

# Appendix A - Literature Search Strategy

## MEDLINE

### Cochrane CENTRAL Register of Controlled Trials

### Cochrane Database of Systematic Reviews

1. exp \*Registries/
2. ((patient or patients or disease\* or population surveillance) adj5 (registry or registries or register or registers)).tw.
3. 1 or 2
4. exp Population Surveillance/mt [Methods]
5. Data Collection/lj, mt, og, st [Legislation & Jurisprudence, Methods, Organization & Administration, Standards]
6. models, theoretical/ or models, organizational/
7. "organization and administration"/ or exp governing board/ or knowledge management/ or mandatory programs/ or organizational objectives/ or planning techniques/ or program development/ or public health administration/ or total quality management/ or voluntary programs/
8. Accreditation/
9. "Forms and Records Control"/
10. Benchmarking/
11. (barrier\* or best practice\* or creating or creation or design\* or develop or developing or development or establish\* or evolving or evolution or facilitator\* or guidelines or implementing or implementation or infrastructure\* or lessons learned or maintenance or maintain\* or methodology or model or models or quality or standards or trends).tw.
12. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13. 3 and 12
14. exp \*Registries/mt, og, st [Methods, Organization & Administration, Standards]
15. 13 or 14
16. limit 15 to English
17. limit 16 to animals
18. limit 16 to (animals or humans)
19. 17 not 18
20. 16 not 19
21. limit 20 to (comment or editorial or letter)
22. 20 not 21
23. exp \*Tissue Donors/ or exp \*"Tissue and Organ Procurement"/
24. ((organ or organs or tissue\*) adj5 (donor\* or donat\*)).tw.
25. education.fs.
26. exp "substance-related disorders"/
27. exp "drug and narcotic control"/
28. exp street drugs/
29. ((drug or drugs or pharmaceutical\*) adj5 (registry or registries or register or registers)).tw.
30. exp vital statistics/
31. ((marriage or birth or death) adj5 (registry or registries or register\*)).tw.
32. exp \*vaccination/ or exp \*immunization/
33. (immunisation\* or immunization\* or vaccination\* or vaccine\*).ti.
34. (cochrane adj5 register).tw.
35. 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34
36. 22 not 35

## PubMED

1. Registries[Majr]
2. ((patient or patients or disease\* or population surveillance) AND (registry or registries or register or registers))[tiab]

3. 1 or 2
4. Population Surveillance/mt [Methods][MeSH]
5. Data Collection/lj, mt, og, st [Legislation & Jurisprudence, Methods, Organization & Administration, Standards][MeSH]
6. models, theoretica[MeSH] or models, organizational[MeSH]
7. ("organization and administration" or governing board or knowledge management or mandatory programs or organizational objectives or planning techniques or program development or public health administration or total quality management or voluntary programs)[MeSH]
8. Accreditation[MeSH]
9. "Forms and Records Control"[MeSH]
10. Benchmarking[MeSH]
11. (barrier\* or best practice\* or creating or creation or design\* or develop or developing or development or establish\* or evolving or evolution or facilitator\* or guidelines or implementing or implementation or infrastructure\* or lessons learned or maintenance or maintain\* or methodology or model or models or quality or standards or trends)[tiab]
12. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13. 3 and 12
14. Registries/mt, og, st [Methods, Organization & Administration, Standards][Majr]
15. 13 or 14
16. limit 15 to English
17. limit 16 to animals
18. limit 16 to (animals or humans)
19. 17 not 18
20. 16 not 19
21. limit 20 to (comment or editorial or letter)
22. 20 not 21
23. Tissue Donors[Majr] or "Tissue and Organ Procurement"[Majr]
24. ((organ or organs or tissue\*) and (donor\* or donat\*)) [tiab]
25. education[fs]
26. "substance-related disorders"[MeSH]
27. "drug and narcotic control"[MeSH]
28. street drugs[MeSH]
29. ((drug or drugs or pharmaceutical\*) and (registry or registries or register or registers)) [tiab]
30. vital statistics[MeSH]
31. ((marriage or birth or death) and (registry or registries or register\*)) [tiab]
32. vaccination[Majr] or immunization[Majr]
33. (immunisation\* or immunization\* or vaccination\* or vaccine\*) [ti]
34. (cochrane register) [tiab]
35. 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34
36. 22 not 35

## EMBASE

1. \*register/
2. ((patient or patients or disease\* or population surveillance) adj5 (registry or registries or register or registers)).tw.
3. 1 or 2
4. \*model/ or \*process model/
5. \*"organization and management"/
6. \*management/ or \*total quality management/
7. \*planning/ or \*strategic planning/
8. \*organization/
9. methodology/ or \*quality control/ or standard/
10. data collection method/
11. \*quality control/
12. \*"board of trustees"/
13. \*knowledge management/
14. \*program development/
15. \*planning/

16. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. 3 and 16
18. ((barrier\* or best practice\* or creating or creation or design\* or develop or developing or development or establish\* or evolving or evolution or facilitator\* or guidelines or implementing or implementation or infrastructure\* or lessons learned or maintenance or maintain\* or methodology or model or models or quality or standards or trends) adj5 (registry or register or registers or registries) adj5 (patient or patients or disease\* or surveillance)).tw.
19. 17 or 18
20. limit 19 to English language
21. limit 20 to animal studies
22. 20 not 21
23. limit 22 to (conference abstract or "conference review" or editorial or letter or note or proceeding or report or trade journal)
24. 22 not 23
25. exp \*donor/
26. exp \*transplantation/
27. ((organ or organs or tissue\*) adj5 (donor\* or donat\*)).tw.
28. exp \*drug dependence/ or exp \*drug abuse/ or exp \*substance abuse/ or exp \*alcoholism/ or exp \*addiction/
29. exp \*drug control/
30. ((drug or drugs or pharmaceutical\*) adj5 (registry or registries or register or registers)).tw.
31. exp \*birth certificate/
32. exp \*death certificate/
33. exp \*"cause of death"/ or exp \*marriage/
34. exp \*vital statistics/
35. ((marriage or birth or death) adj5 (registry or registries or register\*)).tw.
36. exp \*vaccination/
37. exp \*immunization/
38. (immunisation\* or immunization\* or vaccination\* or vaccine\*).tw.
39. (cochrane adj5 register).tw.
40. 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39
41. 24 not 40

### PsycINFO

1. ((barrier\* or best practice\* or creating or creation or design\* or develop or developing or development or establish\* or evolving or evolution or facilitator\* or guidelines or implementing or implementation or infrastructure\* or lessons learned or maintenance or maintain\* or methodology or model or models or quality or standards or trends) adj5 ((patient or patients or disease\* or population surveillance) adj5 (registry or registries or register or registers))).tw.
2. ((organ or organs or tissue\*) adj5 (donor\* or donat\*)).tw.
3. ((drug or drugs or pharmaceutical\*) adj5 (registry or registries or register or registers)).tw.
4. ((marriage or birth or death or vital statistics) adj5 (registry or registries or register\*)).tw.
5. (immunisation\* or immunization\* or vaccination\* or vaccine\*).ti.
6. (cochrane adj5 register).tw.
7. 2 or 3 or 4 or 5 or 6
8. 1 not 7
9. limit 8 to English language
10. limit 9 to (abstract collection or chapter or "column/opinion" or "comment/reply" or dissertation or editorial or letter or review-book or review-media or review-software & other)
11. 9 not 10

### ABI Inform

#### BIOSIS Previews

#### PAIS (Public Affairs Information Service)

1. ((patient or patients or disease\* or population surveillance) and (registry or registries or register or registers))[Keyword]

2. (barrier\* or best practice\* or creating or creation or design\* or develop or developing or development or establish\* or evolving or evolution or facilitator\* or guidelines or implementing or implementation or infrastructure\* or lessons learned or maintenance or maintain\* or methodology or model or models or quality or standards or trends)[Keyword]
3. 1 and 2
4. ((organ or organs or tissue\*) and (donor\* or donat\*)) [Keyword]
5. ((drug or drugs or pharmaceutical\*) and (registry or registries or register or registers)) [Keyword]
6. ((marriage or birth or death) and (registry or registries or register\*)) [Keyword]
7. (immunisation\* or immunization\* or vaccination\* or vaccine\*) [Keyword]
8. (cochrane register) [Keyword]
9. 4 or 5 or 6 or 7 or 8
10. 3 and 9

## Appendix B - Glossary

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**Aboriginal** – a term used to refer collectively to all First Nations, Métis, and Inuit peoples in Canada.

**Biobank/biobanking** – the collection of biological samples including but not limited to blood, tissue, skin, nails, and hair in a centralized repository. This may or may not include information about the individuals who provided the samples.

**Capacity** – with respect to the provision of informed consent, capacity is the individual capability to understand information presented and to understand the potential consequences of any decision made based on such information. .

**Clinical Trial Registry** – a clinical trial registry is typically a registry created during a clinical trial. Clinical trial registries may include device or treatment registries and may be run by investigators or by for-profit entities.

**Informed Consent** – in Canada this is consent provided by an individual participating in research in a manner that is voluntary and given after the individual has been made fully aware of the nature of the research and the possible risks and benefits of participation. Informed consent must also be ongoing and able to be withdrawn at any time.

**Intellectual property (IP)** – the basic legal right conferred by patents, trademarks, copyright and other similar concepts which allows the owner of such property to exclude others from using that property without permission. Typically the property is derived from some form of creative pursuit and thus is referred to as intellectual.

**Research ethics board (REB)** – an appointed institutional body consisting of researchers, community members and other experts (e.g. legal, ethics, medical) which reviews the ethical acceptability of all research activities conducted at the institution or under its jurisdiction.

**Standard operating procedure (SOP)** – a prescribed procedure that is followed every time a task occurs.

**Substitute decision maker** – a person with the necessary legal authority to make decisions on behalf of an individual who lacks the capacity to consent to participate or to continue to participate in a particular research project

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# NOTES