Real World Evidence: What is it and how will it impact the work of librarians/information specialists?

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EAHIL, Basel, Switzerland, June 19, 2019

https://tinyurl.com/yxo5qsqs
Outline

1. Overview of Real World Evidence (RWE) and Real World Data (RWD)
2. Results of our Scoping Review
3. Exercises
4. Some Examples of Filters
5. Implications for Searching

https://tinyurl.com/yxo5qsqs
Strengthening the use of real world evidence and regulations for medical devices

From: Health Canada

This project aims to improve our ability to monitor medical device safety and effectiveness across the product life cycle. It will also help us to develop new regulatory options to prevent and mitigate safety risks.

This project will result in:
- An improved ability to monitor the safety and effectiveness of medical devices throughout the product life cycle.
- A better understanding of the risks associated with medical devices.
- The development of new regulatory tools.

We expect to achieve:
- Better data collection and analysis.
- More effective risk management.
- Improved patient outcomes.

The tasks involved include:
- Identifying relevant datasets.
- Mapping data sources.
- Analysing data.

What are the real-world evidence tools and how can they support decision making?

EMA-EuropaBio Info Day – 22nd November 2016

Dr Alison Cave,
Principal Scientific Administrator,
Pharmacovigilance and Epidemiology Department
What is Real World Evidence?

“Real world evidence (RWE) is the clinical evidence regarding the usage and potential benefits or risks of a medical product derived from analysis of Real World Data (RWD).

Source: https://www.fda.gov/ScienceResearch/SpecialTopics/RealWorldEvidence/default.htm
Why Do We Need Real World Evidence?

- Bridge knowledge gaps left by RCTs
- Address many RCT weaknesses: time, cost, setting
- Wealth of data available, with large sample sizes
- Can explore population subgroups
- Demonstrates real world effectiveness of marketed medications, devices or procedures
- Evaluate budget impact and cost-effectiveness in a real world setting
- Increasing interest from regulatory (FDA/EMA) and assessment agencies
Introductory Activity

Go to menti.com
Real World Evidence (RWE) is generated using Real World Data (RWD)

Image Source: https://privacy-analytics.com/real-world-evidence/
What are Real World Data? A few definitions...

- **ISPOR**: Data used for decision making that are not collected in conventional RCTs
- **ABPI**: Data obtained by any non-interventional methodology that describe what is happening in normal clinical practice
- **RAND**: An umbrella term for different types of data not collected in conventional RCTs
- **IMI-GetReal**: Data collected both prospectively and retrospectively from observations of routine clinical practice. Data can be obtained from many sources.

ABPI: Association of the British Pharmaceutical Industry; ISPOR: International Society for Pharmacoeconomics & Outcomes Research

Types of Real World Data

- Electronic medical records (EMRs or EHRs)
- Administrative claims
- Integrated health systems
- National surveys
- Patient registries

## Sources of Real World Data

### Data Sources:
- Registries (25)
- Electronic health records (22)
- Claims databases (16)
- Administrative databases (10)
- Patient-reported outcomes (10)
- Health surveys (6)
- Hospital data (6)
- Electronic health data (5)
- Clinicians (3)
- Payers (3)
- Social media (3)
- Patient charts (2)
- Pharmacy data (2)
- Clinical databases (1)
- Supplements to RCTs (3)
- Drug utilization studies (1)

### Study Designs:
- Observational studies (28)
- Pragmatic clinical trials (22)
- Postmarketing studies (7)
- Supplements to RCTs (3)
- Drug utilization studies (1)
- Large simple trials (1)

Frequency of occurrence based on article definitions found in the literature (52 sources) and definitions provided during stakeholder interviews (19 sources). Total number of sources = 71.

Examples of Real World Evidence (Studies)

Associations between comorbidities, their treatment and survival in patients with interstitial lung diseases - a claims data analysis.

Schwarzfuchs L, Hill S, Weisser P, Falk M, Koeleman M.

Abstract

BACKGROUND: Interstitial lung diseases (ILDs) are associated with a high burden of disease. However, data on the prognostic impact of comorbidities and comorbidity-related pharmacotherapy are scarce. This study aims to quantify the impact of comorbidities and comorbidity-related pharmacotherapy on mortality in patients with ILDs.

METHODS: Using longitudinal claims data from associated drug treatments, baseline comorbid conditions were identified for the complete ILD cohort. LASSO selection process was used to identify significant comorbidities and comorbidity-related pharmacotherapy. Cox regression analysis was employed to assess the association between comorbidities and comorbidity-related pharmacotherapy on mortality.

RESULTS: In the 32,821 patients with ILDs, chronic obstructive pulmonary disease (COPD) was the most prevalent comorbidity. Treatment with immunosuppressants was associated with reduced mortality. The hazard ratio for COPD was 0.97 vs. 1.33 for other subtypes. Therefore, comprehensive comorbidity assessment is important.

CONCLUSIONS: Our analyses suggest that comprehensive comorbidity assessment is important for the management of patients with ILDs.

KEYWORDS: COPD, ILDs, Mortality, Comorbidities, Immunomodulatory Pharmacotherapy.
Will Real World Evidence overtake RCTs at the top of the hierarchy?
Scoping Review of systematic reviews of real-world studies

Evaluate Search Methodologies

Librarian involvement
Scoping Review

- PRISMA Extension for Scoping Reviews checklist (PRISMA-ScR)

Databases:

- Ovid MEDLINE
- Ovid Embase
- Web of Science
- ProQuest Dissertations & Theses Global

Search conducted: Jan 28, 2019
Search Strategy – Ovid MEDLINE

1. real world evidence.mp.
2. real world data.mp.
3. (RWE or RWD).mp.
4. 1 or 2 or 3
5. limit 4 to "systematic review"
6. systematic review.ti,ab,kf.
7. 4 and 6
8. 5 or 7
9. limit 8 to english language
# Scoping Review

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Mentioned RWE or RWD terms in manuscript</td>
<td>- Do not mention RWE or RWD</td>
</tr>
<tr>
<td>- Searched for real world evidence</td>
<td>- Conference abstracts</td>
</tr>
<tr>
<td>- Systematic reviews</td>
<td>- Not systematic reviews</td>
</tr>
<tr>
<td>- Health sciences</td>
<td></td>
</tr>
<tr>
<td>- English language</td>
<td>- Non-English language</td>
</tr>
</tbody>
</table>
361 articles retrieved

110 duplicates removed

251 articles for title/abstract screening

120 articles excluded

131 articles for full-text screening

85 articles excluded

46 articles for data extraction
Preliminary Findings
Country of Publication
Librarian Involvement

- 8.7% of studies involved a librarian in the search

4 (8.7%) Co-author(s)  
42 (91.3%) Librarian/Information Specialist
Funding Source

- 19 (41.3%) Industry Sponsored
- 27 (58.7%) Other
At least one database of the Cochrane Library was searched.
Subject Headings Used

EMTREE

Subject Headings Used (documented more than once)

- Not reported: 21
- None: 14
- Case-Control Studies: 8
- Cross-Sectional Studies: 6
- Cohort Studies: 6
- Observational Study: 6
- Prospective Studies: 5
- Retrospective Studies: 5
- Longitudinal Studies: 4
- "Observational Study as Clinical Trial": 3
- Cross-Over Studies: 3
- Epidemiologic Studies: 4
- "Observational Study as Clinical Trial": 3

Subject Heading
Other Strategies Used

- Searching for existing registries on a topic
- Removing RCTs or other publication types from the search
How Study Types were Identified

- Screening: 17
- Search and Screening: 23
- Search terms: 2
- Not reported: 4

Strategy used to identify Study Types
Identified Themes Related to Searching

- No surprises with databases searched
- Keyword with highest frequency - “Observational”
- Subject heading with highest frequency - “Case Control Studies/”
- Searches not well reported:
  - 46% of studies used keywords related to RWE
  - Only 24% of studies used subject headings to retrieve RWE
Other Themes

- No consistent definition of RWE used
- Librarian involvement minimal
- No standardized method of RWE searching
Study Limitations

- English language limitation
- “Real world studies” wasn’t included in search

Recommendations

- Need agreed-upon definition of RWE
- Involve librarians in search!!
If you had to create a search filter for RWE, what kind of terms would you use?
Possible Keywords

- Administrative claim/data/record
- Big data
- Billing data/record
- Birth certificate/data/record
- Claims data
- Claims based
- Data links/linkage
- Data mining
- Data repository
- Database management system
- Death certificate/data/records
- Discharge abstract
- EHR data/reviews/analysis
- EMR data/reviews/analysis
- Factual data
- Health claim/data/record
- Healthcare claim/data/record
- Hospital/hospitalization data/record
- Inpatient data/record
- Institutional data
- Insurance claim/data/record
- International/national survey/data
- Coroner’s data
- Dark data
- Data repository
- Digital data
- Digital health monitoring devices / Fitbit data
- Medication utilization
- Pharmacy data
- Pragmatic data/trials
- Secondary use data
- Social media data
- Reimbursement data/record
- RCD (acronym for routinely collected data)

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
Possible MeSH Terms

- Databases, factual/
- Datasets as topic/
- Databases as topic/
- exp Medical records systems, computerized/
- exp Registries/
- Database management systems/
- Geographic information systems/
- National practitioner data bank/
- Decision support systems, clinical/
- Health information systems/
- **exp Big data/**
- exp Data mining/
- exp Records as topic/
- exp Drug prescriptions/
- exp Drug utilization/
- Medicare/sn
- Medicaid/sn

- Insurance, health, reimbursement/sn
- Insurance/sn Reimbursement/sn
- Hospitalization/sn
- Dataset.pt /sn qualifier = statistics & numerical data

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
Modular Approach

- May be useful to organize filter by types of RWD
- Some projects may require one specific type
- A modular approach may be most useful
- Can combine with study design or other filters (observational, qualitative, economic evaluations)

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
Start Your Own Filter (7-10 min)

Identify keywords & MeSH terms to retrieve studies/RWE related to one of following types of RWD:

1. **Patient registries** (for a particular condition)
2. **Electronic health records** (patient’s charts, medical history, immunization dates, allergies, lab results)
3. **Administrative databases** (billing, patient visits, insurance, claims data)
Is a standardized method of searching for RWE even feasible?
1. Medicare/sn
2. Hospitalization/sn
3. 2 not 1
4. Medicare/
5. 4 not (1 or 2)
7. 6 not (1 or 2 or 4)
8. administrative.tw.
9. 8 not (1 or 2 or 4 or 6)
10. Health Services/ut
11. 10 not (1 or 2 or 4 or 6 or 8)
13. 12 not (1 or 2 or 4 or 6 or 8 or 10)
14. California/
15. 14 not (1 or 2 or 4 or 6 or 8 or 10 or 12)
16. Health Services Accessibility/sn
17. 16 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14)
18. Hospital Mortality/
19. 18 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16)
20. Registries/
21. 20 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18)
22. Cohort Studies/
23. 22 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20)

Source: van Walraven C, Bennett C, Forster AJ. Derivation and validation of a MEDLINE search strategy for research studies that use administrative data. Health Serv Res 2010 Dec;45(6, pt 1):1836-45.
24. Longitudinal Studies/
25. United States/
26. 24 and 25
27. 26 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22)
28. 25 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 24)
29. Comorbidity/
30. 29 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 25)
31. Health Care Costs/
32. 31 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 25 or 29)
33. Health Care Surveys/
34. 33 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 25 or 29 or 31)
35. “Outcome Assessment (Health Care)”/
36. 35 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 25 or 29 or 31 or 33)
37. “Quality of Health Care”/
38. 37 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 25 or 29 or 31 or 33 or 35)
39. “Costs and Cost Analysis”/
40. 39 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 25 or 29 or 31 or 33 or 35 or 37)
41. “Length of Stay”/
42. 41 not (1 or 2 or 4 or 6 or 8 or 10 or 12 or 14 or 16 or 18 or 20 or 22 or 25 or 29 or 31 or 33 or 35 or 37 or 39)
43. 1 or 3 or 5 or 7 or 9 or 11 or 13 or 15 or 17 or 19 or 21 or 23 or 27 or 28 or 30 or 32 or 34 or 36 or 38 or 40 or 42
44. Limit 43 to (addresses or bibliography or classical article or clinical conference or clinical trial, all or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or clinical trial or comparative study or congresses… or validation studies)

Source: van Walraven C, Bennett C, Forster AJ. Derivation and validation of a MEDLINE search strategy for research studies that use administrative data. Health Serv Res 2010 Dec;45(6, pt 1):1836-45.
PubMed EHR search strategy (pt. 1)


AND


Source: https://www.nlm.nih.gov/services/queries/ehr_details.html
PubMed EHR search strategy (pt. 2)

OR


AND


Source: https://www.nlm.nih.gov/services/queries/ehr_details.html
Routinely collected health data (RCD) search filter

#1 Search Administrative[All fields]
#2 Search claim*[All fields]
#3 Search "Insurance, Health, Reimbursement"[mh]
#4 Search reimbursement[All fields]
#5 Search utilization[All fields]
#6 Search utilisation[All fields]
#7 Search "Drug Utilization Review"[mh]
#8 Search Prescription*[All fields]
#9 Search Insurance[mh]
#10 Search Insur*[All fields]
#11 Search medicare[All fields]
#12 Search medicare[mh]
#13 Search medicaid[All fields]
#14 Search medicaid[mh]
#15 Search routine*[All fields]
#16 Search certificat*[All fields]
#17 Search record*[All fields]
#18 Search electronic*[All fields]
#19 Search "Personal Health*[All fields]
#20 Search EMR[All fields]
#21 Search EHR[All fields]
#22 Search PHR[All fields]
#23 Search "Electronic Health Records*[mh]
#24 Search "Health Records, Personal*[mh]

Routinely collected health data (RCD) search filter

#25 Search "Medical Record Linkage"[mh]
#26 Search "Medical Records Systems, Computerized"[mh]
#27 Search "Registries"[mh]
#28 Search register*[All fields]
#29 Search registr*[All fields]
#30 Search database*[tiab]
#31 Search "health care databases"[All fields]
#32 Search "healthcare databases"[All fields]
#33 Search "health care database"[All fields]
#34 Search "healthcare database"[All fields]
#35 Search "healthcare data"[All fields]
#36 Search "health care data"[All fields]
#37 Search "national database"[All fields]
#38 Search #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9…OR #37
#41 Search "Registries"[mh] OR register*[All fields] OR registr*[All fields]
#42 Search database*[tiab] OR "health care databases"[All fields] OR "healthcare databases"[All fields] OR "health care database"[All fields] OR "healthcare database"[All fields] OR "healthcare data"[All fields] OR "health care data"[All fields] OR "national database"[All fields]
#43 Search #39 OR #40 OR #41 OR #42
#44 Search #38 AND #43 …

1. Epidemiologic Methods/
2. exp Epidemiologic Studies/
3. Observational Studies as Topic/
4. Clinical Studies as Topic/
5. (Observational Study or Validation Studies or Clinical Study).pt.
6. (observational adj3 (study or studies or design or analysis or analyses)).ti,ab,kf.
7. cohort*.ti,ab,kf.
8. (prospective adj7 (study or studies or design or analysis or analyses)).ti,ab,kf.
9. ((follow up or followup) adj7 (study or studies or design or analysis or analyses)).ti,ab,kf.
10. ((longitudinal or longterm or (long adj term)) adj7 (study or studies or design or analysis or analyses or data)).ti,ab,kf.
11. (retrospective adj7 (study or studies or design or analysis or analyses or data or review)).ti,ab,kf.
12. ((case adj control) or (case adj comparison) or (case adj controlled)).ti,ab,kf.
13. (case-referent adj3 (study or studies or design or analysis or analyses)).ti,ab,kf.
14. (population adj3 (study or studies or analysis or analyses)).ti,ab,kf.
15. (descriptive adj3 (study or studies or design or analysis or analyses)).ti,ab,kf.
16. ((multidimensional or (multi adj dimensional)) adj3 (study or studies or design or analysis or analyses)).ti,ab,kf.

CADTH: Canadian Agency for Drugs and Technology in Health
17. (cross adj sectional adj7 (study or studies or design or research or analysis or analyses or survey or findings)).ti,ab,kf.
18. ((natural adj experiment) or (natural adj experiments)).ti,ab,kf.
19. (quasi adj (experiment or experiments or experimental)).ti,ab,kf.
20. ((non experiment or nonexperiment or non experimental or nonexperimental) adj3 (study or studies or design or analysis or analyses)).ti,ab,kf.
21. (prevalence adj3 (study or studies or analysis or analyses)).ti,ab,kf.
22. case series.ti,ab,kf.
23. case reports.pt.
24. (case adj3 (report or reports or study or studies or histories)).ti,ab,kf.
25. organizational case studies/
26. or/1-25
1. Databases, Factual/
2. National practitioner data bank/
3. Databases as Topic/
4. Decision Support Systems, Clinical/
5. Geographic Information Systems/
6. Health Information Systems/
7. exp Medical Records Systems, Computerized/
8. Datasets as Topic/
9. exp Records as Topic/
10. exp Registries/
11. exp Drug Prescriptions/
12. exp Drug Utilization/
13. Database Management Systems/
14. exp Data Mining/
15. (administrative adj2 (claim* or data* or record*)).ti,ab,kf.
16. adverse drug reaction reporting system*.ti,ab,kf.
17. big data*.ti,ab,kf.
18. (birth adj2 (certificate* or data* or record*)).ti,ab,kf.
19. ((claim or claims) adj2 data*).ti,ab,kf.
20. claims based.ti,ab,kf.

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
D. Kaunelis’ RWE Filter (2 of 4)

21. (data* adj2 (links or linked or linkage* or linking)).ti,ab,kf.
22. (data* adj2 (mining or mine or mined)).ti,ab,kf.
23. (data* adj2 repositor*).ti,ab,kf.
24. database management system*.ti,ab,kf.
25. dataset.pt.
26. (death adj2 (certificate* or data* or record*)).ti,ab,kf.
27. discharge abstract*.ti,ab,kf.
28. factual data*.ti,ab,kf.
29. ((health or healthcare) adj3 (claim* or data* or record*)).ti,ab,kf.
30. (hospital* adj2 (data* or record*)).ti,ab,kf.
31. (inpatient* adj3 (data* or record*)).ti,ab,kf.
32. (insurance adj3 (claim* or data* or record*)).ti,ab,kf.
33. ((international or national or nationwide) adj3 (survey* or data*)).ti,ab,kf.
34. (managed care adj3 data*).ti,ab,kf.
35. medical record*.ti,ab,kf.
36. medical transcription data*.ti,ab,kf.
37. (medicare or medicaid).ti,ab,kf.
38. (nursing data* or nursing record*).ti,ab,kf.
39. (patient adj3 (data* or record*)).ti,ab,kf.
40. (billing adj3 (record* or data*)).ti,ab,kf.

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
D. Kaunelis’ RWE Filter (3 of 4)

41. ((prescription* or prescrib*) adj3 (claim* or data* or record* or pattern*)).ti,ab,kf.
42. (real world adj5 (data* or evidence or research or effective*)).ab.
43. real world.ti,kf.
44. (registries or registry).ti,ab,kf.
45. ((register or registers) adj3 (link or links or linked or linkage* or linking or data*)).ti,ab,kf.
46. (routine* adj5 data*).ti,ab,kf.
47. ((utilization or utilisation) adj3 (data* or record* or pattern*)).ti,ab,kf.
48. participant data*.ti,ab,kf.
49. (real-life adj5 (data* or evidence or research or effective*)).ti,ab,kf.
50. physician claims.ti,ab,kf.
51. (Canadian Institute for Health Information or CIHI or "Centre for Health Services and Policy Research" or Health Council of Canada or Health Quality Council of Alberta or Institute for Clinical Evaluative Sciences or Manitoba Centre for Health Policy or "Newfoundland and Labrador Centre for Health Information" or Saskatchewan Health Quality Council or Statistics Canada or Public Health Agency of Canada).ti,ab,kf.
52. (Canadian Primary Care Sentinel Surveillance Network or Canadian Network of Observational Drug Effect Studies or CNODES or Canadian Chronic Disease Surveillance System or Registered persons database or Discharge Abstract Database or Discharge Abstracts Database or National Ambulatory Care Reporting System or NACRS or NPDUIS or National Prescription Drug Utilization Information System or National Physician Database or Home Care Reporting System or National Rehabilitation Reporting System or Continuing Care Reporting System or Ontario Case Costing Initiative or OCCI).ti,ab,kf.

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
53. (Ontario Drug Benefit or Ontario Health Insurance Plan or Ambulatory Care Classification System or Regie de l'assurance maladie du Quebec or RAMQ or Non-Insured Prescription Drug Plan or Non-Insured Health Benefits).ti,ab,kf.

54. ((EMR or EMRs or EHR or EHRs) adj2 (data* or review* or analys*)).ti,ab,kf.

55. ((institutional or multiinstitutional) adj2 data*).ti,ab,kf.

56. exp medicare/sn

57. medicaid/sn

58. or/1-57

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
### Terms and Concepts Being Tested at CADTH

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<thead>
<tr>
<th>Term</th>
<th>Canadian RWE data sources</th>
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<tr>
<td>Big data/</td>
<td>Canadian RWE data sources</td>
</tr>
<tr>
<td>Vital data</td>
<td>Stats Can</td>
</tr>
<tr>
<td>National health data</td>
<td>CNODES</td>
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<tr>
<td>Genomic data</td>
<td>DSEN</td>
</tr>
<tr>
<td>Billing data</td>
<td>CIHI</td>
</tr>
<tr>
<td>Chart adj3 data</td>
<td>CCSH</td>
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<tr>
<td>Database studies</td>
<td>ARCC</td>
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<tr>
<td>Medical charts</td>
<td>Health Canada (ARR, RMP, PSVR, MMA, CMDSNet)</td>
</tr>
<tr>
<td>Wearables data</td>
<td>Ontario sources</td>
</tr>
<tr>
<td>Commissioning</td>
<td>Ontario Drug Policy Research Network</td>
</tr>
<tr>
<td>Through evaluation (NHS</td>
<td>HQO – Field Evaluation Studies</td>
</tr>
<tr>
<td>England term)</td>
<td>Cancer Care Ontario (Evidence Building Program)</td>
</tr>
<tr>
<td>Active surveillance</td>
<td>ICES Data &amp; Analytic Services</td>
</tr>
</tbody>
</table>

**ICD-9**

- Stats Can
- CNODES
- DSEN
- CIHI
- CCSH
- ARCC
- Health Canada (ARR, RMP, PSVR, MMA, CMDSNet)

**ICD-10**

- Ontario sources
- Ontario Drug Policy Research Network
- HQO – Field Evaluation Studies
- Cancer Care Ontario (Evidence Building Program)
- ICES Data & Analytic Services
- IMS 360 database

**Pragmatic trial***

- Active surveillance
- Through evaluation (NHS England term)

**Large sample trial***

- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Apps?**

- Chart adj3 data
- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Social media**

- Database studies
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Sensors**

- Chart adj3 data
- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Machine learning**

- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Patient charts**

- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Health surveys**

- Chart adj3 data
- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Secondary use data**

- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**Pragmatic RCT**

- Medical charts
- Wearables data
- Commissioning
- Through evaluation (NHS England term)

**EMR (electronic medical record)**

- Commissioning
- Through evaluation (NHS England term)
Implications for Searching

● Keep in mind RWE/RWD are umbrella terms and you may need to search for more specific terms related to the request.

● Authors, requestors, audience, information specialists need to be on the same page with respect to the definition of RWD before starting the search.

● Consider the type of study designs should be included:
  ○ All Observational? More specific?

● What sources of RWD are needed? i.e. administrative data, electronic health records, study data, etc.

● Are you searching for a specific jurisdiction or condition? there may be patient registries or databases or datasets for that specific region or condition.
Role of Information Specialists

- May be involved in locating RWD sources
- Will be expected to find publications (RWE) that have used real world data
- May require a search filter to aid in retrieval

Source: Kaunelis D. Searching the literature for real world evidence. Health Technology Assessment International Annual Meeting; 2018 June 1-5; Vancouver (BC); Health Technology Assessment International, 2018.
Acknowledgements

We’d like to thank:

● Our colleague Dagmara Chojecki who was involved in developing the workshop
● David Kaunelis from CADTH for sharing his slide desk and RWE filter with us as well as providing a list of terms and MeSH that are currently being tested.
Thank you!
Questions?

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