Research Topic: Reproductive Health Registries, hRHR Project
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Norway

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

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[1] Stein Emil Vollset, ‘Health registries for research in Norway: examples and challenges’, seminar presentation given at the Norwegian Institute of Public Health, Department of Public Health and Primary Health Care, University of Bergen, Bergen, Norway, <http://retki.stakes.fi/NR/rdonlyres/7BCDFF4E-F64D-494E-8CA8-6FDFC433AA90/0/110405_Vollsten.pdf> accessed at 25th April 2012; this quotes Dag Moster et al. ‘Long-Term Medical and Social Consequences of Preterm Birth’ (2008) New Engl J Med 262-273.

Legislation, regulation and guidelines

Legislation:	**Key points:**	**Website:**
Health Registry Act (2001)*	• Series of regulations: ○ Cause of death registry; ○ Medical Birth Registry; ○ Cancer registry; ○ Prescription Registry; ○ Norwegian Patient Registry etc	Not currently available on lovdata in English
Personal Health Data Filing System Act (2001)		It seems likely that this is the same as the Health Registry Act. Available from the following websites: http://www.datatilsynet.no/Global/english/Personal%20Health%20Data%20Filing%20System%20Act_20011030.pdf http://www.ub.uio.no/ujur/ulovdata/lov-20010518-024-eng.pdf
The Health Personnel Act 1999	• With amendments 2002 • **§ 1***Objective of this Act* ○ The objective of this Act is to contribute to safety for patients and quality within the health service as well as trust in both health personnel and the health service.	Unofficial English translation available here- http://www.regjeringen.no/nb/dep/hod/dok/lover_regler/reglement/2002/act-of-2-july-1999-no-64-relating-to-hea.html?id=107079

- **§ 2***Scope of this Act*
    - This Act applies to health personnel and facilities where health care is being provided.
    - 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.
- **§ 21***General rule relating to the duty of confidentiality*
    - 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.
- **§ 22***Consent to give information*
    - 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.
    - For persons below 16 years of age, the provisions of the Patients Rights Act section 4-4 and section

	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.	
Therapeutic Biobank Act (2003)	• Regulates the use of human cells in clinical treatment.	Not currently available on lovdata in English
Research Ethics Law (2006)		Not currently available on lovdata in English
Data Registers Act 1978	• one of the most restrictive privacy acts in Europe • resulted in the founding of the Data Inspectorate	
EU Directive 95/46/EC	• Established committee to examine what amendments were required to the Data Registers Act • Resulted in the Personal Data Act 2000.	
Statistics Act (1989)	•	Not currently available on lovdata in English
Personal Data Act (2001)	• Came into force in January 2001 • Section 42 governs Data Inspectorate. • Also, Personal Data Regulations	
Personal Data Regulations	• ***Section 7-25. Processing of patient records by healthcare personnel and social workers not subject to public authorisation or holding a licence.*** ○ The processing of patient/client data by health or	Available in Norwegian at - http://www.lovdata.no/cgi-wift/ldles?doc=/sf/sf/sf-20011221-1476.html Available in English at-

	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. ○ Amended by the Regulations of 23 December 2003 No. 1798 (in force from 1 January 2004, formerly section 7-23), 24 April 2008 no. 396 (ratification). • ***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	http://www.datatilsynet.no/Global/english/Personal_Data_Regulations_20100215.pdf [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].

	patients, ▪ b) work as an appointed expert, or ▪ c) preparation of statistics. ○ Amended by the Regulations of 23 December 2003 No. 1798 (in force from 1 January 2004, formerly section 7-24), 24 April 2008 no. 396 (ratification). • ***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,	

	▪ c) the project shall be terminated at a time that is established prior to commencement of the project, ▪ d) the material collected is anonymised or erased upon completion of the project, and ▪ e) the project does not make use of the electronic alignment of personal data filing systems. ○ Amended by the Regulations of 23 December 2003 No. 1798 (in force from 1 January 2004, formerly section 7-25), 24 April 2008 no. 396 (ratification).	
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.	Available in English at- http://www.ub.uio.no/ujur/ulovdata/lov-20080620-044-eng.pdf Information from European Network of Research Ethics Committees- 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).

	• § 2-7. The right of the child to information about a sperm donor • 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. • Also, regulates use of human cells for research purposes.[3]	http://www.eshre.eu/ESHRE/English/Guidelines-Legal/Legal-documentation/Norway/Donor-anonymity/page.aspx/186
Guidelines Delivery of data from central personal health data filing systems	• Govern researchers' access to data from registers. • **2.1 specifies who can access such data-** ○ 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). ○ 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	Guidelines accessible in English- http://www.fhi.no/dav/4db1cb039e.pdf [link is not working at present, will check again].

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[3] For more information please refer to http://tidsskriftet.no/article/2228394/en_GB/#fotnote21

	Norwegian Directorate of Health.	
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: ○ MoBa questionnaire data: Access requires approval from the MoBa SMG. ○ MBRN data for MoBa participants: Access requires approval from the MoBa SMG. ○ MoBa ultrasound data: Access requires approval from the MoBa SMG ○ 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 Previously, I accessed them here- 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 [Note: this link takes you to a page which has the Protocol, as well as other relevant documents on data access].
Act on Public Administration (1967)	•	Available in English at- http://www.ub.uio.no/ujur/ulovdata/lov-19670210-000-eng.pdf
Guidelines for access to data from central personal health data filing systems	• 5 types of data: ○ Statistical; ○ Anonymous on an individual level;	Available in English at: http://www.fhi.no/dokumenter/4db1cb039e.pdf

	○ Pseudonymous; ○ De-identified; ○ And person-identifiable data Access to data, who can access data? **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 implies for access to de-identified data. [I suspect “implies” should read **“applies”**].	
Guidelines for CONOR Materials	Data access, who can apply?	http://www.fhi.no/eway/default.aspx?pid=23

	"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.	8&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0:0:::0:0
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	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0:0:::0:0

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[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

	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

Institutional Bodies

Name of organisation:	**Key points:**	**Website:**
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/ Further information from- 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-

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]

	○ 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	Full regulations available in Norwegian at- http://www.lovdata.no/cgi-wift/ldles?doc=/sf/sf/sf-20031017-1246.html 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
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=MainArea_5811&MainArea_5811=5895:0:15,2825:1:0:0:::0:0 Modernising national health registries: http://www.fhi.no/eway/default.aspx?pid=238&trg=MainLeft_5853&MainArea_5811=5853:0:15,2825:1:0:0:::0:0&MainLeft_5853=5825:52966::1:5857:1:::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.	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5853:0:15,3894:1:0:0:::0:0&MainLeft_5853=5825:52966::1:5857:1:::0:0
Norwegian Mother and Child Cohort Study (MoBa)	- ongoing pregnancy cohort study, aiming to include 100 000 pregnancies by 2008.	Main website-

	• 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	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,3046:1:0:0:::0:0 Forms for applications for accessing data available here- http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,4278:1:0:0:::0:0&MainLeft_5903=5954:0:15,4278:1:0:0:::0:0

	Data Inspectorate for DNA analysis, but for analysis of biomarkers in plasma they only need to be given notice. It may be necessary to collect exemption from confidentiality.	
Regional Committee for Medical Research Ethics (REK).	• Administratively REK is organized under the medical faculties at the four large universities in Norway. So: ○ REK North under the University of Tromsø, ○ REK Mid under the University of Trondheim, ○ REK West under the University of Bergen, ○ 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 Also, in English- 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/
The National Committee for Research Ethics in Science and Technology (NENT)	• Established in 1990, together with the National Committee for Medical Research Ethics and another for Social Sciences and Humanities.	Main website in English- http://www.etikkom.no/en/In-English/Committee-for-Research-Ethics-in-Science-and-Technology/

	• Several areas of special concern: ○ Biotechology and genetic engineering – ○ information technology, privacy, safety and security issues ○ risk and safety ○ 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- ○ "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:::0:0 [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.	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5217:1:0:0:::0:0
The Norwegian Directorate of Health	- Has a Code of Conduct for Information Security,[5] which is applicable to the healthcare, care and social services sector. [An updated version of the Code was	Norwegian version of the website- 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

	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] ○ Access control; ○ Use of data processor; ○ Agreements and authorisations relating to research; ○ Information security for research projects; ○ And patient access to incident registers.	English version of the website- http://www.helsedirektoratet.no/english/Sider/default.aspx

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

Registers

"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 of approval from the Regional Committee for Medical Research Ethics (REK).

Register:	**Functions and relevant information:**	**Website:**
Harmonized Reproductive Health Registries (hRHR) project	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."	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5459:1:0:0:::0:0
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/General/About-the-Cancer-Registry/About-the-organization/

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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

	Regional Health Authority and is organized as an independent institution under Oslo University Hospital Trust, with its own board. • 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. • Responsible for national screening programmes	
The Health Personnel Register	• daily updated register of all persons with authorisation or licence to work as health personnel in Norway • searchable in Norwegian	http://www.safh.no/english/index.html
Register of Pregnancy Termination	• national health register of all induced abortions in Norway • Since 2006, the NIPH manages the Register of Pregnancy Termination and is the data controller. • Collection and processing of health information about the terminations in the Register are determined in the Register of Pregnancy Termination Regulations.	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5352:1:0:0:::0:0
Norwegian Cardiovascular disease registry (2012)	• Established in 2010 • The Norwegian Institute of Public Health is the data controller for the registry, which will begin during the first half of 2012. • Purpose is to contribute to knowledge about the incidence, prevalence, treatment, morbidity and	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5355:1:0:0:::0:0

	mortality of cardiovascular disease in the population. • Governed by the Personal Health Data Filing System Act	
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).	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5160:1:0:0:::0:0
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/eway/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-

	information: ○ about maternal health before and during pregnancy, ○ any complications during pregnancy or birth. ○ This includes information about: Medicine used in- ○ pregnancy, ○ labour interventions, ○ birth complications, ○ maternal complications after birth, ○ whether the baby is born alive, ○ any diagnoses in the child or evidence of congenital abnormalities. 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.	wift/ldles?doc=/sf/sf/sf-20011221-1483.html 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
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.	

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.[8]	http://www.nsd.uib.no/polsys/data/en/forvaltning/enhet/37606
PolSys Data on the Political System	• contains information about institutions, persons and resources in (mainly) the Norwegian political and civil	http://www.nsd.uib.no/polsys/en/help/about.html

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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 helseregistre 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).

Midlertidig lov om prøveordning med lokaler for injeksjon av narkotika (sprøyteromsloven)
Accessed via http://www.nsd.uib.no/polsys/data/en/forvaltning/enhet/37606/lovdata

	service area.	
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: ○ 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. ○ 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

Regulatory body:	**Functions and relevant information:**	**Websites:**
Maternal Mortality-Centre for Maternal and Child Enquiries (CMACE) ***Note:*** The other way to research maternal mortality is through official death certification to the Registrars General (the Office for National Statistics and its equivalents).	• 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. • Latest report from 2011- Saving Mothers' Lives BJOG -An International Journal of Obstetrics and Gynaecology-Reviewing maternal deaths to make motherhood safer: 2006–2008 • Publishes reports on: ○ Child Death ○ Maternal Death ○ Perinatal Mortality	http://www.patient.co.uk/doctor/Maternal-Mortality.htm#ref2 Reports available from- http://www.hqip.org.uk/cmace-reports/
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. • 2009 table to be released in May to June 2012.	http://www.statistics.gov.uk/hub/release-calendar/index.html?newquery=*&title=Birth+cohort+tables%2C+England+and+Wales&pagetype=calendar-entry&lday=&lmonth=&lyear=&uday=&umonth=&uyear=
Information Communications Office (ICO)	• Responsible for administering: ○ the Data Protection Act ○ The Privacy and Electronic Communications	http://www.ico.gov.uk/

	(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	
Human Fertilisation and Embryology Authority (HFEA)	• Administers the Human Fertilisation and Embryology Act 2008. • Is responsible for the HFEA Register. • Publishes annual reports. • Main functions are to: ○ license and monitor clinics carrying out in vitro fertilisation (IVF) and donor insemination ○ license and monitor establishments undertaking human embryo research ○ maintain a register of licences held by clinics, research establishments and storage centres ○ regulate storage of gametes (eggs and sperm) and embryos ○ 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.	13_HFEA_Annual_Report__Accounts_201011.PDF Summaries based on national statistics available at- http://www.hfea.gov.uk/104.html You can also subscribe for e-updates.
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.	http://www.nigb.nhs.uk/ecc http://www.hfea.gov.uk/5826.html http://www.nigb.nhs.uk/s251 Annual reports accessible here: http://www.nigb.nhs.uk/pubs/annual
General Registrar Office	• Responsible for birth and death registrations	http://www.gro.gov.uk/gro/content/
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)	http://www.hpa.org.uk/gumcad GUMCAD and HIV Data Sharing Policies available at-

	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.	http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1247816526850 Tables and reports available- http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1203348026613
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	http://www.publications.parliament.uk/pa/cm/cmallparty/register/sexual-and-reproductive-health-in-the-uk.htm And main website-

	Sexual Health and HIV, the FPA, and the Faculty of Sexual and Reproductive Healthcare. • It conducts inquiries and produces reports on key issues in sexual health. • Its latest report, Healthy Women, Healthy Lives? The Cost of Curbing Access to Contraception Services, was released in July 2012 and is available here- http://www.fpa.org.uk/media/uploads/campaignsandadvocacy/advocacy-and-lobbying/healthy-women-healthy-lives-full-report-july-2012.pdf	http://www.fpa.org.uk/campaignsandadvocacy/advocacyandlobbying/all-party-groups-on-sexual-health/appg-uk
The Family Planning Association UK (FPA)	• Aims to educate and inform people about sexual and reproductive health.	http://www.fpa.org.uk Fact sheets on matters of sexual health available at- http://www.fpa.org.uk/professionals/factsheets

Registers

Name of register:	Functions and information:	Website:

HFEA Register	• governed by the HFEA
	• collects data on:
	  ○ IVF/ICSI
	  ○ donor treatments and
	  ○ the storage of embryos, eggs and sperm.
	
	Donor-conceived children?
	• The Register records information on donors and on any children conceived as a result of their donation.
	• 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.
	Since 2005, the Register now collects the following information regarding donors:
	• their physical description (height, weight, eye and hair colour) if provided by the donor
	• the year and country of their birth
	• their ethnicity
	• whether they had any children, how many and their gender
	• their marital status
	• their medical history
	• a goodwill message to any potential children, if provided by the donor
	• identifying information (the donor's name, date of
		http://www.hfea.gov.uk/5447.html
		
		Information regarding donor-conceived children:
		http://www.hfea.gov.uk/112.html

	birth and last known address). What data be accessed? - Can be accessed for research purposes - Donor-conceived offspring can access information regarding their biological parents. - Donor-conceived people who are conceived after 1 April 2005 can: **at 16 years old** 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). And when they reach 18 years old, they can apply to the HFEA to find the information their donor provided, including identifying information. Anonymised data? - The HFEA will be publishing an anonymised version of our Register. - 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.	
UK Donor Link	- Voluntary register, - It allows people conceived through donated sperm, and / or eggs, their donors and half-siblings to exchange information and where desired to contact	http://www.ukdonorlink.org.uk/

	each other. • 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. • The register is available throughout the UK.□ • Has funding from Department of Health	

Legislation

Legislation:	Key points:	Website:
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- http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf Further information and explanatory notes available at- http://services.parliament.uk/bills/2010-12/healthandsocialcare.html http://www.fpa.org.uk/media/uploads/campaignsandadvocacy/advocacy-and-lobbying/health-and-social-care-bill-and-sexual-health-services-march-2012.pdf
Human Fertilisation and Embryology Act 2008	• Administered by the Human Fertilisation and Embryology Authority (HFEA)	http://www.legislation.gov.uk/ukpga/2008/22/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 Abortion (Amendment) (England) Regulations 2002 The Abortion (Amendment) Regulations 2008		
Data Protection Act 1998.		
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

Regulatory body or project:	**Functions and relevant information:**	**Websites:**
The National Commission for Protection of Child Rights (NCPCR)		http://ncpcr.gov.in/
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
The Drug Technical Advisory Board and Central Drugs Standard Control Organization		http://cdsco.nic.in/html/GCP1.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 The website also contains copies of all applicable legislation, regulations and rules.
Humanitarian Technology Challenge	•	http://ieeehtc.org

Post-Graduate Institute of Medical Education and Research (PGIMER)	- PGIMER is in the process of computerising all its patient records.[9]	http://pgimer.nic.in
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: ○ Fertility control; ○ Maternal and child health; ○ And control of nutritional disorders.	http://www.icmr.nic.in
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	http://www.ncpcr.gov.in Details for all the state commissions are available at- http://www.ncpcr.gov.in/scpcr.htm

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[9] Smriti Sharma Vasudeva, PGI decides to place all patient records online, *The Indian Express,* available at: http://www.indianexpress.com/news/pgi-decides-to-place-all-patient-records-online/908894/

	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 Potection of Child Rights	

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[10] The Notification is available at: http://www.ncpcr.gov.in/StateCommissions/Notification%20JSCPCR%20Rules%20Oct%202011.pdf

	(OSCPCR); ○ Punjab- soon to be constituted in accordance with the notification issued in 2011, Notification No. 5/1/2006-1SS/916;[11] ○ Rajasthan State Commission for Potection of Child Rights (RSCPCR)- Notification No. F/DWCD /ICDS/ Uni-Cons/ 09-10/ 11919 and Notification no- F()WCD/ ICDS/ Uni-Cons/ ICDS/09 -10/26112; ○ Sikkim Commission for Protection of Child Rights (SCPCR); ○ Tamil Nadu Commission for Protection of Child Rights(TNCPCR)- Notification No. G.O. (Ms) No. 202;[12] ○ Uttrakhand Commission for Protection of Child Rights (UCPCR). Several Working Groups have also been created including: ○ The Working Group on Female Feticide and Infanticide; ○ The Working Group for "Review of Child Labour (Prohibition and Regulation) Act 1986 and the Right to Education Bill.[13]	
Family Planning Association India	• Established in 1949. • 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	http://www.fpaindia.org

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

[12] Notification available at: http://www.ncpcr.gov.in/StateCommissions/TNSCPCR%20Rules.pdf

[13] Working Group Constitution available at: http://www.ncpcr.gov.in/Working_Groups/Working_Group_Order_dated_13_10_2007.pdf

	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	

	○ State AIDS Cell ○ FHI (Family Health International) ○ CORT (Centre for Operations Research and Training) ○ Humanas ○ Avert Society	
Ministry of Health and Family Welfare (MOHFW)	• Consists of 4 departments: ○ Department of Health & Family Welfare ○ Department of Ayush ○ Department of Health Research ○ Department of AIDS Control	http://mohfw.nic.in
Reproductive and Child Health Programme II	•	http://www.mohfw.nic.in/NRHM/RCH/Index.htm
Reproductive Health Programme, (project of the Population Council)	• Is an international, nonprofit, NGO "that seeks to improve the well-being and reproductive health of current and future generations around the world and to help achieve a humane, equitable, and sustainable balance between people and resources." • It conducts research and runs programmes in many countries,	http://www.popcouncil.org/what/hivaids.asp
Norway-India Partnership Initiative (NIPI)	• This initiative began in 2006 to support an existing Indian project, the ***National Rural Health Mission (NRHM).*** • The project was set to run until 2011, and focussed on 5 states: ○ Bihar; ○ Madhya Pradesh; ○ Orissa; ○ Rajasthan;	http://www.unops.org/english/whatwedo/UNOPSinaction/Pages/norway-india-partnership-initiative.aspx http://www.norad.no/en/tools-and-publications/publications/publication?key=157459

	○ and Uttar Pradesh. • “NIPI is run by a partnership between the focus states, the government, UNICEF, WHO and UNOPS. The focus states are the key stakeholders in the partnership and NIPI works as a catalyst to help them innovate and pilot new ways of delivering health services.”	http://india.gov.in/outerwin.php?id=http://www.orissa.gov.in/health_portal/index.html
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.	http://india.gov.in/citizen/health/health.php?id=47 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- Stephen S Lim et al. India's Janani Suraksha Yojana, a conditional cash transfer programme to increase births in health facilities: an impact evaluation. *The Lancet.* **375,** 9730, 2009 - 2023,(2010).
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 new-borns in Government health institutions. • Has established guidelines to assist with implementation of the scheme.	http://202.71.128.172/nihfw/nchrc/index.php?q=content/government-guidelines-guidelines-antenatal-care-and-skilled-attendance-birth-anmslhvssns
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."	http://202.71.128.172/nihfw/nchrc/
Human Rights Law Network (HRLN)	• has launched many legal cases seeking accountability for "maternal health violations".	http://www.hrln.org/hrln/

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[14] Center for Reproductive Rights, '2011 Update, Maternal Mortality in India, Using International and Constitutional Law to Promote Accountability and Change', (New York, 2011), 11; People's Union for Civil Liberties (PUCL) v. Union of India & Others, W.P. Civ. 196 of 2001, Supreme Court , Order dated Nov. 20, 2007, para. 14.

Registers

Name of register:	Functions and information:	Website:
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
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
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/

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."[15]

Name of register or project:	**Functions and information:**	**Website:**
Births and Death Register, Gujurat	• "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."	http://valsaddp.gujarat.gov.in/valsad/english/shakhao/statistic-branch/birth_death.htm
Tamil Nadu Maternal Death Audit reporting system	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.[16]	http://cbhi-hsprod.nic.in/listdetails.asp?roid=22 http://mohfw.nic.in/NRHM/State%20Files/ta

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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:

[16] For more information please see the following:
P. Padmanaban et al. Innovations and Challenges in Reducing Maternal Mortality in Tamil Nadu, India. *J Health Popul Nutr.* **27 (2),** 202–219 (April, 2009), available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2761773/ ; M. Prakasamma, Maternal Mortality-reduction Programme in Andhra Pradesh. *J Health Popul Nutr*. **27(2),** 220–234 (April, 2009).; Sue J. Goldie et al. Alternative Strategies to Reduce Maternal Mortality in India: A Cost-

		milnadu.htm
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	http://111.93.47.72/rbd/ For information on OLIR, see- 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."[17] • "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 ○ Goa Medical College, Bambolim – Goa.	http://www.goa.gov.in/departments/health.html

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Effectiveness Analysis. *PLoS Med*. **7(4),** e1000264. (April, 2010).; Sharad D. Iyengar et al. Maternal Health: A Case Study of Rajasthan. *J Health Popul Nutr.* **27(2),** 271–292 (April, 2009).

[17] Please see http://www.goa.gov.in/howdoi/birthcertificate.html

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	(Please note, GMC will register only if event took place in GMC.)	
Reproductive Child Health Service in Urban Slum, Assam	• "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."	http://hsprodindia.nic.in/listdetails.asp?roid=29
NIPI in Orissa	•	http://india.gov.in/outerwin.php?id=http://www.orissa.gov.in/health_portal/index.html

Legislation and policy

Federal legislation and policy

Legislation and guidelines etc:	**Key points:**	**Website:**
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
ICMR Ethical Guidelines For Biomedical Research on Human Participants		http://icmr.nic.in/ethical_guidelines.pdf
ICMR Cancer Management Guidelines- - Guidelines for Management of Stomach Cancer - Guidelines for Management of Cervix Cancer - Guidelines for Management of Buccal Mucosa Cancer		http://icmr.nic.in/guide/cancer/Cancer%20Mgmt%20Guide.htm
ICMR Guidelines for Stem Cell Research (Draft) Indian		http://icmr.nic.in/stem_cell_guidelines.pdf
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
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
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 For more information on blood banks please see- http://cdsco.nic.in/html/guideline.htm
Drugs & Cosmetics Amendment Act 2008	•	http://cdsco.nic.in/D&C_ACT_AMENDMENT_2008_file.pdf
National Blood Policy	• Issued in 2002	
The Commission for Protection of Rights of the Child enactments- • The Commissions for Protection of Rights of the Child Act, 2005.[18] • National Commission for Protection of Rights of the Child Rules, 2006.[19] • The Commissions for Protection of Rights of the Child (Amendment) Act 2006.[20]	• Established the Commission for Protection of Rights of the Child (NCPCR) • Rule 17(e) and (d) mandates that the Commission: ○ 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

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[18] Act available at: http://www.ncpcr.gov.in/Acts/National_Commission_for_Protection_of_Child_Rights_Act_2005.pdf
[19] Rules available at: http://www.ncpcr.gov.in/Acts/National_Commission_for_Protection_of_Child_Rights_NCPCR_Rules.pdf
[20] Act available at: http://www.ncpcr.gov.in/Acts/National_Commission_for_Protection_of_Child_Rights_Act_Amendment_2006.pdf

	perspectives ○ Promotes, respects and seriously considers the views of children in its work and in that of all government departments and organisations dealing with children • And the "Commission's functioning is also informed by Article 12 of the United Nations Child Rights Charter indicating that, "States Parties shall assure to the child who is capable of forming his or her own views, the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child". Children are active stakeholders in defining and deconstructing their problems and addressing their vulnerabilities."[21]	
The Transplantation of Human Organs Act 1994 (Central Act 42 0f 1994)	•	Available at- http://www.transplantindia.com/tho_act/thobill1cont.asp
The Medical Termination of Pregnancy Act 1971	• Specifies circumstances under which medical abortions can legally be carried out.	
The Medical Termination of Pregnancy	• Makes some minor amendments.	

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[21] NCPCR, *Child Participation*, available at: http://www.ncpcr.gov.in/child_participation.htm

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.	

State legislation

Legislation and guidelines etc:	**Key points:**	**Website:**
Gujarat Registration of Marriages Act, 2006	•	Available at- http://www.gujhealth.gov.in/Portal/Tender/1/4_Marriagesacteng.pdf
Reproductive Child Health, RCH II, 2005 (Orissa)	•	
Tamil Nadu, Registration of Births and Deaths Rules 2000.	•	Available at- http://www.tn.gov.in/acts-rules/hfw/birth_death_rules_e.pdf

Delhi State Rules for Registration of Births & Deaths 1999	•	
Punjab Birth and Death Rules (2004)	•	Available at- http://pbhealth.gov.in/pdf/RTI/BIRTH%20AND%20DEATH.PDF
Rajasthan Medical Act 1952	• Governs registration of medical practitioners in Rajasthan.	http://rmcjaipur.org/rma.aspx
	•	

Ghana

Institutional Bodies and projects

Institutional bodies and projects:	Functions and relevant information:	Websites:
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).[22] • The National Health Insurance Scheme provides 3 main types of insurance: ▪ The District-Wide Mutual Health Insurance Scheme. ▪ The Private Mutual Health Insurance Scheme. ▪ The Private Commercial Health Insurance Scheme.	http://www.nhis.gov.gh

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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

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/
The Assisted Conception Unit, (ACU) Finney Hospital and Fertility Centre	• Recently established. • Provides current ART facilities	http://www.finneyhospital.com/fertility.html
EngenderHealth runs the following programmes in Ghana: • Reducing Maternal Morbidity and Mortality (R3M) program • Quality Health Partners (QHP) initiative • Work to expand HIV and AIDS prevention and treatment	• 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.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: ○ Promote voluntary counselling and testing for HIV	

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[23] Available at http://www.engenderhealth.org/our-work/major-projects/qhp.php

[24] Please see http://www.ghanaqhp.org/index.php?id=352

	○ Encourage sound infection control practices at health clinics ○ Integrate HIV prevention with maternal health services ○ Provide high quality antiretroviral drug treatment ○ Foster efforts to reduce stigma and discrimination against HIV-positive people.	
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://pdf.usaid.gov/pdf_docs/PNACT263.pdf
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	http://www.ipas.org/en/Who-We-Are.aspx Abortion attitude transformation: A values clarification toolkit for global audiences,

	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 http://www.ipas.org/en/Resources/Ipas%20Publications/Abortion-attitude-transformation--A-values-clarification-toolkit-for-global-audiences.aspx Other resources also available at http://www.ipas.org/en/Resources.aspx
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 - http://www.indepth-network.org/index.php?option=com_content&task=view&id=20&Itemid=30 iSHARE – http://www.indepth-ishare.org

	• Data sharing? ○ Has established iSHARE in order to share its data over the Internet. ○ Data is not currently available for Ghana, but it may be in the future.	
Reducing Maternal Morbidity and Mortality (R3M) (project of the Population Council)	• Project begun in 2006. • It aims to reduce unwanted fertitilty 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	http://www.popcouncil.org/projects/130_ReducMaternalMorb.asp

	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."	
Strengthening Evidence for Programming on Unintended Pregnancy (STEP UP) (project of the Population Council)	• "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)." •	http://www.popcouncil.org/projects/325_STEPUP.asp http://stepup.popcouncil.org

Registers

Name of register:	**Functions and information:**	**Website:**
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

Legislation:	**Key points:**	**Website:**
Registration of Births and Deaths Act, 1965 (Act 301)	•	
National Blood Policy for the Health Sector 2006	• Clause **3.1-** Its aim is to "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."	Available at- http://www.who.int/bloodsafety/transfusion_services/GhanaNationalBloodPolicy2006.pdf
National Health Insurance Act 2003	• established the National Insurance Scheme	
Insurance Act, 2006 (Act 724)	• current Act governing the National Insurance Scheme	http://www.nicgh.org/live/images/photos/downloads/Insurance_Act_724_2006.pdf
Infectious Diseases Act 1908	•	Available at – http://www.epa.gov.gh/ghanalex/acts/Acts/INFECTIOUS%20DISEASE%20ACT,1908.pdf
Guidelines and Procedures on Births and Deaths Registration.	• Sets out procedures for birth and death registration. • Different procedures apply depending on the timing of the birth or death.	http://www.bdrghana.gov.gh/procedures.php

Other African Nations

Organisations and Projects-

Project name	**Functions and relevant information:**	**Websites:**
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
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/

	continuous demographic surveillance system (DSS) in a sub-population of 35,000”. - Primarily funded by Wellcome Trust since 1996.	
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.	http://cdckemri.org/index.php?option=com_content&view=article&id=94:health-and-demographic-surveillance-system&catid=43:about-us
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:[25] ○ 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; ○ Use these and related evidence to advocate and advance policy and action in meeting the health needs and wellbeing challenges of the urban	http://www.aphrc.org

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[25] http://www.aphrc.org/insidepage/?articleid=24

	poor at various local, national, regional and global forums; ○ Build the research capacity of young and promising African scholars through doctoral research grants and related efforts, and ○ 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.	

Australia

National institutional bodies and projects

Organisation and registers:	**Functions and information:**	**Website:**
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.[26] • 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 Other information- http://ehealth.gov.au/internet/ehealth/publishing.nsf/Content/faqs-consumer#.UDVSkkK4Ss-
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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[26] Please see Tim Barlass, 'Patients reject eHealth System', *The Age*, available at http://www.theage.com.au/it-pro/government-it/patients-reject-ehealth-system-20120811-24179.html ; and http://www.zdnet.com/aus-govt-looks-to-outsource-e-health-record-management-7000001602/ and http://www.abc.net.au/news/2012-07-17/canberra-e-health-records-still-not-online/4135330/?site=canberra

	(UNSW) and based in Sydney Children's Hospital (SCH), Randwick Hospitals Campus. • 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: ○ UNSW Ethics Committee ○ AIHW Ethics Committee	
National Health Information Standards and Statistics Committee (NHISSC)	• Established in August 2008. • Its functions are to: ○ Provide strategic advice to AHMC on issues relating to health information standards; ○ Endorse national information standards for the health sector; and ○ 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	http://www.ahmac.gov.au/site/membership.aspx

	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.	http://www.nba.gov.au Annual Reports available here- http://www.nba.gov.au/pubs/annual-report.html#/pubs/errata10-11.pdf
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."	http://www.aihw.gov.au/csdwg/

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.	http://www.ahcdo.org.au Guidelines available at- http://www.ahcdo.org.au/publications/cid/1/parent/0/t/publications/parent_name/Guildelines
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	

	(CIDMU). • Registries 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	http://www.aihw.gov.au/families-and-children/

	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."[27]	
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."[28] • Its projects include: ○ 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."	http://www.preru.unsw.edu.au/PRERUWeb.nsf/page/National+Maternity+Data+Development http://www.aihw.gov.au/nmdd/

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[27] Australian Institute of Health and Welfare (AIHW), *About AIHW,* available at: http://www.aihw.gov.au/about/

[28] National Maternity Data Development, available at: http://www.preru.unsw.edu.au/PRERUWeb.nsf/page/National+Maternity+Data+Development

	○ Maternity Information Matrix, (MIM) which aims "to develop a nationally consistent and comprehensive maternity data collection in Australia."[29] It provides a "web-based electronic index of maternity data items organised on a topic-by-topic basis, representing the maternity pathway. It provides a snapshot of data items and metadata collected at a point in time and provides a basis for future data development."[30] ○ Nomenclature for Models of Care. This "seeks to develop a coherent system of nomenclature that will encompass the entire range of models of maternity care proposed across all Australian states and territories."[31]	
Robinson Institute Research Centre for Reproductive Health (RCRH)	**Scope** • 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	http://www.adelaide.edu.au/rcrh/about/aims/

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[29] Maternity Information Matrix, available at: http://www.preru.unsw.edu.au/PRERUWeb.nsf/page/Maternity%20Information%20Matrix ; see also Maternity Information Matrix, Guide for Use, available at: http://www.npesu.com.au/maternityinformation/guide.php

[30] MIM, available at: http://www.npesu.com.au/maternityinformation/index.php

[31] Nomenclature for Models of Care, available at: http://www.preru.unsw.edu.au/PRERUWeb.nsf/page/Nomenclature%20for%20Models%20of%20Care

	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.	

	Conducts research in the following areas: - Ovarian and Follicular Function - Oocyte and Early Embryo Development - Uterine Biology - Embryo Implantation and Placental Development - Male Reproduction - Reproductive Immunology - Reproductive Biotechnology - Nutrition, Environment and Reproduction - Early Life Programming of Fetal Development and Adult Health - Menopause - Infectious Diseases of the Reproductive and Gestational Tissues - Cancers of the Reproductive System - Breast Biology and Cancer	
Australian Reproductive Health Alliance	- This organisation ceased its operations in September 2011. - 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."[32]	http://www.arha.org.au/

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[32] http://www.arha.org.au/about.html

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: ○ "State and Territory Maternal Mortality Committees, ○ Royal Australian and New Zealand College of Obstetricians and Gynaecologists, ○ Australian and New Zealand College of Anaesthetists, ○ Royal Australian and New Zealand College of Psychiatrists, ○ Royal College of Pathologists of Australasia, ○ Australian Commission for Safety and Quality in Health Care, ○ the Maternity Alliance, School of Public Health and Community Medicine (UNSW), ○ Australian College of Midwives, and expert clinicians."[33]	http://www.preru.unsw.edu.au/preruweb.nsf/page/NACMM
Reproductive Technology Accreditation Committee (RTAC)	• responsible for licensing ART clinics	http://www.fertilitysociety.com.au/rtac/
The Fertility Society of Australia	• "representing scientists, doctors, researchers,	http://www.fertilitysociety.com.au/home/ab

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[33] National Advisory Committee on Maternal Mortality, available at: http://www.preru.unsw.edu.au/preruweb.nsf/page/NACMM

(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.”	out/
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.”[34]	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.”[35] • “All Australian states and territories have legislation	http://www.aihw.gov.au/cancer/aacr/

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[34] Australasian Maternity Outcomes Surveillance System (AMOSS),

[35] AACR, What is the AACR? Available at: http://www.aihw.gov.au/cancer/aacr/

	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.” o 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 • Is responsible for maintaining the maintains the Australian Cancer Database, which holds information on “all cancer cases diagnosed in Australia from	http://www.aihw.gov.au/national-cancer-statistics-clearing-house/ Protocol available at: http://www.aihw.gov.au/WorkArea/Downloa

	1982 onwards, and compiled from state and territory cancer registry data."[36]	dAsset.aspx?id=10737421344
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."	http://www.aihw.gov.au/cancer/cmag/
ACCESS - Australia's National Infertility Network	• National organisation representing the interests of infertile people.	http://www.access.org.au/
Flinders Reproductive Medicine (FRM)	• "one of the first fertility clinics in the world, and helped to conceive South Australia's first IVF baby in	http://www.flindersivf.com.au/

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[36] NCSCH, available at: http://www.aihw.gov.au/national-cancer-statistics-clearing-house/

	1982."[37] - Offers individualised fertility treatment.	

National Registers

Register:	**Key points and data access:**	**Websites:**
Australian Registry of Births Deaths and Marriages	- A division of the Federal Government, their website provides links to the State authorities, which are responsible for registering births, deaths, marriages and other life events.	http://australia.gov.au/topics/law-and-justice/births-deaths-and-marriages-registries/
The Voluntary Register of Information about Donation in Assisted Reproduction	"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."	http://www.voluntaryregister.health.wa.gov.au/home/
Australian Bleeding Disorders Registry (ABDR)	- It is a clinical database and business system designed for use by a variety of persons including: ○ Clinicians ○ Nurses ○ Physiotherapists ○ Social workers ○ and data managers involved in the treatment of people with bleeding disorders.	ABDR Annual Reports available at- http://www.nba.gov.au/abdr/abdr-annual-report.html Additional information on the ABDR and data access are available here-

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[37] Flinders Reproductive Medicine, About Us, available at: http://www.flindersivf.com.au/about/overview/

	• 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."	http://www.ahcdo.org.au/abdr
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	http://www.registries.org.au

	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.	
Australian Childhood Immunisation Register (Immunisation Register)	• 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.”	http://www1.hic.gov.au/general/acircirgacir
Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS)	• 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.	http://www.ccretherapeutics.org.au/information/currentresearch/anzscts/anzscts.html

	- It publishes annual reports, the most current report is for 2011.	
Australian Organ Donor Register	- Is the only Australian national register for organ and tissue donations. - Allows people to register as donors online.	http://www.humanservices.gov.au/customer/services/medicare/australian-organ-donor-register
The Australian Twin Registry (ATR)	- Established in 1981. - Non-profit organisation which supports medical and scientific research involving twins with the aim of improve general health and wellbeing. - It maintains a national register of twins and those members of their family willing to participate in research. - Currently, there are more 35,000 pairs of twins on the Register, which makes it one of the largest voluntary registers in the world. - Twins can join the register online. - They currently have 50 studies either recruiting or collecting data. - Affiliated with: ○ the Australian Multiple Birth Association (AMBA); ○ Western Australian Twin Child Health Cohort (WATCH Cohort); ○ and the Western Australian Twin Registry (WATR). - Data access: ○ Governed by ethical principles, guidelines and	http://www.twins.org.au ATR's Guidelines governing data access are available at- http://www.twins.org.au/atr/processes/ATR_Guidelines_2_web.pdf The DTA is available here- http://www.twins.org.au/atr/processes/APPROVED_LEX_19360_Template_approved_by_Legal_Services_21May2012.pdf

	privacy legislation, which “allow all Australian researchers access to its service on a fair, reasonable and equitable basis.” ○ All researchers must execute a Data Transfer Agreement (DTA) between the ATR and their research institution. ○ Researchers are encouraged to make contact with the ATR Management to discuss their proposed research.[38]	

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[38] ATR, *Application Process,* available at http://www.twins.org.au/researchers/application-process

State Organisations and Registers

Organisation:	**Functions and information:**	**Website:**
New South Wales Health Central Register	- 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."	http://www.health.nsw.gov.au/art/index.asp
The New South Wales Registry of Births, Deaths and Marriages (NSW)	- registers life events of NSW citizens, including: ○ births ○ deaths ○ marriages ○ 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: ○ *Births, Deaths and Marriages Registration Act, 1995; and* ○ *Commonwealth Marriage Act, 1961.*	http://www.bdm.nsw.gov.au/aboutUs.htm
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."[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."[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[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	

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[39] NSW Pregnancy and Newborn Services Network, More about the NSW Pregnancy and Newborn Services Network, available at http://www.psn.org.au/index.php?option=com_content&task=category&sectionid=3&id=19&Itemid=58

[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

[41] SEA-ORCHID: Optimising Reproductive and Child Health Outcomes in Developing Countries, available at http://www.psn.org.au/index.php?option=com_content&task=view&id=36&Itemid=37 ; for more information see SEA-ORCHID, http://www.seaorchid.org/about/

	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." [42] •	
Western Australian Cancer Registry	• Collects information about cancer in people diagnosed with cancer within the state. • Information about patients with cancer includes: ○ name and address ○ date of birth ○ country of birth ○ whether they are of Aboriginal or Torres Strait Islander descent ○ location and type of each cancer ○ 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	http://www.health.wa.gov.au/wacr/home/ Information about the functioning of the Human Research Ethics Committee and how to apply for access to data is available here- http://www.health.wa.gov.au/healthdata/hrec/index.cfm

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[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

	Ethics Committee." - What type of data is available to researchers? - "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."	

Reproductive Technology Council – Western Australia	- Established in accordance with Human Reproductive Technology Act 1991.
	- Section 14 of the Act sets out its main functions.
	- Its primary functions are:[43]
	  - formulate and review a Code of Practice to govern the use of artificial fertilisation and storage procedures carried on by licensees;
	  - advise the Commissioner of Health on the suitability of applicants, and compliance of licensees with conditions of their licences;
	  - 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;
	  - advise the Minister for Health on matters related to reproductive technology;
	  - 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	

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[43] Reproductive Technology Council, Functions of the Council, available at: http://www.rtc.org.au/about/index.html

	○ to promote informed public debate and education on these issues.	
University of Sydney, Reproductive, Maternal and Child Health		http://sydney.edu.au/medicine/research/themes/reproductive/index.php
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	http://www.ocba.sa.gov.au/bdm/index.html
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:[44]	http://www.ors.act.gov.au/community/births_deaths_and_marriages

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[44] ACT Government, Births, Deaths and Marriages, Legislation, available at: http://www.ors.act.gov.au/community/births_deaths_and_marriages/legislation

	○ ACT Civil and Administrative Tribunal Act 2008 ○ ACT Civil and Administrative Tribunal Regulation 2009 ○ Adoption Act 1993 ○ Adoption Regulation 1993 ○ Births, Deaths and Marriages Registration Act 1997 ○ Births, Deaths and Marriages Regulation 1998 ○ Civil Partnerships Act 2008 ○ Civil Partnerships Regulation 2010 ○ Coroners Act 1997 ○ Coroners Regulation 1994 ○ Freedom of Information Act 1989 ○ Freedom of Information Regulation 1991 ○ Legislation Act 2000 ○ Legislation Regulation 2003 ○ Marriage Act 1961 (Cwlth) ○ Marriage Regulations 1963 (Cwlth) ○ Parentage Act 2004 ○ Privacy Act 1988 (Cwlth) ○ Privacy Regulations 2006 (Cwlth) ○ Registrar-General Act 1993 ○ Registration of Deaths Abroad Act 1985 (Cwlth) ○ Registration of Deaths Abroad Regulations 1985 (Cwlth) ○ Statutory Declarations Act 1959 (Cwlth) ○ Statutory Declarations Regulations 1993 (Cwlth)	
Northern Territory Registry of	• Registers births, deaths and marriages and other life	http://www.nt.gov.au/justice/bdm/index.sh

Births, Deaths and Marriages (NT)	events.	tml

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:
	  ○ Maternal health[45]
	  ○ Women's reproductive choices.
		http://www.childrenandfamilies.nt.gov.au/Office_of_Womens_Policy/

Victorian Registry of Births, Deaths and Marriages	- Registers:
	  ○ Births;
	  ○ Deaths;
	  ○ Marriages;
	  ○ 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:
	  ○ "record information about the people who are connected to assisted reproductive treatment (ART), such as:
		http://online.justice.vic.gov.au/CA2574F700805DE7/HomePage?ReadForm&1=Home~&2=~&3=~

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[45] NT Office of Women's Policy, Factsheet, What are my maternity rights? available at: http://www.ntwwc.com.au/uploads/File/factsheets%202010/fact%20sheet%20what%20are%20my%20maternity%20rights.pdf

	▪ 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	
Victorian Assisted Reproductive Treatment Authority (VARTA)	•	http://www.varta.org.au/
Sands Victoria	• "self-help support group comprised of parents who have experienced the death of a baby through miscarriage, stillbirth, or shortly after birth".	http://www.sandsvic.org.au/about/
SIDS and Kids Australia	• "dedicated to saving babies and children's lives	http://www.sidsandkids.org/about-us/

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[46] Please see http://online.justice.vic.gov.au/CA2574F700805DE7/page/Births-Donor+treatment+registers?OpenDocument&1=10-Births~&2=20-Donor+treatment+registers~&3=~

	through the elimination of sudden and unexpected infant deaths during pregnancy, birth and childhood, supporting bereaved families and funding research into stillbirth.”	
Queensland Registry of Births, Deaths and Marriages	•	http://www.justice.qld.gov.au/justice-services/births-deaths-and-marriages
Registry of Births, Deaths and Marriages in Western Australia	• Registers: ○ Births; ○ Deaths; ○ Marriages.	http://www.bdm.dotag.wa.gov.au
Tasmanian Registry of Births, Deaths and Marriages	• Registers: ○ Births; ○ Deaths; ○ Marriages; ○ Deeds of relationships; ○ and change of name. •	http://www.justice.tas.gov.au/bdm

Legislation

Federal Legislation and Policy

Legislation:	Key points:	Website:
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.	
Prohibition of Human Cloning for Reproduction Act 2002 (PHCR Act)		
Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research (2007) (ART Guidelines)	• Originally issued in 2004 and then updated in 2007. • "The ART Guidelines address both clinical and research aspects of assisted reproductive technology. The guidelines are primarily intended for ART practitioners, researchers, infertility clinic administrators, Human Research Ethics Committees and governments."	http://www.nhmrc.gov.au/guidelines/publications/e78

	- These Guidelines will be reviewed every 5 years.	
National Statement on Ethical Conduct in Human Research (2007)		http://www.nhmrc.gov.au/guidelines/publications/e72-0
National Blood Authority Act 2003 and the National Blood Agreement	- Part 2 of the Act established the National Blood Authority (NBA).	National Blood Authority Act 2003 available at- http://www.comlaw.gov.au/Details/C2004A01114 National Blood Agreement available at- http://www.nba.gov.au/policy/pdf/agreement.pdf Amendment to the National Blood Agreement available at- http://www.nba.gov.au/policy/pdf/amendment.pdf Full Varied National Blood Agreement available at- http://www.nba.gov.au/policy/pdf/varied.pdf

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."

Legislation:	**Key points:**	**Website:**
Assisted Reproductive Treatment Act 2008 (VIC)	•	http://www.austlii.edu.au/au/legis/vic/consol_act/arta2008360/
Reproductive Technology Act 1988 (SA)		http://www.legislation.sa.gov.au/LZ/C/A/ASSISTED%20REPRODUCTIVE%20TREATMENT%20ACT%201988/CURRENT/1988.10.UN.PDF
Assisted Reproductive Treatment Regulations 2010 (SA)		http://www.legislation.sa.gov.au/LZ/C/R/ASSISTED%20REPRODUCTIVE%20TREATMENT%20REGULATIONS%202010/CURRENT/2010.166.UN.PDF
Human Tissue Act 1983 (NSW)		http://www.legislation.nsw.gov.au/viewtop/

		inforce/act+164+1983+FIRST+0+N/ http://www.legislation.nsw.gov.au/viewtop/inforce/act+164+1983+FIRST+0+N/
Assisted Reproductive Technology Act (2007) (NSW)	•	http://www.legislation.nsw.gov.au/viewtop/inforce/act+69+2007+cd+0+N/?autoquery=(Content%3D((%22Assisted%20Reproductive%20Technology%20Act%20%22)))%20AND%20((Type%3D%22act%22%20AND%20Repealed%3D%22N%22)%20OR%20(Type%3D%22subordleg%22%20AND%20Repealed%3D%22N%22))%20AND%20(%22Historical%20Document%22%3D%220%22)&dq=Document%20Types%3D%22Acts,%20Regs%22,%20Exact%20Phrase%3D%22Assisted%20Reproductive%20Technology%20Act%22,%20Search%20In%3D%22Text%22&fullquery=(((%22Assisted%20Reproductive%20Technology%20Act%20%22)))
Human Tissue Regulation 2010 (NSW)		http://www.legislation.nsw.gov.au/viewtop/inforce/subordleg+253+2010+cd+0+N/?dq=Regulations%20under%20Human%20Tissue%20Act%201983%20No%20164
Guideline - Human Tissue - Requirements of the Human Tissue Act 1983 in relation to research & use of tissue	"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"	http://www.health.nsw.gov.au/policies/gl/2006/pdf/GL2006_021.pdf
Assisted Reproductive Technology Amendment (Transitional Provisions	• "The Amending Regulation extends the transitional provisions for women who	http://www.legislation.nsw.gov.au/sessionalview/sessional/sr/2012-201.pdf

Relating to Donated Gametes) Regulation 2012 (Amending Regulation)	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]	
Surrogacy Act 2008 (WA)		http://www.rtc.org.au/docs/090513_A1_Surrogacy_Act_2008_(WA).pdf
Human Reproductive Technology Act 1991 (WA)		http://www.austlii.edu.au/au/legis/wa/consol_act/hrta1991331/

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[47] NSW Health Central Register, available at http://www.health.nsw.gov.au/art/index.asp ; the Regulation is available in PDF format at http://www.legislation.nsw.gov.au/sessionalview/sessional/sr/2012-201.pdf

New Zealand

Institutional Bodies

Institutional bodies:	**Functions and information:**	**Website:**
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
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
Medical Sciences Council of New Zealand	• Main regulatory body for: ○ Anaesthetists ○ Medical laboratory scientists • Administers the Health Practitioners Competence Assurance Act 2003.	http://www.mscouncil.org.nz
New Zealand Multiple Birth Association	• Provides information and support to Multiple Birth clubs and members	http://www.multiples.org.nz
Biological and Life	• "Provides advice on matters of concern to	http://www.royalsociety.org.nz/orga

Sciences Advisory Panel, Royal Society of New Zealand	the biological and life sciences community, and responds, on request, with advice on biological and life sciences issues to the Society." - The Society also supports research through funding grants and scholarships and publication in journals.	nisation/panels/biological/

Registers and Projects

Register:	**Key points and data access:**	**Websites:**
Births, Deaths and Marriages, (BMD) Department of Internal Affairs	- "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."	http://www.dia.govt.nz/Births-deaths-and-marriages
The New Zealand Cancer Registry (NZCR)	- Established in 1948 and used to rely primarily on information sent in from public hospitals. - New legislation has been introduced to improve reporting, namely: ○ Cancer Registry Act 1993; ○ and Cancer Registry Regulations 1994 - This is a "population-based register of all primary malignant tumours diagnosed in New Zealand, excluding squamous and basal cell skin cancers". -	http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/new-zealand-cancer-registry

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." ○ "90-95% of patients consent to their details	NZ Breast Cancer Foundation- http://www.nzbcf.org.nz/our-work/breast-cancer-patient-registers Auckland Breast Cancer Register- http://www.adhb.govt.nz/AucklandBreastCancerRegister/ Waikato Breast Cancer Register- http://www.wbct.org.nz/About+Us/Waikato+Breast+Care+Register.html

	being included in a 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).”	
Human Assisted Reproductive Technology (HART) Register	• Run by the Births, Deaths and Marriages division of the Department of Internal Affairs. • The Register has been operating since the 22nd of August 2005. • Governed by Human Assisted Reproductive Technology (HART) Act 2004. • “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.” • Access to information: ○ “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. ○ The Human Assisted Reproductive Technology (HART) Act restricts the release of some information,	

	depending on when the donation was made and who wants to access the information.	
New Zealand Neurological Foundation Human Brain Bank, School of Medical Sciences, University of Auckland	• 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. ” • The bank contains tissue received from over 300 normal and diseased human brains. • So far the bank has collaborated with researchers in Europe, Scandinavia and Japan. • Has ethically approved procedures in place for the collection of post-mortem healthy and diseased brains.	http://www.fmhs.auckland.ac.nz/sms/anatomy/research/brain_bank.aspx
National Immunisation Register (NIR)	• Keeps records of children’s immunisation. • Records are stored for the lifetime of the person plus 10 years. • Parents can opt-out of the scheme , but they must complete an opt-out form.	https://www.healthed.govt.nz/resource/national-immunisation-register-nir-–-english-version
New Zealand Neuromuscular Disease Registry	•	http://www.nmdregistry.co.nz/dmd/nz/
ASCIA Primary	• Access to the Register:	http://www.immunodeficiency.org.a

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.[48]	u
New Zealand Birth Defects Registry (NZBDR)	•	http://www.nzbdmp.ac.nz

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[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.

Legislation:	**Key points:**	**Website:**
Status of Children Act 1969		
Marriage Act 1955		
Civil Unions: • Civil Union Act 2004 • Civil Union (Prescribed Information, Fees, and Forms) Regulations 2005 • Civil Unions (Recognised Overseas Relationships) Regulations 2005		
Adult Adoption Information Act 1985		http://www.legislation.govt.nz/act/public/1985/0127/latest/DLM80513.html?search=ts_act%40bill%40regulation%40deemedreg_adoption_resel_25_h&p=1
Adoption Act 1955		http://www.legislation.govt.nz/act/public/1955/0093/latest/DLM292661.html

Births Deaths Marriages and Relationships Registration Act 1995		http://www.legislation.govt.nz/act/public/1995/0016/latest/DLM359369.html?search=ts_act%40bill%40regulation%40deemedreg_birth_resel_25_h&p=1
Births, Deaths, Marriages, and Relationships Registration (Non-Disclosure Direction) Regulations 2008		http://www.legislation.govt.nz/regulation/public/2008/0414/latest/versions.aspx?search=ts_act%40bill%40regulation%40deemedreg_birth_resel_25_h&p=1
Births, Deaths, Marriages, and Relationships Registration (Prescribed Information) Regulations 1995		http://www.legislation.govt.nz/regulation/public/1995/0183/latest/versions.aspx?search=ts_act%40bill%40regulation%40deemedreg_birth_resel_25_h&p=1
Privacy Act 1993	•	Available at- http://www.legislation.govt.nz/act/public/1993/0028/latest/DLM296639.html
Health Information Privacy Code 1994	Amended in 2008	Available at- http://privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-incl.-amendments-revised-commentary.pdf

Human Tissue Act 2008		http://www.legislation.govt.nz/act/public/2008/0028/latest/DLM1152940.html?search=ts_act%40bill%40regulation%40deemedreg_human+tissue_resel_25_h&p=1
Human Assisted Reproductive Technology Act 2004		http://www.legislation.govt.nz/act/public/2004/0092/latest/DLM319241.html?search=ts_act%40bill%40regulation%40deemedreg_reproductive_resel_25_h&p=1
Human Assisted Reproductive Technology (Fees) Regulations 2005		http://www.legislation.govt.nz/regulation/public/2005/0210/latest/DLM340590.html?search=ts_act%40bill%40regulation%40deemedreg_reproductive_resel_25_h&p=1
Human Assisted Reproductive Technology Order 2005		http://www.legislation.govt.nz/regulation/public/2005/0181/latest/DLM335192.html?search=ts_act%40bill%40regulation%40deemedreg_reproductive_resel_25_h&p=1
Health (Retention of Health Information) Regulations 1996		http://www.legislation.govt.nz/regulation/public/1996/0343/latest/DLM225616.html?search=ts_act%40bill%40regulation%40deemedreg_health+information_resel_25_h&p=1

Health Act 1956		http://www.legislation.govt.nz/act/public/1956/0065/latest/DLM305840.html?search=ts_act%40bill%40regulation%40deemedreg_Health+Act_resel_25_h&p=1
Guidelines for the Use of Human Tissue in Unspecified Research		

Canada

Institutional Bodies and projects

Institutional bodies and projects:	**Functions and relevant information:**	**Websites:**
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] • Many of its functions will be taken over by Health Canada.	http://www.ahrc-pac.gc.ca/v2/index-eng.php
BC Women's Centre for	• Founded in 1981.	http://www.ubcfertility.com/index.php

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[49] Reference Re Assisted Human Reproduction Act, 2010 SCC 61, [2010] 3 S.C.R. 457, see http://scc.lexum.org/en/2010/2010scc61/2010scc61.html

Reproductive Health		
Child & Family Research Institute (CFRI)	• Conducts research wide range of children's and women's health concerns. •	http://www.cfri.ca/reproductive-health-research.asp
Nunavut Status of Women Council	Its main objectives are:[50] • "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

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[50] Nunavut Status of Women Council, Mandate, available at http://www.qnsw.ca/mandate-2

Registers

Name of register:	Functions and information:	Website:
Vital Statistics Division of Service Nova Scotia and Municipal Relations (Nova Scotia)	- Responsible for registering: ○ births, ○ deaths, ○ marriages, ○ stillbirths ○ and domestic partnerships.	http://www.gov.ns.ca/snsmr/access/vitalstats.asp
Vital Statistics, (Service Alberta)	- Responsible for registering: ○ births, ○ deaths, ○ marriages, ○ stillbirths ○ 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 "provides statistical information to other provincial and federal governments and approved health related agencies for comparison and research purposes."	http://www.servicealberta.gov.ab.ca/VitalStatistics.cfm
Vital Statistics Agency, (British Columbia)	- Maintains a research database for the current and historical records called Vital Statistics Information System (VISION). - Responsible for registering: ○ Births;	http://www.vs.gov.bc.ca

	○ deaths; ○ marriages; ○ stillbirths; ○ name changes. • Publishes reports on a wide variety of health related topics.	
Vital Statistics Agency (Manitoba)	• Responsible for registering: ○ births, ○ deaths, ○ marriages, ○ stillbirths ○ name changes • Privacy legislation governs who has access to the Agency's records. • Their database provides records of all vital events occurring in Manitoba from 1882 to the present. These records are kept in perpetuity.	http://vitalstats.gov.mb.ca
Vital Statistics Office (New Brunswick)	• 3 main functions: • the collection, storage, maintenance, and retrieval of vital events data (births, deaths, stillbirths, and marriages); • the synthesis and analysis of vital events data; and, • the provision of vital events documents for personal use (birth certificates, marriage licenses, death certificates).[51]	http://www.snb.ca/e/1000/1000-01/e/index-e.asp

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[51] Vital Statistics Office, Introduction, available at http://www.snb.ca/e/1000/1000-01/e/intro-e.asp

	• Published annual reports on its statistics from1998 to 2008 and also makes statistics available online. Most recent report 2008, but 2011 statistics are available.	
Vital Statistics Division (Newfoundland and Labrador)	• Responsible for registering: ○ births, ○ deaths, ○ marriages, ○ name changes ○ adoptions	http://www.servicenl.gov.nl.ca/birth/index.html
Vital Statistics, The Health Services Administration division (Northwest Territories)	• Responsible for registering: ○ births, ○ deaths, ○ marriages,	http://www.hlthss.gov.nt.ca/english/services/vital_statistics/default.htm
Vital Statistics, Health and Social Services, (Nunavut)	• Not as much information available at this time.	http://www.hss.gov.nu.ca/en/Vital%20Statistics%20Birth.aspx
Vital Statistics, Department of Health and Wellness (Prince Edward Island)	• registers: ○ births, ○ deaths, ○ stillbirths, ○ adoptions, ○ marriages, ○ divorces, ○ and change of name •	http://www.gov.pe.ca/health/index.php3?number=1020357
Register of civil status (Quebec)	• Responsible for registering: ○ Births; ○ Marriages;	http://www.etatcivil.gouv.qc.ca/en/default.html

	○ Civil unions; ○ and deaths. • Access to records is governed by the Civil Code of Quebec. • 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.	
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.health.gov.sk.ca/Default.aspx?DN=e5fc4552-1af0-4c27-854a-0ce1226aa91f http://www.isc.ca/VitalStats/Pages/default.aspx Vital Statistics Privacy Statement- http://www.isc.ca/About/Corporate/Legal/Privacy/VitalStatisticsPrivacyStatement/Pages/default.aspx The Health Information Protection Act available at- http://www.qp.gov.sk.ca/documents/english/Statutes/Statutes/H0-021.pdf All Saskatchewan law available at- http://www.qp.gov.sk.ca

Vital Statistics, (Yukon)	• Registers: ○ births; ○ deaths; ○ marriages; ○ and other vital events.	http://www.hss.gov.yk.ca/vitalstats.php

Federal Legislation and Policy

Legislation:	Key points:	Website:
Assisted Human Reproduction Act 2004	• Governs ART in Canada. • It prohibits certain activities under sections 5-8, including human cloning and the purchase or offering for sale of sperm or ova.[52]	https://www.cfas.ca/images/stories/pdf/a-13.4.pdf

Provincial legislation and policy

Legislation:	Key points:	Website:
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
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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[52] Act available in full at http://laws-lois.justice.gc.ca/eng/acts/A-13.4/page-3.html#docCont

[SBC 2008] CHAPTER 38[53] - Vital Statistics Act [RSBC 1996] CHAPTER 479[54] - Marriage Act [RSBC 1996] CHAPTER 282 - Public Health Act [SBC 2008] CHAPTER 28 - Public Health Act Information Regulation - Adoption Act [RSBC 1996] CHAPTER 5 -	banks". It also sets out criteria for when information is permitted to be disclosed.	
Manitoba- - The Vital Statistics Act,[55] - The Marriage Act, - The Change of Name Act - The Public Health Act 2006[56] - The Personal Health Information Act 1997[57] - The Privacy Act 1987	-	All legislation available at- http://web2.gov.mb.ca/laws/search.php
Ontario- - Health Protection and Promotion Act R.S.O. 1990 (HPPA)[58] - Public Health Standards (OPHS) - Healthy Babies Healthy Children	- The HPPA makes the Ministry of Health responsible for four of the OPHS: ○ Reproductive health; ○ Child health; ○ Prevention of injury and	OPHS main website- http://www.health.gov.on.ca/english/providers/program/pubhealth/oph_standards/ophs/ophsprotocols.html

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[53] Available at http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_08038_01
[54] Available at http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96479_01
[55] Available at http://web2.gov.mb.ca/laws/statutes/ccsm/_pdf.php?cap=v60
[56] Available at http://web2.gov.mb.ca/laws/statutes/ccsm/_pdf.php?cap=p210
[57] Available at 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#

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."[59] • A Reproductive Health Guidance Document released in 2010.[60]	OPHS on Reproductive Health- http://www.health.gov.on.ca/english/providers/program/pubhealth/oph_standards/ophs/rephealth.html
New Brunswick- • Vital Statistics Act[61] and Vital Statistics Access to Records Regulations[62] • The Marriage Act[63] • The Public Health Act[64]		
Northwest Territories- • Vital Statistics Act[65]		

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[59] Please refer to the Healthy Babies Healthy Children Protocol, available at: http://www.health.gov.on.ca/english/providers/program/pubhealth/oph_standards/ophs/progstds/protocols/hbhc.pdf

[60] Available at:http://www.mhp.gov.on.ca/en/healthy-communities/public-health/guidance-docs/ReproductiveHealth.pdf

[61] Available at: http://laws.gnb.ca/en/ShowPdf/cs/V-3.pdf

[62] Available at:http://www.justice.gov.nt.ca/PDF/REGS/VITAL_STATS/Access_to_Records.pdf

[63] Available at:http://laws.gnb.ca/en/ShowPdf/cs/2011-c.188.pdf

[64] Available at:http://laws.gnb.ca/en/ShowPdf/cs/P-22.4.pdf

[65] Available at: http://www.justice.gov.nt.ca/PDF/ACTS/Vital_Statistics.pdf

• Human Tissue Act[66] • Public Health Act[67]		
Prince Edward Island- Vital Statistics Act[68]	•	
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		
Saskatchewan- • Vital Statistics Act, 2009 • The Marriage Act, 1995 • Change of Name Act, 1995.		All legislation available at- 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.		All legislation available at- http://www.gov.yk.ca/legislation/tps/tps_v.html#vitalstatisticsact Discussion paper- http://www.hss.gov.yk.ca/pdf/health_privacy_discussion_paper.pdf And- http://www.hss.gov.yk.ca/healthprivacy.php

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[66] Available at: http://www.justice.gov.nt.ca/PDF/ACTS/Human_Tissue.pdf
[67] Available at: http://www.justice.gov.nt.ca/PDF/ACTS/Public%20Health.pdf
[68] Available at: http://www.gov.pe.ca/law/statutes/pdf/v-04_01.pdf?PHPSESSID=a37482661d3e6fdf84d32273b8de713e

USA

Institutional Bodies and projects

Institutional bodies and projects:	**Functions and relevant information:**	**Websites:**
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 Information on Data and Statistics- http://www.cdc.gov/reproductivehealth/Data_Stats/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/
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: http://apps.nccd.cdc.gov/cPONDER/

(CDC).		
The Maternal and Child Health Epidemiology Program (MCHEP), project of Centers for Disease Control and Prevention (CDC).	• "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."	http://www.cdc.gov/reproductivehealth/MCHEpi/index.htm
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: ○ preterm birth; ○ infant mortality; ○ tobacco use; ○ cesarean section rates; ○ and health insurance coverage.	http://www.marchofdimes.com/peristats/about.aspx

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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.	http://web.sph.harvard.edu/mch-data-connect/
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- http://grants.nih.gov/grants/policy/hs/index.htm

National Registers and Projects

Name of register:	**Functions and information:**	**Website:**
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

	▪ 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	

	data quality and reduce missing data. ○ Communicate progress to CDC via quarterly reports, conference calls, and an annual reverse site visit.	
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.[69] • 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	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 and standard forms are available at http://www.cdc.gov/nchs/nvss/vital_certificate_revisions.htm

	Monthly Vital Statistics Report) ○ Other selected reports.	
National Birth Defect Registry	• It "collects information about birth defects, learning and attention disorders, childhood cancers and other childhood disabilities."	http://www.birthdefects.org/registry/main.asp

State Registers and Projects

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

Name of register:	Functions and information:	Website:
New York Citywide Immunization Registry (CIR)		http://www.nyc.gov/html/doh/html/cir/cir-home.shtml
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
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

	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."	
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
Arizona Birth Defects Monitoring Program (ABDMP)	-	http://www.azdhs.gov/phs/phstats/bdr/index.htm

Global Registers and Projects

Name of register or project:	**Functions and information:**	**Website:**
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.[70]	http://www.icmartivf.org
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.	http://www.redlara.com/aa_ingles/default.asp

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[70] Tool Box and accompanying materials available at http://www.icmartivf.org/toolbox/toolbox-main.html

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: ○ assess interventions in terms of their outcome ○ monitor trends on safety and efficacy among centers, countries and regions ○ empower infertile couples in the evaluation of costs & benefits ○ 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
Global database on blood safety	• Established in 1998. • 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=c

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[71] http://www.redlara.com/aa_ingles/REGISTRO.ASP

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 authorieties. 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	om_content&view=article&id=91&Itemid=220&lang=en [**Please note:** some parts of their website are not functioning properly at present].
Population Council	• Runs wide variety of research projects and programmes throughout the world.	http://www.popcouncil.org

Europe

Name of register or project:	**Functions and information:**	**Website:**
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 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 Latest news update for August 2012, available at http://www.eshre.eu/binarydata.aspx?type=doc&sessionId=5v3qgg45ww4ist55r3vl1v55/ESHRE_Update_August_2012.pdf
Finland, National Institute for Health and Welfare (STAKES)	•	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/

	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.”	
Danish IVF Register	•	http://www.sst.dk/English.aspx?sc_lang=en#
European Childhood Obesity Surveillance Initiative (COSI)	• “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.”	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

Other countries

Name of body or register:	**Functions and information:**	**Website:**
Japan, Japan Society for Reproductive Medicine.	• Website currently available in Japanese, but the English language version is under construction.	http://www.jsrm.or.jp/en/index.html
Brazil, Fiocruz, Instituto de Pesquisa Clínica Evandro Chagas – Fundação	• • IPEC-FIOCRUZ was established in 1996 to investigate “the natural history of women seeking	

Oswaldo Cruz (IPEC-FIOCRUZ) HIV Women's Cohort	HIV care."[72]	
Brazil: Currently, has plans for new registries to be developed, including registries for DMD/BMD and SMA.[73]	• Brazil is now the largest recipient of Norwegian aid.[74]	
Chile: Has made considerable progress in reducing its maternal mortality rate.	Please refer to the following articles[75]	
Pakistan Initiative for Mothers and Newborns (PAIMAN)	• 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.	http://www.popcouncil.org/projects/75_PAIMAN.asp

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[72] Jordan E Lake et al. Participation of women in HIV clinical trials: the IPEC-FIOCRUZ experience. *HIV AIDS (Auckl).* 3, 61–68 (2011).

[73] Please see http://www.treat-nmd.eu/registry/299/

[74] Please see http://www.norad.no/en/countries/latin-america/brasil

[75] Elard Koch et al. Women's Education Level, Maternal Health Facilities, Abortion Legislation and Maternal Deaths: A Natural Experiment in Chile from 1957 to 2007. *PLoS ONE* 7(5), e36613 (2012) doi:10.1371/journal.pone.0036613
Michael J. New, Why the Chilean Maternal-Mortality Study Is Important. *National Review Online,* (16th May, 2012), available at: http://www.nationalreview.com/corner/300129/why-chilean-maternal-mortality-study-important-michael-j-new

Multiple Birth Registers and Research Projects

Register or project:	**Key points:**	**Websites:**
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: ○ 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. ○ 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	http://www.fhi.no/eway/default.aspx?pid=238&trg=MainArea_5811&MainArea_5811=5903:0:15,5031:1:0:0:::0:0

	Health and the relevant institution. A contract gives the right to study one or more research questions for a defined limited period of time.	
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/

	working towards an open access model with support from the Wellcome Trust.”	
Swedish Twin Registry	• Run by the Department of Medical Epidemiology and Biostatistics at Karolinska Institutet. • This is the largest twin registry in the world. • Begun in the 1960s • It “consists of several birth cohorts.” • “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.” • Provides useful historical information, as it was “established with birth information for all twins born between the years 1886 and 1925.” 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.[76]	http://ki.se/ki/jsp/polopoly.jsp?d=13013&l=en
Chilean School Age Twin Registry		Website currently only available in Spanish- http://www.inta.cl
International Society for Twin Studies (ISTS)	• Founded in 1974, it aims to support research and public education in fields related to twins and twin	http://www.ists.qimr.edu.au

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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

	studies. • It has its own journal, *Twin Research and Human Genetics.*	
National Twin Registry, the National Institute of Environmental Health Sciences		http://www.niehs.nih.gov/news/events/pastmtg/2005/twin/index.cfm
Sri Lankan Twin Registry (SLTR)		http://infolanka.com/org/twin-registry/
Netherlands Twin Registry		http://www.tweelingenregister.org/en/
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.	http://wiki.helsinki.fi/display/twineng/Twinstudy;jsessionid=DCC7DB6D5AB1C1CE38AE793585CC6AFE
Twins Study @ Harvard	• This is a long-term study of language development in twins.	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.	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.	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: ○ In the first instance, researchers who are	http://www.matr.vcu.edu Guidelines for research are available at- http://www.matr.vcu.edu/info-researchers/research-guidelines.html

	interested in accessing the MATR DNA Repository should contact MATR Administrator, Emily Lilley at echlilley@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