, and tribal levels and to use and apply sound epidemiologic research and scientific information to maternal and child health programs and policies. This mission is accomplished domestically and internationally by developing Maternal and Child Health (MCH) Epidemiology leaders, promoting peer exchange forums, supporting continued education and training, and providing fellowship opportunities.”</th>
<th><a href="http://www.cdc.gov/reproductivehealth/MCHEpi/index.htm">http://www.cdc.gov/reproductivehealth/MCHEpi/index.htm</a></th>
</tr>
</thead>
</table>
| Peristats | • Provides online free access “ to maternal and infant health-related data at the US, state, county, and city level, and was developed to ensure that health professionals, researchers, medical librarians, policy-makers, students, and the media have easy access to this information. Data are updated throughout the year, and useful for multiple tasks, including fact-finding, health assessments, grant writing, policy development, lectures and presentations.”  
• It provides data on a variety of topics including:  
  o preterm birth;  
  o infant mortality;  
  o tobacco use;  
  o cesarean section rates;  
Research Topic: Reproductive Health Registries  
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX  
Date: August 16th 2012

### National Registers and Projects

<table>
<thead>
<tr>
<th>Name of register:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Sudden Unexpected Infant Death Case Registry -from Centers for Disease Control and Prevention (CDC) | • Sudden Unexpected Infant Death (SUId) Registry is a pilot programme.  
• The purpose of this programme is to establish-  
  - a state-based surveillance system that supplements current vital statistics-based surveillance methods. The SUId-CR builds upon the National Center for Child Death Review (NCCDR) system funded by HRSA MCHB.  
• 5 states were awarded funding for the programme. These are:  
  - Colorado,  
  - Georgia, | [http://www.cdc.gov/sids/CaseRegistry.htm](http://www.cdc.gov/sids/CaseRegistry.htm) |

---

MCH Data Connect, Maternal and Child Health/ Children Youth and Families (MCH/CYF) Harvard School of Public Health.  
- Provides a searchable database of maternal and child health data sets, interactive tools and other resources.  
- The database is designed and intended for use by health professionals, researchers, policy makers and students.  

National Institutes of Health. Office of Extramural Research (OER)  
- “provide the leadership, oversight, tools and guidance needed to administer and manage NIH grants policies and operations”.  
- Also publishes annual reports, the most recent available is 2010.  
For guidance on Research Involving Human Subjects, please see-  
- Michigan,
- New Jersey,
- and New Mexico

- These 5 states began collecting data in January 2010
- July 2010- CDC granted funding to Minnesota and New Hampshire and these states began data collection on January 1st, 2011.

- All state grantees are required to:
  - Develop an efficient and timely method for case identification for all SUID deaths in the state. Grantees strive to identify and review cases within 3 months.
  - Access the following required data sources for each case: death certificates, medical examiner or coroner records (e.g., [Sudden Unexplained Infant Death Investigation Reporting Form](#) or autopsy reports), and law enforcement records. Ideally grantees also have access to infant medical records since birth (including newborn screening results), birth certificates, mother’s obstetric records and any social service records that pertain to the case.
  - Follow the CDC SUID-CR and NCCDR manual of procedures and protocols.
  - Enter data into the NCCDR Web-based Case Reporting System.
  - Implement a quality assurance plan to improve...
| National Vital Statistics System (NVSS) | - Compiles data relating to births, deaths, marriages and other events, on a national level, utilising the National Center for Health Statistics (NCHS) and state registers.  
- All births must be registered within the state where the person is born, but federal law requires national collection of such data.  
- Model procedures are available to facilitate consistency in registration of vital events and data collection.  
- Some of its programmes include:  
  - Linked Birth and Infant Death Data Set  
  - National Survey of Family Growth  
  - Matched Multiple Birth Data Set  
  - National Death Index  
  - National Maternal and Infant Health Survey  
  - National Mortality Followback Survey  
- It also now makes data available in electronic form through the:  
  - Vital Statistics of the United States,  
  - National Vital Statistics Reports (formerly the [NVSS](http://www.cdc.gov/nchs/nvss/about_nvss.htm)) |

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69 See [http://www.cdc.gov/nchs/products/misc_pubs.htm#modelstate](http://www.cdc.gov/nchs/products/misc_pubs.htm#modelstate) and standard forms are available at [http://www.cdc.gov/nchs/nvss/vital_certificate_revisions.htm](http://www.cdc.gov/nchs/nvss/vital_certificate_revisions.htm)

Monthly Vital Statistics Report
- Other selected reports.
**State Registers and Projects**

30 states in the USA have population-based birth defects registries.

<table>
<thead>
<tr>
<th>Name of register:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| Illinois Women’s Health Registry       | • Database intended “to be used to assist investigators to better understand the relationship between environmental exposures, stress, health symptoms, health trends and disease by gathering data on large numbers of women.”
• “The Registry is intended to foster research in the area of women’s health by serving as an informational resource as well as a recruiting tool. The Registry will also make a concerted effort to include women from diverse social classes and racial/ethnic backgrounds in order to promote diversity in research studies and clinical trials.”
• All female Illinois residents over the age of 18 can join the Register, either online or by paper application.                                                                                           | [https://whr.northwestern.edu](https://whr.northwestern.edu) |
| Florida Birth Defects Registry (FBDR)  | • “statewide, population-based surveillance system that has identified birth defects in children born in Florida since 1999. The                                                                                     | [http://www.fbdr.org](http://www.fbdr.org) |

Research Topic: Reproductive Health Registries
Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX

Date: August 16th 2012
| **Texas Birth Defects Epidemiology and Surveillance Branch (BDES)** | • established in 1993, its work focuses on tracking birth defects and supporting research. | http://www.dshs.state.tx.us/birthdefects/  
Data access policy available at- http://www.dshs.state.tx.us/birthdefects/BD_data.shtm |
|---------------------------------------------------------------|-----------------------------------------------------------------------------|-----------------------------------------------------------------------------------|

FBDR is operated by the Florida Department of Health Bureau of Environmental Public Health Medicine and works in conjunction with the Children’s Medical Services and other state agencies.”
## Global Registers and Projects

<table>
<thead>
<tr>
<th>Name of register or project:</th>
<th>Functions and information:</th>
<th>Website:</th>
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</thead>
</table>
| The International Committee Monitoring Assisted Reproductive Technologies (ICMART) | • "is an independent, international non-profit organization that has taken a leading role in the development, collection and dissemination of worldwide data on assisted reproductive technology (ART). We provide information on availability, effectiveness and safety to health professionals, health authorities and to the public.”  
• Its “glossary, which has been developed in cooperation with the World Health Organization (WHO), facilitates dissemination of ART data through a set of agreed-upon definitions, as seen in the most recent World Collaborative Report on Assisted Reproductive Technology. It provides a conceptual framework for further international terminology and data development for ART.”  
• It provides a Tool Box which is intended to assist with establishing systems o monitor and collect data on ART cycles and outcomes.  
  
| Latin America Network of Assisted Reproduction (RED) | • Established in 1995 and now has a network of 154 centres involved,  
• It maintains the Latin American Registry of Assisted Reproduction (RLA), which catalogues data on techniques from participating centres.  
• It also provides a Continuing Education Programme.  
  
| The Latin American Registry of Assisted Reproduction (RLA) | “main responsibility is to collect, analyze, and disseminate the results of Assisted Reproduction Technology (ART) procedures performed in centers that have been certified by REDLARA.”
  | The main objectives of the RLA are to:
  | o assess interventions in terms of their outcome
  | o monitor trends on safety and efficacy among centers, countries and regions
  | o empower infertile couples in the evaluation of costs & benefits
  | o robust data base for epidemiological studies and as external QC for individual centers.⁷¹
  | Publishes reports, the most recent of which is for 2009. | http://www.redlara.com/aa_ingles/REGISTRO.ASP |
| UN Refugee Agency Health Information System (HIS) Toolkit | Provides a variety of tools, models and forms to assist with data collection and monitoring. | http://www.unhcr.org/4a3374408.html |
  | It aims “to address global concerns about the availability, safety and accessibility of blood for transfusion.”
  | “The objective of this activity is to collect and analyse data from all countries on blood and blood product safety as the basis for effective action to improve blood transfusion services globally.”
  | Also, publishes reports, the most recent is 2011. | http://www.who.int/bloodsafety/global_database/en/ |
| Pan American Health | It is a public health organisation working to improve | http://new.paho.org/hq/index.php?option= |
| Organisation (PAHO) | the health and living standards of all countries in the Americas.  
- It also serves as the Regional Office in the Americas for the WHO.  
- It publishes reports and runs the Regional Mortality database.  
- The database is comprised of data on "deaths registered in national vital registration systems and reported to PAHO by national authorities. Underlying causes of death, sex and age groups -- variables included in these files-- have been reviewed and validated according to International Classification of Diseases (ICD)." These data are official national statistics. |
<table>
<thead>
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<tbody>
<tr>
<td>Population Council</td>
<td>• Runs wide variety of research projects and programmes throughout the world.</td>
</tr>
</tbody>
</table>
### Europe

<table>
<thead>
<tr>
<th>Name of register or project:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
</table>
| European Society of Human Reproduction and Embryology (ESHRE) | • Comparative Analysis of Medically Assisted Reproduction in the EU: Regulation and Technologies - Final Report  
• ESHRE was contracted by the European Commission, DG SANCO, to outline the situation ‘as is’ regarding MAR legislation, reimbursement and MAR establishments in the European Union.  
• ESHRE’s ability to organise data collection covering most of the 27 EU Member States together with its previously shown MAR-related expertise, has been essential for the collaboration with the European Commission in the scope of this study.  
• Two surveys were conducted among all 27 Member States. The findings of the study and the views expressed are purely those of ESHRE and may not in any circumstances be regarded as stating an official position of the European Commission. | [http://www.eshre.eu/home/page.aspx/2](http://www.eshre.eu/home/page.aspx/2)  
Report is available and I have saved it, but it is quite lengthy. You can download it at: [http://www.eshre.eu/guidelines_and_legal/page.aspx/16](http://www.eshre.eu/guidelines_and_legal/page.aspx/16)  
| Finland, National Institute for Health and Welfare (STAKES) | | [http://www.stakes.fi/EN/index.htm](http://www.stakes.fi/EN/index.htm) |
| Finland National Public Health Institute (KTL) | • Has a various programmes, including one for Child and Adolescent Health. This particular programme is run by the Department of Child and Adolescent | [http://www.ktl.fi/portal/english/research__people__programs/child_and_adolescent_health/](http://www.ktl.fi/portal/english/research__people__programs/child_and_adolescent_health/) |
Health and “produces new information concerning the health of children and adolescents, makes research data available to municipalities, improves the health of children and adolescents through national guidance services, and supports especially the maternity and child health care system and school health care service.”

<table>
<thead>
<tr>
<th>Name of body or register:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
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<tbody>
<tr>
<td>Danish IVF Register</td>
<td>•</td>
<td><a href="http://www.sst.dk/English.aspx?sc_lang=en">http://www.sst.dk/English.aspx?sc_lang=en</a> #</td>
</tr>
<tr>
<td>European Childhood Obesity Surveillance Initiative (COSI)</td>
<td>“The WHO Regional Office for Europe has established a European childhood obesity surveillance system in fifteen countries in the Region. The system aims to routinely measure trends in overweight and obesity in primary school children (6-9 years), in order to understand the progress of the epidemic in this population group and to permit intercountry comparisons within the European Region.”</td>
<td><a href="http://www.euro.who.int/en/what-we-do/health-topics/disease-prevention/nutrition/policy/member-states-action-networks/childhood-obesity-surveillance/european-childhood-obesity-surveillance-initiative-cosi">http://www.euro.who.int/en/what-we-do/health-topics/disease-prevention/nutrition/policy/member-states-action-networks/childhood-obesity-surveillance/european-childhood-obesity-surveillance-initiative-cosi</a></td>
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Other countries

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<tr>
<th>Name of body or register:</th>
<th>Functions and information:</th>
<th>Website:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brazil, Fiocruz, Instituto de Pesquisa Clínica Evandro Chagas – Fundação</td>
<td>• IPEC-FIOCRUZ was established in 1996 to investigate “the natural history of women seeking</td>
<td></td>
</tr>
<tr>
<td>Research Topic: Reproductive Health Registries</td>
<td>Research conducted by: Andelka M. Phillips, DPhil Candidate HeLEX</td>
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<td>---------------------------------------------</td>
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<tr>
<td>Brazil:</td>
<td>Current plans for new registries include registries for DMD/BMD and SMA.</td>
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<tr>
<td>Chile:</td>
<td>Has made considerable progress in reducing maternal mortality.</td>
<td></td>
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<tr>
<td>Pakistan Initiative for Mothers and Newborns (PAIMAN)</td>
<td>This was a 5 year project, which started in 2004. Its aim was to help the Government of Pakistan to introduce interventions to improve maternal and child health.</td>
<td></td>
</tr>
</tbody>
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73 Please see http://www.treat-nmd.eu/registry/299/
74 Please see http://www.norad.no/en/countries/latin-america/brasil
## Multiple Birth Registers and Research Projects

<table>
<thead>
<tr>
<th>Register or project:</th>
<th>Key points:</th>
<th>Websites:</th>
</tr>
</thead>
</table>
| Norwegian Twin Registry (NTR) | • This project started in 2008.  
• The aim is “to create a national and international scientific resource that brings together and builds upon data, biobank material and competence from all three Norwegian twin panels. It will be population-based and include health history information of approximately 14 000 twin pairs.”  
• Guidelines on data access are not yet available in English, and researchers are encouraged to contact NTR if they are interested in accessing data.  
• However, the website summarises the guidelines as follows:  
  o Researchers who have an interest in using data for research purposes can apply for access to data. Any delivery of data will be considered as a sub-project in NTR.  
  o The applicant has to be affiliated with an institution with competence in conducting research projects that is willing to be responsible for a sub-project. Inexperienced researchers must have a scientific supervisor belonging to such an institution. All sub-projects must have a principal investigator with scientific responsibility for the project.  
  o For each sub-project, a contract will be written between the Norwegian Institute of Public Health and NTR. | [http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5031:1:0:0::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5031:1:0:0::0:0) |
| University of Washington (UW) Twin Registry | - Is a recently established database, which aims to help scientists improve our understanding of disease causes and health.  
- It is open to citizens of Washington State, other American states and citizens of other countries.  
- It has established a data repository of epidemiological and biological information.  
- It has developed guidelines for data access, is the Registry recognises the importance of sharing data, while also protecting the confidentiality of participants.  
- Researchers are encouraged to begin by enquiring directly to Bethany Osterman at bethany2@u.washington.edu | http://depts.washington.edu/uwccer/uwtr/twin-about.php |
| TwinsUK, DTR Twin Register | - The largest [and now only] adult twin registry in the UK with 12,000 people registered.  
- Its “initial main aim was to investigate the incidence of osteoporosis and other rheumatologic diseases in a small cohort of several hundred monozygotic (identical) twins. Since then the registry has expanded in number and areas of research covered.”  
- It is a project of the Department of Twin Research and Genetic Epidemiology at King’s College London.  
- The Register has collaborated with over 60 groups worldwide.  
- “The DTR twin register is run as a supported access resource through our oversight committee for the research community and it is in the process of | http://www.twinsuk.ac.uk/about-us/ |
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<td><strong>Swedish Twin Registry</strong></td>
<td><strong>International Society for Twin Studies (ISTS)</strong></td>
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<tr>
<td>- Run by the Department of Medical Epidemiology and Biostatistics at Karolinska Institutet.</td>
<td>- Founded in 1974, it aims to support research and public education in fields related to twins and twin epidemiology and genetics.</td>
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<tr>
<td>- This is the largest twin registry in the world.</td>
<td>- Website currently only available in Spanish-</td>
</tr>
<tr>
<td>- Begun in the 1960s</td>
<td><a href="http://www.ista.edu.au">http://www.ista.edu.au</a></td>
</tr>
<tr>
<td>- It “consists of several birth cohorts.”</td>
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<tr>
<td>- “It is a national health-related database, and is updated monthly with regards to the Address Register and annually with regards to the Cancer Registry, and the Cause of Death Registry. Additional information is collected depending on specific needs for ongoing projects.”</td>
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<tr>
<td>- Provides useful historical information, as it was “established with birth information for all twins born between the years 1886 and 1925.”</td>
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<td>- In 1998-2002, the Registry conducted the SALT-study, which involved telephone interviews with all living twins who were born between 1886 and 1925 and 1926-1958.</td>
<td></td>
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<tr>
<td>- Website: <a href="http://ki.se/jsp/polopoly.jsp?d=13013&amp;l=en">http://ki.se/jsp/polopoly.jsp?d=13013&amp;l=en</a></td>
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76 The results of this study were published in P. Lichtenstein et al. The Swedish Twin Registry: a unique resource for clinical, epidemiological and genetic studies. *Journal of Internal Medicine* **252**, 184–205 (2002), this article is available at http://ki.se/content/1/c6/03/63/58/STR%20-%20JIM%20sept02.pdf; and other articles and information regarding studies conducted by the Swedish Register are available at http://ki.se/ki/jsp/polopoly.jsp?d=13013&l=en Date: August 16th 2012
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<tr>
<th>National Twin Registry, the National Institute of Environmental Health Sciences</th>
<th>[Link](<a href="http://www.niehs.nih.gov/news/events/past">http://www.niehs.nih.gov/news/events/past</a> mtg/2005/twin/index.cfm)</th>
</tr>
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<td>Sri Lankan Twin Registry (SLTR)</td>
<td><a href="http://infolanka.com/org/twin-registry/">Link</a></td>
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<tr>
<td>Netherlands Twin Registry</td>
<td><a href="http://www.tweelingenregister.org/en/">Link</a></td>
</tr>
</tbody>
</table>
| Finnish Twin Cohort Study, University of Helsinki | • Began in 1974 with the Older Cohort studies.  
• Subsequently, there have been Finntwin16 and Finntwin12 studies and the follow-up study has continued to this day with three baseline projects.  
• Several studies have also been completed to some smaller cohorts. [Link](http://wiki.helsinki.fi/display/twinen g/Twinstudy;jsessionid=DCC7DB6D5AB1C1CE38AE793585CC6AFE) |
| Twins Study @ Harvard | • This is a long-term study of language development in twins. [Link](http://twins.wjh.harvard.edu) |
| Southern California Twin Project | • Twins and their families can join the Register.  
• It is open to twins of all ages.  
• The Project is currently seeking twins born between 1990 and 1995 to join the Register. They want twins who live within driving distance of USC. [Link](http://www-rcf.usc.edu/%7Elbaker/twins/Twin_Register.html) |
| Center for the Study of Multiple Births (CSMB) | • Support research in the area of multiple births  
• It has compiled several collections of statistics which are available for download from its website. [Link](http://www.multiplebirth.com/statistics.html) |
| Mid Atlantic Twin Registry (MATR) | • “is a population-based registry of twin pairs ascertained from birth records and the school systems of Virginia, North Carolina, and South Carolina.”  
• It currently contains data from approximately 300,000 twin pairs born between 1915 and 2007.  
• Data access:  
  o In the first instance, researchers who are [Link](http://www.matr.vcu.edu)  
  Guidelines for research are available at- [Link](http://www.matr.vcu.edu/info-researchers/research-guidelines.html) |
| Interested in accessing the MATR DNA Repository should contact MATR Administrator, Emily Lilley at echililley@vcu.edu. | The Repository has more than 1000 blood samples available for DNA analysis. | Privacy Policy available at: [http://www.matr.vcu.edu/privacy-policy.html](http://www.matr.vcu.edu/privacy-policy.html) |