Health librarians and Grey Literature: what do we need to know?

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- Royal Melbourne Hospital
  9.30 am – 12.30 pm, July 15th 2014
  (A Health Libraries Inc. Event)

- Royal Adelaide Hospital
  9.30 am – 12.30 pm, September 25th 2014
  (A SA Health Libraries Event)
Health libraries, what do we do?

Here’s a Wordle depicting the scope and mission of health libraries and librarians, whether you work in hospitals, universities or other health and research organisations.


For our value and ROI (return on investment) see: Questions of life and death: an investigation into the value of health library and information services in Australia

When we think of GL do we think of this? Is this sort of stuff still around? Sometimes when people retire and offices are cleaned out the contents are donated to the library. What do you do in your library with this sort of donation? Whose responsibility is it, or should it be? It costs money to catalogue it, but for some of this material once its gone, its gone.
The other picture of GL is this. The bottom line is that there is simply too much data available for any search engine to reach the entire deep web. Intelligent searching and informed approaches can compensate for some of this and retrieve a great deal of value.

http://witnessthis.wordpress.com/2009/12/14/the-dark-web-explained-2/
When we do literature searches we usually start with the black (academic, scholarly, commercial) databases and the published literature, and that’s I think, how it should be. You would choose a number of black databases and search them well.
Most researchers would use the same core black literature .... When it comes to the grey literature the paths diverge.

Given the same research question we would all probably choose the same or similar black databases, but after that, it gets interesting. Our pathways would diverge quite considerably and become far less prescriptive. Creativity in approach is the order of the day.
What is GL? There are lots of definitions but the Pisa Declaration is the latest one.....
http://greyguide.isti.cnr.it/include/pisadeclarationmay2014.pdf
Generally GL means unpublished in a commercial sense.
We know what GL might look like. We have the most recent definition. We know looking for it is going to take some creativity.
Why would we bother - is it worth it?
Cochrane says Yes.

In a recently updated Cochrane methodology review all five studies showed that: “Published trials tend ..... bias into their review”


See also Cochrane Handbook for Systematic Reviews of Interventions
http://handbook.cochrane.org/

6.2.1.8 Grey literature databases “ failure to identify trials reported in conference proceedings and other grey literature might affect the results of a systematic review.”
Campbell says Yes

**Campbell Collaboration** is similar in intent to Cochrane with relevant coverage of health research topics where it overlaps with (social, behavioural and educational interventions). Cochrane describes Campbell as “a sibling organisation to Cochrane, which prepares, maintains and promotes the accessibility of systematic reviews in areas such as education, criminal justice, social policy and social care.”

Campbell Collaboration can be found here: [http://www.campbellcollaboration.org](http://www.campbellcollaboration.org)

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**Recognition of the value of GL: Campbell Collaboration**

• “Campbell reviews must include a systematic search for unpublished reports (to avoid publication bias)” (Campbell Collaboration, nd)

“Locating studies ..... [search] multiple sources of grey literature (websites, special registers, reference lists, listservs, personal contacts)” (C2 2010)
Recognition of the value of GL:
Joanna Briggs Institute

- “In addition to databases of published research, there are several online sources of Grey or unpublished literature that should be considered.”
- “Grey literature has the potential to complement and communicate findings to a wider audience, as well as to reduce publication bias.”

(Thomas, 2008)

Joanna Briggs Institute says Yes
http://joannabriggs.org/

“The comprehensiveness of searching and documenting the databases searched is a core component of the systematic review’s. In addition to databases of published research, there are several online sources of Grey or unpublished literature that should be considered.”

“A JBI review should consider papers published in both commercial (black literature) and in non-commercially operated databases (grey literature).

JBI 2014 Reviewers Manual
ERA (Excellence in Research for Australia) is administered by the ARC (Australian Research Council) which aims to identify and promote excellence across the full spectrum of research activity in Australia’s higher education institutions. Recently they have stated that research reports (GL) will be recognised as “research activity” which was not previously the case. Mainly relevant to universities but noteworthy in relation to GL.

http://www.arc.gov.au/era/

Amanda Lawrence posted this on APO (Australian Policy Online)

“This is a very encouraging step towards recognizing and rewarding the production of alternative forms of publication, ones that often have the greatest impact for policy and practice. This follows the inclusion of reports in the 'Other' category in the previous round of ERA which was rather obscure and not taken up as an option by many academics.

We would encourage researchers to take up this option and begin to change the culture of only measuring journal output. This is the change that has often been called for and must now be utilised if it is going to have any effect. There will be various challenges however, such as ensuring reports are publicly available, have correct metadata and are able to be assessed effectively. The GLS project has made a submission to the consultation and we look forward to working further with the ARC to help ensure this change is adopted and successful.”

http://greylitstrategies.info/news/draft-guidelines-next-era-round-emphasises-role-grey-literature#
So…..what are the different types of GL?
Book chapters are controversial and probably considered GL because they are not well indexed and so considered grey in the sense of being difficult to retrieve. Some databases index book chapters: Sociological Abstracts, PsycInfo, Book Citation Index (ISI), AGRICOLA… Also could try Google Books.
## Types of grey literature

- Bulletins
- Government documents
- Technical reports
- Scientific reports
- Bibliographies
- Non-commercial translations
- Trade magazines
- Repair manuals
- Preprints
- E-prints
- Memoranda
- Legislation
- Symposia
- White papers
- Surveys
- Guidelines
## Types of grey literature

- Blogs
- Lectures
- Announcements
- Course materials
- Bulletins
- Bulletin boards
- Catalogues
- Posters
- Toolkits
- Press releases
- Essays
- Speeches
- Statistics
- Tenders
- Interviews
- Directories
- Programs
- Questionnaires

Are there others you think we should include?
This is just to get us thinking...

“Here’s a second scenario. You’re at a dinner party and seated next to Stephen Hawking, who in conversation tells you that he has been working on a new theory regarding black holes. Encouraged by your great interest, and in a mood to share enthusiasms he asks his assistant to sketch out the basic principles onto a dinner napkin which is then given to you. As the science writer for a major newspaper you can’t believe your luck but you know your editor will not accept such “anecdotal information’ even from one as eminent as Stephen Hawking. You take a chance and email the great man, reminding him of your conversation, and he duly replies, reiterating the points he made to you earlier, at the dinner party.

Does it matter that the information was verbal, was sketched onto a serviette, or came via email?”

Or does it matter that it came from Stephen Hawking?

Taken from “How low can you go: towards a hierarchy of grey literature” J Tyndall. http://hdl.handle.net/2328/3326
AACODS was drawn up in 2010 from the original description in the conference paper “How low can you go …”

The AACODS checklist was designed to enable evaluation and critical appraisal of grey literature and have the flexibility “to be applied to the widest range of resources: from models of primary healthcare to dissertations, maps, diaries, podcasts, blogs and so on. A checklist which brings together the guidance of the following sources...
Joanna Briggs Institute: “Expertise, experience and opinion”
UpToDate: “the clinical experience and observations of our authors, editors and peer reviewers”
SEVAL standards: Propriety, Accuracy, Utility and Feasibility
Glover: “background information/expert opinion”
Wormald: “opinions of respected authorities, based on clinical experience; descriptive studies or reports of expert committees”
... and uses common sense to meld them together with the generally accepted web evaluation criteria of: Authority, Accuracy, Objectivity, Coverage, Date, Significance which can be applied to each and every item of grey literature”. Significance was included to cover Impact.

AACODS is described as being Format Agnostic and its flexibility has led to the recent endorsement by the UKHF (UK Health Forum) to appraise resources for their new
PICE (Prevention Information & Evidence eLibrary) and by NICE (National Institute for Healthcare Excellence) in the UK. as their checklist (1.9) to evaluate GL for their 2014 service guidance development.
Medical/clinical research

• Traditionally has relied on meta-analysis of published clinical trials.
• Now there is a strong endorsement for the consideration of inclusion of unpublished (grey) trials
• Found in sources like ClinicalTrials.gov Cochrane Central Register of Controlled Trials and Current Controlled Trials

We’ll come back to different types of GL but first let’s address medical /clinical research and start off with trials….many of which are unpublished in the commercial sense.
Many clinical trials are grey or unpublished.

A clinical trial is “any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes.”

Here is the **meta Register of Controlled trials** [http://www.controlled-trials.com/mrct/](http://www.controlled-trials.com/mrct/)

Other following large online registers allow users to search, register and share information about new, ongoing and completed clinical trials. Follow-up details are part of the entries for each trial:

**International Standard Randomised Controlled Trial Number (ISRCTN) Register** [isrctn.org/](http://isrctn.org/)

**Australian New Zealand Clinical Trials Registry** [http://www.anzctr.org.au/](http://www.anzctr.org.au/)

**WHO Registry** [http://apps.who.int/trialsearch/](http://apps.who.int/trialsearch/)
ClinicalTrials.gov is the big U.S. government registry

http://clinicaltrials.gov/

Like the other registries, Clinicaltrials.gov provides information about many trials which never reach publication.
Why is that?
Where’s the data?

Here is some discussion of the “unpublished” issue and the cost to human participants “exposed to the risk of trial participation without the societal benefits which accompany the dissemination of trial results”

http://www.futurity.org/clinical-trials-go-unpublished/
The BMJ journal article which raised this issue:

“Results: Of 585 registered trials, 171 (29%) remained unpublished. These 171 unpublished trials had an estimated total enrolment of 299,763 study participants. The median time between study completion and the final literature search was 60 months for unpublished trials. Non-publication was more common among trials that received industry funding (150/468, 32%) than those that did not (21/117, 18%), P=0.003. Of the 171 unpublished trials, 133 (78%) had no results available in ClinicalTrials.gov.”
One more important source of published and unpublished trials: **Cochrane Central Register of Controlled Trials** (Central), Cochrane Library

http://www.thecochranelibrary.com/view/0/index.html

Searchers can also select Source: Conference to specifically identify trials discussed as part of a conference paper or presentation.
Unpublished systematic reviews need to be addressed by health researchers. Despite the prevailing view that SRs are published, in reality, many are not. Often they are produced by government, NGOs, agencies and academic institutions. This one is from the UK Health Foundation, an independent charity working to improve the quality of healthcare in the UK.

“We carry out research and in-depth policy analysis, run improvement programmes to put ideas into practice in the NHS, support and develop leaders and share evidence to encourage wider change.”

From the **EPPI-Centre** (The Evidence for Policy and Practice Information and Co-ordinating Centre) which is part of the Social Science Research Unit at the Institute of Education, University of London. The EPPI-Centre conducts systematic reviews of research evidence across a range of topics. Major areas include education, health promotion, employment, social care and justice. The reviews on these topics can be found in an Online Evidence Library, which provides evidence overviews of broad topic areas as well as summaries and full reports of specific reviews conducted or supported by the EPPI-Centre.

http://eppi.ioe.ac.uk/cms/LinkClick.aspx?fileticket=FEJt5HyrgzGM%3D
Two Australian examples here of grey SRs.

One from **APHCRI**, whose mission is “Provide national leadership in improving the quality and effectiveness of primary health care through the conduct of high quality priority-driven research and the support and promotion of best practice. It focuses on important sectoral questions relating to the organisation, financing, delivery and performance of primary health care, including its interaction with public health and the secondary and tertiary health care sectors.”


The other SR was commissioned by **ACON**, a health promotion organization with a central focus on HIV/AIDS and produced by the Burnet Institute.

And two more. one from NHMRC
and the other from Cancer Australia, government body. This one was subsequently published in an academic journal.
One rich but often overlooked source of unpublished SRs is the dissertation or thesis. There are a number of big collections of these organised into online, searchable databases with a large amount of full-text content.

**PQDT Open**

http://pqdtopen.proquest.com/search.html
Here's the full-text available online. The SR can be the basis of a dissertation or the dissertation itself.

What else can theses be useful for? Great sources of research. They can be useful when we are asked about examples of specific research methodologies. They can include SRs or RCTS.
We’ve already seen directories and registers of trials like Clinicaltrials.gov - this is an example of an unpublished RCT which forms the basis of a dissertation.
Theses themselves are of course, GL. We've already seen **PQDT Open** – let's look at some other theses collections ....
Australian theses were collected into a repository, Australasian Digital Theses (ADT) which is now incorporated into TROVE, the National Library of Australia catalogue. This search on Paramedics and education has been limited to Format Thesis and Availability Online.
trove.nla.gov.au/ Apply format limit
A comparison of the practice of rural and urban paramedics: Bridging the gap between education, training and practice

by

Peter Mulholland BA, Assoc. Dip Health Science

Submitted in fulfilment of the requirements for the Degree of Master of Medical Science

University of Tasmania
May 2010

Full-text is freely available
The **Networked Digital Library of Theses and Dissertations** is an international organization dedicated to promoting the adoption, creation, use, dissemination, and preservation of electronic theses and dissertations (ETDs)

http://www.ndltd.org/

Remember to change to English on LHS search screen
Search results can be ordered by date or relevance and RHS of screen offers keyword to refine the search.
Theses Canada

http://www.collectionscanada.gc.ca/thesescanada/index-e.html
A Simulation Analysis of
an Emergency Department Fast Track System

by
Jennifer La

A thesis
presented to the University of Waterloo
in fulfilment of the
thesis requirement for the degree of
Master of Applied Science
in
Management Sciences

Waterloo, Ontario, Canada, 2010

A search on “Emergency” and limited to electronic full-text produced this 224 page, 2010 dissertation
The British Library ETHOS (Electronic Theses Online Services) offers a search of over 350,000 doctoral theses. Master theses are not available here but can be requested...

ETHos.bl.uk
DART-Europe is a partnership of research libraries and library consortia who are working together to improve global access to European research theses. Promises access to over half a million open access research theses from 562 Universities in 28 European countries

http://www.dart-europe.eu/basic-search.php
A 2014 doctoral dissertation in English and full-text

For theses we’ve looked at PQDT Open, TROVE, NDLTD, Theses Canada, EThOS and DART-Europe.

Some databases index theses including CINAHL, Sociological Abstracts, DAI (Dissertations Abstracts international), PsycInfo and Proquest.
Like theses and dissertations, conference papers and proceedings have value in their own right and are themselves GL. They can also alert us to trials, studies and R & D that may have taken place but not been published.

See Cochrane Handbook for Systematic Reviews of Interventions, in particular 6.2.2.4 Conference abstracts or proceedings http://handbook.cochrane.org/

“Although conference proceedings are not indexed in MEDLINE and a number of other major databases, they are indexed in the BIOSIS databases (http://www.biosis.org/).

Over one-half of trials reported in conference abstracts never reach full publication, and those that are eventually published in full have been shown to be systematically different from those that are never published in full (Scherer 2007). It is, therefore, important to try to identify possibly relevant studies reported in conference abstracts through specialist database sources and by hand-searching or electronically searching those abstracts that are made available in print form, on CD-ROM or on the internet. Many conference proceedings are published as journal supplements. Specialist conference abstract sources are listed in Box 6.2.f.”
Where can you find conference papers?

The **British library** has a strong collection of conference proceedings and anything you find here can be obtained from them via Flinders University Library’s Document Delivery.

Choose Advanced Search

Explore.bl.uk
A search for the phrase “medical students” in the title field gave us 7,793 hits, across the whole of the British Library holdings.

We are able to apply limits chosen from the LHS of the screen and Genre: **Conference literature** was selected, and the search result became 486.

Remember all these are available from the British Library if unable to be obtained elsewhere...
Some databases index conferences and there are some specific ones as well PapersFirst and ProceedingsFirst.

Each database seems to handle this slightly differently so you will need to investigate before you start searching.

**Some Databases index conference proceedings**

- **ISI Web of Science** (choose Conference Proceedings Citation Index: Science or Conference Proceedings Citation Index: Social Science & Humanities)
- **Scopus** (choose document type: Conference paper)
- **Sociological Abstracts** (choose Conference papers & proceedings in Advanced Search: Source Type)
There is a need to be aware of key organisations and associations who hold conferences and make their proceedings available.

Start to collect and build on your own database of relevant sources.

**National Rural Health Alliance**  http://ruralhealth.org.au/
The National Rural Health Alliance make these available online. 12th Conference, 2013 ..... 286 pages, detailed abstracts of papers available, pdf document to search. Some may get into Informit databases but due to limited resources conference papers are usually only selectively indexed and take quite a long time to appear.
HealthInfoNet is a wonderful resource for Australian Indigenous health.
http://www.healthinfonet.ecu.edu.au/
This link leads to a comprehensive list of upcoming health conferences for us to keep our eye on for potential attendance, presenting at or following up proceedings.

To find conference papers on a topic say “Cardiovascular health” click the Chronic conditions tab
Under Chronic conditions choose Cardiovascular health and see under Publications what conference papers have been written .... Note also programs and policies. Like many resources this overlaps as it takes a universal approach to everything on indigenous health, theses, reports, conference papers and so on ..... What other ideas for finding conference resources are there?
Lets move onto another genre now: Guidelines

The Clinical Practice Guidelines Portal is the Australian government portal which has pulled together published and unpublished clinical guidelines. Unfortunately searching can involve lots of tedious clicking through a number of steps via Conditions although the search function works reasonably well with keywords.

Here’s an example of a guideline with lots of organisations involved: Australasian Society for HIV Medicine, Primary developer Department of Health and Ageing, Funded Australian Liver Association.

It would be considered reputable due the developers of the guideline and the fact that it is on record as endorsed by Australasian Society for Infectious Diseases, Australasian Hepatology Association and Australian Practice Nurses Association. But no evidence has been documented or made available.

[some of this information is not shown on screen, and can be found by scrolling through the record online]

Available as a pdf but not “published” – some guidelines appear in MJA or Australian family Physician but are these “reprinted” as opposed to published?
This is the National Guideline Clearinghouse (U.S.) includes some international content.

I searched “carpal tunnel”. Searchers can also drill down through conditions etc. in steps but it is often quicker to keyword search. The Clearinghouse has a great facility where you can choose 2 or 3 guidelines and click Compare

The **Compare Guidelines** option provides a good format which could be built on. Gives evidence summary, links to final recommendations etc etc.
Here is the **Canadian Clinical Guideline** database:
https://www.cma.ca/En/Pages/clinical-practice-guidelines.aspx
And the U.K (from **NICE: National Institute for Health and Care Excellence**). They give the caveat that the guidelines are developed with the UK legislative context, though it is likely they would have wider applicability.

http://www.nice.org.uk/About/What-we-do/Our-programmes/NICE-guidance
International Guideline Library: “Our mission is to lead, strengthen and support collaboration in guideline development, adaptation and implementation”

Search results above for “chronic fatigue”

http://www.g-i-n.net/library/international-guidelines-library
Models, tools and frameworks.

Health librarians may be called upon to find examples of best practice, models and frameworks and so on. This “genre” can be found in many places. Perhaps part of a report or a review, a journal article or standard. This flow chart clearly demonstrates how to develop a model of care, and comes from the ACI website (Agency for Clinical Innovation)

The very useful Australian Resource Centre for Healthcare Innovations (ARCHI) website will transition to the Agency for Clinical Innovation (ACI). The Agency has a mission for “promoting innovation, engaging clinicians and designing and implementing new models of care.

All ACI models of care are built on the needs of patients, and are underpinned by extensive research conducted in collaboration with leading researchers, universities and research institutions.” It produces and collates guidelines, service plans and reports as well as models of care.

There are a lot of similar resources around like this. Here’s health.gov a US govt. website with models and guidelines and tools, research and reports (GL).

There is currently a strong positive culture for governments to put funding and support into building quality open access collections, particularly in health. Make a point of collecting up those that you think show relevance and promise: remember it’s a dynamic area so flag them for alerts or RSS feeds to keep up with moves and changes.

http://www.health.gov/communication/
What about Programs, projects and practices? Some of us who work with public health, community health or primary health care are asked a lot about these. Research often looks for interventions or programs that work, and particularly those that have been evaluated.

Some collections are quite specialised. The National Registry of Evidence-based Programs and Practices (NREPP) is a searchable online database of mental health and substance abuse interventions. All interventions in the registry have met NREPP’s minimum requirements for review and have been independently assessed and rated for Quality of Research and Readiness for Dissemination. The purpose of NREPP is to help the public learn more about available evidence-based programs and practices and determine which of these may best meet their needs. NREPP is one way that SAMHSA is working to improve access to information on evaluated interventions and reduce the lag time between the creation of scientific knowledge and its practical application in the field.

This search is on social anxiety.

http://nrepp.samhsa.gov/Index.aspx
This search: 16 results.
Searchers can refine research by gender, age, study design etc. Quality of research and so on can be accessed by bars along the bottom. Enough details are given for someone to replicate the program and contacts for those interested in implementing the program or who want to know more about the research. The networking aspect of these sorts of resources is a key strength and indicates elements of a community of practice.

Some programs and projects are written up in journal articles but many more are not. Remember the Australian database HEAPS?
Research Registries

As health librarians we are often asked by researchers what other people are doing in their area. Research reports and other (usually unpublished) activities are increasingly being gathered into Registries, sometimes called databases, PHCRIS here calls ROAR a register and an “online network” as it encourages interaction and sharing. These sorts of registries can be about completed, but more often, ongoing research.

PCHRIS states “If you are involved in Australian primary health care research we encourage you to be a part of this exciting research register ….

Some of the benefits of sharing your work in ROAR include the following...

Your areas of research expertise will be promoted

Potential future collaborators, research users, mentors and policy makers can contact you about your research.

Enables others to expand on your work rather than duplicating your effort.”

**REHABDATA** is a database within the NARIC website – this sort of arrangement is quite common.

It indexes published and unpublished material: “reports, studies and papers” from ongoing and completed research in the disability and research area.

http://www.naric.com/?q=REHABDATA
Two examples of GL indexed in REHABDATA. Full-text online versions of both documents available at:
HSRProj (Health Services Research Projects in Progress)

This site indexes ongoing research projects. It gives details of the work that is being undertaken and gives contact information for interested follow-up. An attempt to prevent re-inventing the wheel.

This is an ongoing research study which states:

“To address this gap in knowledge, we will create a database that is needed to inform future intervention studies and trauma-related policies. Specifically, we propose the creation a nationally representative database of injured elderly patients to better define the relationship between health, function, and injury using the Health and Retirement Study (HRS) and HRS-linked Medicare data.”

It is a great example of re-using data and combining existing data to meet a newly discovered gap in current models. Increased visibility and openly sharing of information makes this achievable.
HSRProj (Health Services Research Projects in Progress) is part of a collection of related databases produced by the National Library of Medicine.

This is the homepage for these resources.

Some is research that is completed, some is ongoing. There are also specific databases relating to Artic or Asian American health ......

The resources I’ve been showing you are all ones I’ve personally found to be useful and wanted to highlight. Let’s move away for now from these sorts of examples, to look at the concept of GL and some of the issues involved. Here are some of the challenges of dealing with GL.

**Grey literature: challenges**

- Diffusion, dissemination – often problematic
- Access – grey literature sometimes called ‘fugitive’ literature (literally must be hunted down) – requires creativity
- Impact, value, quality, appraisal
- Dark data
While we’re looking at all these specialised resources for various different things some of you are probably thinking “Do I need to know about this - won’t Google find me everything?”

Google Advanced search and Google Scholar are incredibly valuable for discovering and locating grey literature but the searching seems to be more successful at finding resources where information might be located, than the details of the constituent information.

A lot of what needs to happen in harnessing the value of GL is working out which resources relate to your area of interest and interrogating them.

Won’t Google find me everything?

In fact, only a small percentage of the Web’s content is accessible to Google.

The term “deep Web” refers to the vast portion of the Web that is beyond the reach of the typical “surface Web” crawlers.

Surface Web search engines like Google can’t easily fathom the deep Web because most deep Web content has no links to it.
Deep or Invisible Web

Spiders or crawlers of search engines can't deal with database forms. The spiders can't complete a form, and hit the search button to gain access to the information in databases. They can index the search form itself, but not the wealth behind it.

Another way of putting it ....
Have you heard of **dark data**?

Researchers need to be able to think about whether relevant dark data might exist in their area and how and where this information might be accessed.

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**Dark data**

- “Dark data” is not carefully indexed and stored so it becomes nearly invisible to other potential users and therefore is more likely to remain underutilized and eventually lost.
- Dark data is information and results from research that has not been properly archived and therefore is not known to exist and cannot be utilized.
Dark data might be deliberately concealed or mislaid, filed, missing, inaccessible due to format or location ...
Due to increased recognition of the importance of this data BioMed Central now produces a journal designed to collects some of this data.
“BMC Research Notes is an open access journal publishing scientifically sound research across all fields of biology and medicine. The journal provides a home for short publications, case series, and incremental updates to previous work with the intention of reducing the loss suffered by the research community when such results remain unpublished.
BMC Research Notes also encourages the publication of software tools, databases and data sets and a key objective of the journal is to ensure that associated data files will, wherever possible, be published in standard, reusable formats. We are currently working with researchers across the full spectrum of biomedical research to define appropriate recommendations for domain-specific data file standards.”
http://www.biomedcentral.com/bmcresnotes

One of things about Dark data is being aware of what is under our noses so I’d like to spend a little bit of time looking at something really obvious – Library catalogues.
Libraries as a source of GL

Sometimes we need to remind ourselves that Libraries are key research resources. Here are 4 ways in which libraries contribute:

- Library catalogues index material which is unpublished
- Libraries have Special Collections of material which often has little or no available metadata
- Libraries are often involved with their institutions repositories which contain unpublished research output
- Libraries are taking on the role of web archivists
Library catalogues index material which is unpublished. Searching catalogues here is primarily about identifying existing GL, and after that, locating it.

Check out your own library. What grey material is included?

Then go to our National Library and Trove – here’s an example of a search showing some GL including newspapers, newsletters and images.

trove.nla.gov.au/
International catalogues like **World Cat**: [https://www.worldcat.org/](https://www.worldcat.org/)
While we’re looking at Libraries consider that there are many specialised libraries around. Make it your business to discover others in your areas of interest.

Of course NYAM is special in that it has a GL collection and produces a monthly Grey Literature Report

http://www.nyam.org/library/
You can register to receive their Report as a monthly eAlert. Check their list of key (U.S.) organizations which produce GL.
Here's a search on “teenage pregnancy” with links to online full-text.
Many libraries have **Special Collections** of material which often has little or no available metadata. This is a description of the kind of material collected by Flinders University Library’s Special Collections Dept.
One example of a collection with possible interest to health researchers is the **Tea and Sugar Archive**, which includes

“Reports, notes (in diary form), correspondence, medical notes. RICE (remote and isolated children’s exercise) information/correspondence. Background material (articles).” Flinders Medical Centre provided the medical staff who travelled on the Tea and Sugar train every six weeks, providing medical care to isolated railway workers, their families and pastoral families. Researchers who are interested in working with the collection would need to contact the Library.
Another collection is the **Eros Collection** which consists of material relating to the sex industry in Australia. See Type of Material in the slide above.

This is a basic entry with enough information to allow researchers to know the collection exists. Special Collections will eventually add metadata at a more detailed level to allow more of the contents of collections like these to be discovered. Internationally this type of work is being achieved on a rapid scale.

What about all the other collections exist and where? It’s important to remember that collections are not necessarily related to an institution or it’d study strengths ....
This History of Nursing and Nursing Education Archive collection is at Sydney University.

I found it via **ANDS (Australian National Data Service)**

What about Repositories?

Libraries are often involved with their institutions repositories which contain some unpublished research output.

Here is a list of **Australian Open Access repositories** ... including the universities, as expected, but also CSIRO and others.

http://aoasg.org.au/open-access-repositories-at-australian-institutions/
Here is the **CSIRO** repository.

“Our publications repository contains records of more than 80 years of CSIRO research publications, such as journal articles, conference papers, books and reports. Some recent records may have full-text attachments available where copyright and confidentiality conditions permit.”

The repository is fully searchable. You can also browse the collection by author or publication date

https://publications.csiro.au/rpr/home?execution=e4s1
The Institutional Repository allows access to the contents of all UK university repositories so one search covers a wide field.

http://irs.mimas.ac.uk/
A search here for conference presentations that related to health of travellers gave us 33 results.
There are all sorts of organisational and institutional repositories. Here is **Lenus: the Irish Health Repository**.

“Lenus is Ireland’s foremost repository for health services research and grey literature. It was launched in 2009 and is managed by the Regional Library & Information Service in Dr Steevens’ Hospital, Dublin. Lenus makes available the research output of the many organisations providing healthcare in the Republic of Ireland, along with their administrative, clinical and regulatory publications which together provide the background and context for Irish healthcare”.

http://www.lenus.ie/hse/handle/10147/305514
It also includes digitised historical documents including Cork Street Fever Hospital Board Meeting minutes from 1801-1818, and is planning further digitisation.

Shown here an excerpt from: Grangegorman Mental Hospital Board Minutes 1952 and an unpublished study on patient experience and autonomy at of end of life. http://www.lenus.ie/hse/handle/10147/305514
Médecins Sans Frontières (MSF) also has its own repository. “Whilst MSF is well known for its humanitarian medical work, the organisation also produces important research based on its extensive field experience within vulnerable populations. Its studies have often changed clinical practice and have been used for further humanitarian advocacy..... the vast majority of our medical work, and by extension our research activities, take place in poorer countries where access to scientific publications is often difficult and expensive to obtain ..... we are able to make MSF’s research experience available to health workers, policy makers and researchers in those countries in an easily-searchable format at no cost.”

Conference presentations and slides, posters, research reports and protocols and invaluable resources for those involved in emergency, disaster, humanitarian research. A strong example practice-based evidence: of GL directly from the field. http://msf.openrepository.com/msf/
Virginia Henderson Global Nursing e-Repository is another relevant example for us. “The Virginia Henderson Global Nursing e-Repository (Henderson Repository) is the only repository solely dedicated to sharing works created by nurses. It is an open-access digital academic and clinical scholarship service that freely collects, preserves, and disseminates full-text nursing research and evidence-based practice materials...... Nurses are encouraged to submit their full-text white [i.e. grey] papers, reports, dissertations, articles, or any other research-related or evidence-based practice materials for which they have copyright ownership or written permission” http://www.nursinglibrary.org/
An example of a broader-based “knowledge repository” is ELDIS. A fantastic resource for public and global health, for policy, for developing countries.

“Our aim is to share the best in development policy, practice and research …. latest editorially selected content from over 7,500 development organisations - all available free to download. Share your work with over 80,000 development practitioners”

http://eldis.org/
Here is **OPENDOAR**: a Repository of repositories

You can search the contents of multiple repositories in one search (published and unpublished material, includes PubMed abstracts) or you can search for a particular type of repository by Subject

www.opendoar.org
Here’s a search for the topic “health libraries” across the whole OPENDOAR content … results included the Shelli report
I’ve mainly used OPENDOAR for health in developing countries so this was a surprising find. An 88 page report...
Here I’ve searched for a repository in the Health and Medicine category, which includes conference material.

I selected Aphasiology Archive as relevant as those of us who work with speech pathologists.
The **Aphasiology Archive** provides access to all the full papers of the Clinical Aphasiology Conference from 1972 to 2013
Library as Web Archivist

PANDORA (Preserving and Accessing Networked Documentary Resources of Australia) “was established by the National Library in 1996 and is a collection of historic online publications relating to Australia and Australians. Online publications and web sites are selected for inclusion in the collection with the purpose of providing long-term and persistent access to them.

Collecting scope

The PANDORA Archive is a selective collection of web publications and websites relating to Australia and Australians. It includes materials that document the cultural, social, political life and activities of the Australian community and intellectual and expressive activities of Australians.”

The Australian Government Web Archive (AGWA).

It’s a web archiving initiative of the National Library of Australia and it complements the Library’s long established PANDORA Archive.

The AGWA is a collection of Commonwealth Government websites with the earliest content collected in June 2011. Both these 2 sites are useful. Recently I used them with a researcher interested in documenting Centrelink’s changing definition of the family.

If material is unavailable or you can’t access certain data, there is a possibility you can apply for it via **FOI (Freedom of Information)**


Office of the **Australian Information Commissioner**
In our professional capacity sometimes we might need to know about things like the Coroner’s findings. These can be found and documents appear which can be accessed. Some documents are excluded from the freedom of information process.

Access to more detailed coronial documents, created during the investigation into a reportable death may include:

- a police report
- witness statements
- photographs
- expert reports
- an autopsy report
- a toxicology certificate
- the coroner’s findings.

Access to coronial documents is regulated by the Coroners Act 2003. During investigations these documents are excluded from the freedom of information process and can only be obtained with the coroner’s consent. Most of the material contained on a coronial file is highly sensitive and may be graphic and distressing in nature. Therefore, information is only made available to those who have sufficient interest in the investigation, such as the immediate family of the deceased.

Here is an article “Recent coronial findings” from medicSA: magazine of the Australian Medical Association (SA) vol. 27 (3) June 2014 p. 10

It includes 2 citations (as tearsheets) from Coroners findings. The idea is to draw attention to issues which the medical community needs to learn from and this is usually recommended or directed by the State Coroner,

“Reforms to the *Freedom of Information Act 1982* (the FOI Act) promote a pro-disclosure culture across government and build a stronger foundation for greater openness and transparency in government. A significant change is the introduction of a new information publication scheme for Australian Government agencies. The scheme aims to transform the freedom of information framework from one that responds to individual requests for access to documents to one that requires agencies to take a proactive approach to publishing information. The scheme commences on 1 May 2011.”

The British Library does a great job archiving the social history and culture of the UK. From historical maps of London, medieval cookbooks, Victorian sheet music and recordings of bird sounds and regional accents. And of course it includes some valuable health resources as well.

Note how this slide shows a news item on its newest role in saving “the nation’s digital memory”? We’ll come back to that in a second, but first just an example of a resource with detailed information which could be valuable to researchers.

www.bl.uk
"Life Testimony and Health Promotion Project (Health Education Authority/University of East London)"

The project sought to address gaps in existing knowledge about health beliefs and highlight the value of personal testimony as an evidence base for health promotion. Three priority groups were focused on: homeless, refugees, and 'looked after' children (in care). Interviews explored people's views and experiences of health-related issues in the context of the whole life.

http://cadensa.bl.uk/uhtbin/cgisirsi/x/0/0/5?searchdata1=CKEY6092031&library=ALL
"Stuff out there on the web is ephemeral," said Lucie Burgess, the library's head of content strategy.

"The average life of a web page is only 75 days, because websites change, the contents get taken down. If we don't capture this material, a critical piece of the jigsaw puzzle of our understanding of the 21st century will be lost."

The library is publicising its new project by showcasing just a sliver of its content - 100 websites, selected to give a snapshot of British online life in 2013 and help people grasp the scope of what the new digital archive will hold.
The Curators’ 100

For example, Neverseconds provides researchers with access to primary material on children’s view of food, school lunches, what children actually eat. ....
http://www.bl.uk/100websites/top100.html
Moving away from the direct role of libraries, let's have a look at some databases which are grey or have a significant grey component. When is a database a database?

I made up my own definition when I decided to compile a list of these to support health research and needed some inclusion criteria. I have a reference to this compilation (*Databases for Research in Health*) on one of the last slides.

My definition: “A database is a collection of information that is organised so that it can easily be accessed, managed, and updated … they need to be fully searchable, well organised and wherever possible, to link to full-text.” I also decided to only include websites “if they have strong content and the component that relates to materials, resources or data is arranged in such a way that it can be usefully interrogated by the researcher.”

**Grey databases**

Many specialised (grey) databases exist

- **Factiva** - newspapers
- **Ausstats** – ABS statistics
- **AustLii** – legislation
- **Standards Online**
- **PsycExtra** – grey lit from APA
- **EThOS** – electronic theses online
Here is one of my favourites: the **Circumpolar health bibliographic database**. How do you think this could be relevant to us in Australia?

Some of the content on minority health could relate to the health of our indigenous population.

http://www.aina.ucalgary.ca/chbd/
The search here on “otitis media” gives us an abstract of a conference paper from the 14th International Congress on Circumpolar Health. The link here takes us to the 598 page Proceedings of the 14th International Congress on Circumpolar Health July 11-16, 2009 Yellowknife, Canada. Otitis media is a serious health problem in our indigenous population as well.

Many of you probably know about Caresearch, “Bringing relevant evidence and quality information to palliative care”.

CareSearch is a palliative care “knowledge network” with fully searchable content. It has a Research Studies Register and also some PubMed real time searches on key palliative care topics which use a search filter for guaranteed quality results

CareSearch has a specific Grey Literature collection. Flinders contributes information about theses by our students in the field of palliative care.
Social Care Online is a very useful database with a good proportion of grey literature. There is a strong overlap with health needs of vulnerable populations.

It includes material from “academic institutions, think-tanks and research organisations, government departments, local government, voluntary sector organisations and charities [and] commercial publishers.

All SCIE’s own publications – research briefings, guides, knowledge reviews, Social Care TV films and elearning materials -are also indexed on Social Care Online.”

A search here on nursing homes and staff ....

http://www.scie-socialcareonline.org.uk/
The search was then limited to “practice guidance” and 2010. SCIE (Social care Online) offers a wide range of limits which can be applied to further focus a search result.
POPLINE is another specialised database with “information on population and family planning, specifically research in contraceptive methods, family planning services, research in human fertility, maternal and child health, HIV/AIDS in developing countries, program operations and evaluation, demography, and other related health, law, and policy issues. Many documents are unique to the collection and are unavailable elsewhere.

POPLINE consists of bibliographic citations and abstracts to a variety of materials including journal articles and other scientific, technical, and programmatic publications as well as unpublished documents and project reports (gray literature). Most documents published after 2000 contain links to full-text.”

Search here on “refugee camps” to share the coverage is a bit broader than the name of the database suggests.

http://www.popline.org/
Certainly some reproductive health references but this search also demonstrates references to disability and vaccines.
**TOXNET** is a suite of databases “covering chemicals and drugs, diseases and the environment, environmental health, occupational safety and health, poisoning, risk assessment and regulations, and toxicology.” Some references are to journal articles, others are EPA reports, or give chemical data

TRID is an integrated database that combines the records from TRB’s Transportation Research Information Services (TRIS) Database and the OECD’s Joint Transport Research Centre’s International Transport Research Documentation (ITRD) Database. TRID provides access to more than one million records of transportation research worldwide, including references to journal article but also research, theses etc.

Health aspects include accidents, bystanders, driving, stress, emissions, cycling, commuting, older drivers etc.

I searched cyclists AND report

http://trid.trb.org/
The 3rd citation on the previous screen links us to the UK parliamentary report ....
Transport Committee - Third Report
Cycling Safety

Here you can browse the report together with the Proceedings of the Committee. The published report was ordered by the House of Commons to be printed 14 July 2014.

Contents

Terms of Reference
Summary
1 Introduction
2 How safe is cycling?
3 Cyclist safety measures
   20mph zones
   Education
   Cycle infrastructure

The full-text is available here:
http://www.publications.parliament.uk/pa/cm201415/cmselect/cmtran/286/286.pdf
The **Australian Institute of Criminology** is Australia’s national research and knowledge centre on crime and justice. “We seek to promote justice and reduce crime by undertaking and communicating evidence-based research to inform policy and practice.” It is built around a great searchable database.

There are a number of overlaps with health issues.

Areas of research included in AIC publications are mental illness, domestic violence, disability, child abuse and neglect, public safety and so on...

A specialised grey database on criminal justice which documents material on the many areas where law and health overlap.

Don M. Gottfredson Library of Criminal Justice **Gray Literature Database**

This database contains grey literature publications on all aspects of crime and criminal justice that are available online or in the Don M. Gottfredson Library of Criminal Justice. http://njlaw.rutgers.edu/cj/gray/index.php
Clearinghouses

- A clearinghouse aims to collect valuable information in a specific field and to make that information available to people and groups working in that field. As a central access point, a clearinghouse serves the needs of users of a specific body of knowledge.

- One of its functions is to prevent the duplication of effort by those users, by identifying, describing and evaluating information relevant to their knowledge area. Thus in some of its tasks, a clearinghouse is similar to a library, repository, or a warehouse in that it receives, organises and disseminates information.

Let's shift slightly to what are called Clearinghouses. In my mind the terminology gets quite confused. There's a lot of overlap especially as a well-organised clearinghouse generally includes a searchable database of resources. Though clearinghouses are aimed at a specific group of interested people, the end result is the same. Searching for clearinghouses that relate to a topic is a great idea, just remember, clearinghouse can be one word or two (clearing house)
I did a sample search in Google on: physiotherapy and clearinghouse and discovered this useful resource. Try playing around with your topics and see what you get.

Try “your topic” AND clearinghouse; “your topic” AND “clearing house”

Here are the results....
HUD’s mission is to “create strong, sustainable, inclusive communities and quality affordable homes for all. HUD is working to strengthen the housing market to bolster the economy and protect consumers; meet the need for quality affordable rental homes; utilize housing as a platform for improving quality of life; build inclusive and sustainable communities free from discrimination, and transform the way HUD does business.”

Along the bottom of the screen are some of the reports it makes freely available in its e-bookstore.

www.hud.gov
Australian Homelessness Clearinghouse has a great range of grey literature including conferences, reports, seminars, other data and data sets.

Closing the Gap Clearinghouse: “for research and evaluation evidence on what works to overcome indigenous disadvantage”

Australian Policy Online (APO) is also a clearinghouse, and an invaluable resource for health policy

Access the Health and wellbeing section ... or search across the whole content.

Forced Migration Online is a clearinghouse which has a digital library on all aspects of the topic, including health issues of refugees and asylum seekers.

www.forcedmigration.org/
We’ve already seen HealthInfoNet but I thought I’d show this resource which was launched a couple of months ago:

“The Australian Indigenous Alcohol and Other Drugs knowledge Centre is a web resource, funded by the Department of Health, which aims to provide the evidence base to reduce harmful substance use among Aboriginal and Torres Strait Islander peoples.”

www.aodknowledgecentre.net.au/
What we’ve covered so far ...

- Grey studies/trials, systematic reviews & dark data
- Guidelines
- Models, tools, frameworks
- Programs, projects & practices
- Registries of research output
- Theses/dissertations and conference papers
- Repositories
- Multiple contributions of Libraries
- Specialised databases, clearinghouses, knowledge centres

Next: Gateways, systems, networks...

Just recapping...
Social Science Research Network (SSRN) is devoted to the rapid worldwide dissemination of social science research and is composed of a number of specialized research networks in each of the social sciences.

Each of SSRN's networks encourages the early distribution of research results by publishing submitted abstracts and by soliciting abstracts of top quality research papers around the world.

The SSRN eLibrary consists of two parts: an Abstract Database containing abstracts on over 514,500 scholarly working papers and forthcoming papers and an Electronic Paper Collection currently containing over 420,800 downloadable full text documents in pdf format. A good source of grey literature across a broad range of topics as well as some published work.

This paper is not available for download via SSRN but a Google search locates a full-text copy in the Digital Commons Network, our next resource.
The Digital Commons Network brings together free, full-text scholarly articles from hundreds of universities and colleges worldwide. Curated by university librarians and their supporting institutions, the Network includes a growing collection of peer-reviewed journal articles, book chapters, dissertations, working papers, conference proceedings, and other original scholarly work. It is well organised, easy to use and well-supported.

http://network.bepress.com/
As you move the mouse across the wheel different colour-coded subject areas appear.

As you move to the outer edge of the circle the subject areas become more specific. I’ve arrived at Public Health and Community Nursing and clicked. At any time I can do a search across the entire content of the Commons in the search window (top right)
The contents of this subject area appear for browsing, with facets down the side of the screen for ways of filtering your search. This can be done by institution, by author and in this case by “featured publications”

I clicked on Evidence-based practice project reports....
And discovered a full-text 66 page report (unpublished) from a student enrolled in a Doctor of Nursing Practice, Valparaiso University (which is in Indiana)
OpenGrey, also known as SIGLE (System for Information on Grey Literature in Europe) is “your open access to 700,000 bibliographical references of grey literature (paper) produced in Europe and allows you to export records and locate the documents.”

http://www.opengrey.eu/
Search on dementia and caregivers .. shows a thesis with meta-analyses (eg. of unpublished studies). Searches can be refined by discipline, organisation, author, document type, year etc.
GreyNet International produces GreySource: a selection of web-based resources in grey literature.
http://www.greynet.org/greysourceindex.html
It has a fairly eclectic mix of resources ...
Where else?

- Organisations, associations, professional bodies & centres (including government, universities & libraries)
- Learning communities / Communities of practice
- Networks, discussions groups, forums, directories
- Individuals, experts, enthusiasts, contacts

Where else might you look?
Can you add to this list?
In my work with a researcher interested in “solid waste management” I searched for that exact phrase and “grey literature” on Google, and found this editorial in a published journal, in which the writer discussed with great enthusiasm, various sources of grey literature he knew about.
This led to some specialised collections and sites. Two things: Never underestimate the knowledge of an enthusiast. Never assume you’re the only person interested in a specific topic, no matter how obscure it might be.
I had a look for other examples and did a Google search on “petrol sniffing” and “grey literature”. This came up from the Lowitja institute with some useful points to share.

The authors say: “Once again we found that – while a limited amount of material had been published in refereed journals and other readily accessible sources – much of the potentially useful material was still confined to unpublished sources. We needed to repeat the earlier approach, contacting relevant organisations. By this time the Internet had become a far richer source of unpublished reports and evaluations. Electronic databases were searched, alongside Google and Google Scholar, using a range of terms such as ‘volatile substances’, ‘inhalants’, ‘petrol’, ‘gasoline’ and ‘solvents’. Websites for agencies which worked to prevent [volatile substance misuse] in various countries also proved useful. This enabled us to identify unpublished literature written by individuals and agencies outside our networks.”

In other (researchers’) words

- “Grey literature was identified through the expert knowledge of the authors who are active practitioners and academics in the field”
- “Grey literature was identified pragmatically from works known to researchers, reference lists and from relevant websites”
- “In addition, the names of organisations responsible for collating state and national level statistics were identified from several reports and the corresponding websites were located where possible. The list of databases and websites was complemented with suggestions by experienced librarians and experts in the field of drug dependence research.”

Some comments from researchers about the way they identified and located GL.....
What GL have others used?

• More and more research papers, journal articles and literature reviews (systematic & otherwise) are documenting their grey literature sources and search strategies.
• Remember creativity
• Search whole documents or preface/contents pages/index/appendices
• Many are still dark data (concealed)

And some ways in which you can use other people’s research to lead you to more resources.
We can use this Cochrane review on dementia and driver safety as a good example.
Locate the section where the search methods are documented. This will provide their search strategies and approaches as well as the resources they searched. Sometimes more details are listed in appendices.
This page continues on from the previous one and gives a detailed list of sources. This is where I learned about TRIS, a database we looked at earlier.
This APHCRI systematic review (itself grey) ....
**SEARCH STRATEGIES**

**Electronic Databases Searches**
The first stage of the search was conducted by a qualified librarian and involved scoping 14 black and 10 grey literature databases. The search covered published and unpublished articles from 1990 to February 2006. The primary and secondary key words used in the search are listed in Appendix 2.

### Table 1: Search Databases

<table>
<thead>
<tr>
<th>Black Literature Databases</th>
<th>Grey Literature Databases</th>
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<tr>
<td>- MEDLINE</td>
<td>- GreyNet</td>
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<td>- CINAHL</td>
<td>- SIGLE</td>
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<td>- Cochrane Database of Systematic Reviews</td>
<td>- WHOLIS</td>
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<td>InfoTrac</td>
<td>- GrayLit Network</td>
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<td>- Proquest 5000</td>
<td>- Partners in Information Access for Public Health University Libraries</td>
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<td>- Highwire Press</td>
<td>- Australian Collaboration for Health Equity Impact Assessment</td>
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<tr>
<td>- Proquest Education Complete</td>
<td>- Canadian Institute for Scientific and Technical Information</td>
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<td>- Science Direct</td>
<td>- Universal Availability of Publications UNESCO</td>
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<td>- Swetswise</td>
<td>- Canadian Health Research Database</td>
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<td>- Wiley InterScience</td>
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<td>- Expanded Academic ASAP</td>
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**Hand Searches**
In addition to the systematic scoping of literature through library databases, a hand search was done by a team of investigators to obtain relevant information referenced.

Shows us they have clearly outlined their methods in regard to searching grey literature.
Another APHRI systematic review …
Indexes their search strategy referring to both grey and black literature
‘Grey’ literature
A more pragmatic approach was required in the selection of grey literature. Relevant material was identified from works already known to the researchers, to the reference group, from references listed in the black literature and from searches of websites of government departments, workforce agencies, professional associations, universities and similar organisations. Where a model was known but little information could be found in the black literature (such as the ‘fly-in, fly-out female GP’ model), additional material was sourced from internet searches using key words relevant to the particular model.

A total of 59 items of grey literature were retrieved as full documents for ‘rural’ and 47 for ‘remote’. Of the ‘rural’ documents, 49 dealt with models of service delivery. A further eight contained context-relevant information and two did not meet the inclusion criteria. Of the 47 ‘remote’ documents, 19 met the inclusion criteria. These data were extracted onto the standard data extraction sheets (Appendix 4). For evaluation studies, an additional data extraction sheet to facilitate extraction of evaluation data was utilised (Appendix 5). The full list of documents reviewed follows the ‘Conclusion’ section of the report below.

And provides some nice detail of how they found what they found with the full list of documents made available elsewhere for consultation.
I think this slide sums up the way many of us feel about the information which cascades into our lives, and because of the nature of our professions, consumes our working lives. That’s why I want to spend the last few slides covering “data” - a vastly growing area of GL. So much data (unlike the results which are often written up for publication) remains unpublished due to format, size and so on.

Matt Quin http://www.tibco.com/blog/2013/09/18/all-data-is-more-valuable-than-big-data/
There have been lots of moves to collect, store and keep data safe for posterity, and for re-use.

“Research Data Australia is an Internet-based discovery service designed to provide rich connections between data, projects, researchers and institutions, and promote visibility of Australian research data collections in search engines.”

https://researchdata.ands.org.au/

You run a search in the window provided, or Browse by Subject Index

There is a brochure about ANDS here:
Browse Medical and Health Sciences and get 2087 hits. Here’s a good example of unpublished data. In this case there are access fees but remember the Nursing Collection we saw earlier: History of Nursing and Nursing Education Archives? It was free.

ANDS (Australian National Data Service) is responsible for Research Data Australia. It encourages the re-use of data to produce new research activity.
Sharing and re-use of data from ALSWH has led to almost 500 peer-reviewed papers across domains of clinical medicine, public health, and ageing research.

**The Australian Longitudinal Study on Women’s Health (ALSWH)** is a collaborative project of The University of Newcastle and The University of Queensland and has been funded by the Australian Government for almost two decades. Since 1995 over 50,000 women have been surveyed, most choosing to remain part of the study for many years. ALSWH collects information about changes in the mental, physical, and social health of everyday women and their families over time. It also gathers data about life events, employment, and health service use. This level of detail and longevity is rare and highly valuable on an international scale. ALSWH has enabled data users to produce a rich and accurate portrait of women’s health and the experiences that benefit or hinder their wellbeing.

If you haven’t heard of ALSWH, you’ve probably read a report, paper, or news article based on its data. You may even use a public service or program guided by its findings. Data from ALSWH has led to almost 500 peer-reviewed papers across domains of clinical medicine, public health, and ageing research. These include highly-cited studies that, for example, identify factors contributing to obesity in Australian women and demonstrate the link between increased physical activity and reduced symptoms of depression. ALSWH also contributes directly to national health policies by informing recommendations for services and programs for chronic health conditions (e.g., diabetes, interpersonal violence, cancer, addiction and...)

GRAPHC (re) uses"" location data, spatial analytic methodologies and online mapping to analyse, interpret and display information in ways that promote better understanding of primary health care and the forces that affect it.

The adoption of a geographic approach to primary health care research facilitates the development of the evidence base to inform locally relevant and equitable solutions for targeting health resources and services. The aim is to support community, health care service providers, academia, and policy makers to improve equity and access to health care services through better resource allocation. Powerful and flexible on-line web based mapping platforms to interrogate and analyse health related data.”

http://graphc.aphcri.anu.edu.au/about/about.html
Closely connected to research re-use is secondary data analysis.

“The biggest advantage of using secondary data is economics. Someone else has already collected the data, so the researcher does not have to devote money, time, energy, and other resources to this phase of research. Sometimes the secondary data set must be purchased, but the cost is almost always certainly lower than the expense of collecting a similar data set from scratch, which usually entails salaries, travel/transportation, etc. There is also a huge savings in time.”

http://sociology.about.com/od/Research-Methods/a/Secondary-Data-Analysis.htm
UK Data Archive

The UK's largest collection of digital research data in the social sciences and humanities

“We provide access to over 5,000 digital data collections for research and teaching covering an extensive range of key economic and social data resources”

http://www.data-archive.ac.uk/
I selected **Data by Theme: Health**, then scrolled do to a data set that looked interesting “Survey of carers in households”

http://discover.ukdataservice.ac.uk/
To get to this screen I clicked on Data Access at:
http://discover.ukdataservice.ac.uk/series/?sn=2000051

Then Explore Online:
Here are a few examples of Unpublished datasets – Health – Public Health, England.
Data.bib is an international directory of almost 1000 research data repositories. “Databib is a tool for helping people identify and locate online repositories of research data. Users and bibliographers create and curate records that describe data repositories that users can search.”

http://databib.org/index.php
An example of one of these data repositories I found is the Terrorism and Preparedness Data Resource Centre.

I searched incarceration AND health, with these results. Published and unpublished material is indexed.

http://www.icpsr.umich.edu/icpsrweb/TPDRC/
GL Appraisal

So many resources, so little time!

And once we’ve found them, we need to decide if we can use them. While each (re)searcher has their own inclusion criteria, there are some ways to appraise grey literature.

Generally use the same appraisal tools (like CONSORT) as for published equivalents if they exist, then find out about tools like PEMAT developed to appraise specific types of material. AACODS was designed to appraise all types of GL.
Here is the CONSORT checklist for appraising RCTs

http://www.consort-statement.org/
Here is PEMAT (Patient Education Materials Assessment Tool) developed by the Agency for Healthcare Research and Quality (AHRQ)

“Patient educational materials, such as brochures, medical instructions, and audiovisual aids, are often complex and lack clear information about what the patient is supposed to do. AHRQ’s “PEMAT and User’s Guide provides a systematic method to evaluate and compare the understandability and actionability of patient education materials. By selecting health materials that score better on the PEMAT, you can be more confident that people of varying levels of health literacy will be able to process and explain key messages, and identify what they can do based on the information presented.”

www.ahrq.gov/pemat/
UKHF (UK Health Forum) have recently started producing the **Prevention Information & Evidence (P.I.E)**, an e-Library and weekly briefing service.

The PIE Library is updated daily and contains content on environment and public health, including fuel poverty and air quality and chronic disease risk factors including obesity, nutrition and physical activity.

(Inset comment from the Chartered Institute of Information and Library Professionals re UKHF decision to use AACODS for appraisal: it’s main appeal is that it is “format agnostic”)

http://www.ukhealthforum.org.uk/prevention/pie/Comment
GL is everywhere and anywhere, with no easy answers or magical, definitive list of sources. Individual researchers need to construct their own portfolios of databases, knowledge networks, clearinghouses, organisations, experts and resources.

It’s much more challenging for librarians. We have a crucial role in bringing Grey literature into focus when working with clinicians, practitioners and researchers. We need to have a much broader awareness of what is available so we can contribute to all the different topics and approaches that come to us on a daily basis.

This presentation is an attempt to bring some sort of shape and structure to the mix.
PS and FYI:
Here’s a guide I produce once or twice a year (Databases for Research in Health) which includes both black and grey literature. Websites are only included if they have strong content and the component that relates to materials, resources or data is arranged in such a way that it can be usefully interrogated by the researcher. My definition of a database is a collection of information that is organised so that it can easily be accessed, managed, and updated. The resources I have selected for inclusion meets these criteria, although they may not always immediately be seen as databases in the traditional sense. Thanks to my colleague Catherine Brady it now has a handy subject index.
Thank you
Questions?
Feedback, comments welcome

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Thanks very much – comments, questions, feedback all welcome.