Supporting health research proposals; a day in the life of an NIHR Research Design Service information specialist

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Can I check if it’s been done before?

https://www.flickr.com/photos/kstatelibraries/3151830414/in/photostream/ accessed 01-09-16 (CC BY-NC-SA 2.0)
Session overview

- Research competitions, research waste and literature searches
- NIHR Research Design Service, RDS Information Specialists
- Type of information services provided
- Search methods, sources and strategies
- Costing a librarian into a research project
- How can you support research proposals?
• Winning research grants is increasingly competitive (1)
  – 2014-15 applications to Research Councils UK (RCUK) grew 12% on previous year
  – RCUK success rate just under 28% in 2014-15
  – 22% for MRC

Completing applications is very time consuming 😞

‘Research Waste Agenda’ – growing awareness and attempts to reduce unfundable, poor quality proposals
Avoiding Research Waste – a brief history

- 85% biomedical research funding unnecessarily wasted \(^{(2)}\)

- ‘the principle that the initiation of research without a systematic review of already known evidence is unethical, unscientific & wasteful.’ \(^{(3)}\)

- 2014 Lancet series ‘Biomedical research: increasing value, reducing waste’. 5 reviews lead to 17 recommendations e.g. improved publishing, reporting, research design.

- 2015 progress update \(^{(3)}\)

- Recommendation 3 - Librarians can help 😊
Recommendation 3 – What do we already know?

- “Research funders and regulators should demand that proposals for additional primary research are justified by systematic reviews, showing what is already known, and increase funding for the synthesis of existing evidence” (3)

NIHR and DFG (German funder) require references to existing systematic reviews and review of relevant evidence including ongoing research in research applications.

NIH (US), CIHR (Canada), NHMRC (Australia), MRC (UK) do not (yet…)
“To increase the number and proportion of high quality applications for funding …”

“of clear relevance to NHS services, clinicians and users”

http://www.rds.nihr.ac.uk/
Research Design Service (RDS)
Expertise

• “Each RDS must at its core have access to methodological expertise”
  • Research methodology
  • Health economics
  • Statistics
  • Systematic reviews
  • Health psychology and behavioural science

• “Must also be able to draw on other expertise as necessary or provide advice and guidance on all aspects of research design and conduct”
RDS – Improving Research Proposals

• Promoting the services available to support researchers in the NHS

• Increasing engagement with NHS staff, developing ‘balanced’ research team

• Research funding awareness events, tips for applicants

• Face-to-face advice clinics
NIHR RDS Information Specialists
Preliminary survey results

• Often part of their wider role as Information Specialist in a University research department (e.g. few hours per week funded by NIHR RDS)

• Available in North East, Yorkshire, E Midlands, W Midlands. East of England? South West?

• In other regions, the researchers and other advisors do searches

• Time per enquiry ranges from few hours to several days. ½ day -1 day seems to be usual

• Variation in funding, time spent and type of services offered across the regions

• No formal national communication but informal networks
E.g.s of Information advice work (from ongoing RDS survey)

• Literature searches:
  – Current research checks
  – Scoping literature searches
  – Systematic review searches

• Other advice
  – Checking references, putting references in EndNote
  – Document acquisition
  – Commenting on proposal as a whole
  – Signposting to other RDS advisors and possible collaborators
  – Training in systematic review methods
  – Who might fund this?
  – How much would it cost to include Librarians in the research project?
Dr Ken has a research idea to demonstrate that a questionnaire is particularly good for GPs to diagnosing dementia.

Contact RDS
Explains research idea and plans on RDS online form

Meet RDS Advisor
Discusses
What is known already about dementia diagnosis
How viable plans are
Possible funders and collaborators

Contact Info Specialist
Plan searches to check:
Evidence base
Research recommendations
Ongoing research
Choosing sources for proposal searches

- Research recommendations
  - James Lind Alliance top 10 (DUETs no longer maintained)
  - Systematic Review and journal paper recommendations

- Ongoing and recent research databases

- Overviews of evidence – systematic reviews and summaries

- Prioritise databases, choose most important 1-3 for your question.
  - Eg. PsycInfo for Mental Health may take priority over Medline
Search methods - Strategies

- Quick searches (not exhaustive) – using clinical queries and filters…
  - simple, concept searches
  - targeted searches – using MeSH, focussed terms, title searches
  - Use ready made filters, clinical queries e.g. Clinical Trial publication type for Therapy studies, or clinical queries searches.

- Look in a few key databases
Research Recommendations

- Top 10s of priorities for research
  http://www.jla.nihr.ac.uk/top-10-priorities/

- Funder’s ‘Special Calls’ e.g. Obesity
- Systematic reviews may recommend further research
Dementia Top 10

1. What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?

2. How can the best ways to care for people with dementia, including results from research findings, be effectively disseminated and implemented into care practice?

3. What is the impact of an early diagnosis of dementia and how can primary care support a more effective route to diagnosis?

Particular questions were raised about the impact of early diagnosis on:

- Health-related outcomes for people with dementia and their carers (including impact on the progression of the disease and life expectancy, mental health, quality of life, attitudes of healthcare professionals to treatment for people with dementia, and on outcomes for carers, including quality of life and mental health).
- Wider outcomes in society for people with dementia and carers/family (including financial planning, insurance issues, employment prospects, independence, access to other healthcare services, driving).
- Health and social care services.

Particular questions about more effective routes to diagnosis in primary care included:

- Routes to faster referral to specialists, where appropriate.
- The best way to communicate a diagnosis of dementia, including who is the best person to communicate the diagnosis and where it should be delivered; how best to involve relatives and carers taking confidentiality into account.
- The psychological impact of a diagnosis of dementia on the person and carers.

4. What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with dementia?
Researcher should at least Google!

Google search for "early diagnosis for dementia in primary care"

About 540,000 results (0.67 seconds)

Scholarly articles for early diagnosis for dementia in primary care

Dementia: timely diagnosis and early intervention | The BMJ
www.bmj.com/content/350/bmj.h3029
by L Robinson - 2015 - Cited by 12 - Related articles
16 Jun 2015 - Primary and secondary care doctors play complementary roles in dementia diagnosis; differential diagnoses include cognitive impairment due ...

Dementia: diagnosis and early Intervention in primary care
www.rcgp.org.uk/.../Dementia/CIRC_RCGP%20Fact Sheet%20Dementia%20diagnosis...
by A Thomas - Related articles
Dementia: diagnosis and early intervention in primary care. Key learning points. Dementia is an increasingly important public health issue, due to our rapidly ...

The benefits of early diagnosis and intervention - Alzheimer's Disease
Service provision for dementia diagnosis and early stage care 16. Is diagnosis feasible in primary care? 16. Screening to facilitate identification of dementia in ...

The benefits of early diagnosis and intervention
Service provision for dementia diagnosis and early stage care – a global .... practice-based educational programs in primary care, b) the introduction of ...

Primary care and dementia - Alzheimer's Society
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=306...
While much emphasis has been placed on the role of primary care in early detection and diagnosis of dementia, its role in regular assessment, support and ...
• Cochrane Library
• NHS Evidence
• other databases with SR filter e.g. PsycInfo for Mental Health.
Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review

01 July 2010 - Publisher: Springer

Abstract: Background: The diagnosis of dementia in primary care is perceived as a problem across countries and systems, resulting in delayed recognition and adverse outcomes for patients and their carers. Improving its early detection is an area identified for

Read Summary - Remove: Systematic Reviews filter

World Alzheimer report 2011: the benefits of early diagnosis and intervention [PDF]

12 September 2011 - Publisher: Alzheimer's Disease International

This report shows that there are interventions that are effective in the early stages of dementia, some of which may be more effective when started earlier, and that there is a strong economic argument in favour of earlier diagnosis and timely intervention.

Read Summary - Remove: Evidence Summaries filter

Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) for the diagnosis of dementia within a general practice (primary care) setting

Source: Cochrane Database of Systematic Reviews - 03 July 2014

...particular utility in primary care / general...against a clinical diagnosis of dementia (the reference...ALOIS/Cochrane Dementia and Cognitive Improvement...cognitive screening and dementia. We used standardized...increasing globally. Early diagnosis of dementia...

Remove: Systematic Reviews filter

The accuracy of family physicians' dementia diagnoses at different stages of dementia: a systematic review

Source: SCIE Social Care Online - 01 January 2012

...physicians' dementia diagnoses at different stages of dementia: a systematic...recognition and diagnosis of dementia are critical if...importance of early diagnosis, the...different stages of dementia in a primary care setting...

Read Summary - Remove: Systematic Reviews filter
Ovid Embase
Proposal Reviews Search

Additional limits & clinical queries – useful shortcuts

Focused headings (sometimes), title searches, simple searches
Ongoing trials registers
- ClinicalTrials.gov
- ICTRP International Clinical Trials Registry Platform (WHO)
- Medline-in-Process, Daily update… (Ovid)

PubMed

PROSPERO – International Prospective Register of Systematic Reviews

Funding body web pages e.g NIHR Evaluation Trials and Studies Portfolio Search
Advanced Search

Fill in any or all of the fields below. Click on the label to the left of each search field for more information or read the Help.

Search Terms:

Recruitment:
- All Studies
- Active, not recruiting
- Recruiting
- Expanded Access: Available

Study Type:
- All Studies
- Open Studies
- Not yet recruiting
- Recruiting
- Expanded Access: Available

Eligibility Criteria:
- Closed Studies
- Active, not recruiting
- Terminated
- Terminated
- Suspended
- Withdrawn
- Enrolling by invitation
- Expanded Access: Temporarily not available
- Expanded Access: No longer available
- Expanded Access: Approved for marketing

Targeted Search:

Conditions: dementia OR alzheimers

Interventions:

Title Acronym/Titles: early diagnosis

Outcome Measures:

Sponsor/Collaborators:

Sponsor (Lead):

Study IDs:

Locations:

State 1: Optional
Country 1: Optional
State 2: Optional
Country 2: Optional
State 3: Optional
Country 3: Optional
<table>
<thead>
<tr>
<th>Rank</th>
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<tbody>
<tr>
<td>1</td>
<td>Terminated</td>
<td>Early Diagnosis of Alzheimer-like Dementia: Benefit of MRI and PET Imaging</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conditions: Alzheimer Disease; Mild Cognitive Impairment; vascular Dementia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interventions: Other: Magnetic resonance imaging; Other: Positron emission tomography</td>
</tr>
<tr>
<td>2</td>
<td>Recruiting</td>
<td>Early Diagnosis of Alzheimer's Disease - A Multidisciplinary Approach</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conditions: Mild Cognitive Impairment; Alzheimer's Disease; Dementia With Lewy Bodies; Vascular Dementia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interventions:</td>
</tr>
<tr>
<td>3</td>
<td>Recruiting</td>
<td>Korean Brain Aging Study for Early Diagnosis and Prediction of Alzheimer's Disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conditions: Alzheimer's Disease; Mild Cognitive Impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interventions:</td>
</tr>
<tr>
<td>4</td>
<td>Active, not recruiting</td>
<td>Vagus Somatosensory Evoked Potentials and Near-Infrared Spectroscopy in the Early Diagnosis of Dementia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conditions: Alzheimer's Disease</td>
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<tr>
<td></td>
<td></td>
<td>Interventions:</td>
</tr>
<tr>
<td>5</td>
<td>Completed</td>
<td>Early Diagnosis of Alzheimer's Disease: Clinical, Neuropsychological and Neuroimaging Follow-up of a Cohort of Patients With an Isolated Memory Impairment</td>
</tr>
<tr>
<td></td>
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<td>Conditions: Alzheimer's Disease</td>
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<td></td>
<td></td>
<td>Interventions: Other: Neurological and neuropsychological consultation, MRI; Other: Neurological and neuropsychological consultation, MRI, Studies in imaging of dop, DNA</td>
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<tr>
<td>6</td>
<td>Recruiting</td>
<td>Developing a New EEG Method for the Early Diagnosis of Dementia</td>
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<tr>
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<td></td>
<td>Conditions: Dementia</td>
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</table>

Modify this search | How to Use Search Results

Include only open studies | Exclude studies with Unknown status

Show Display Options

Download | Subscribe to RSS
<table>
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<th>#</th>
<th>Searches</th>
<th>Results</th>
<th>Type</th>
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<tr>
<td>1</td>
<td>exp *dementia/</td>
<td>111920</td>
<td>Advanced</td>
</tr>
<tr>
<td>2</td>
<td>(dementia or alzheimer*).ti.</td>
<td>87631</td>
<td>Advanced</td>
</tr>
<tr>
<td>3</td>
<td>1 or 2 [Dementia]</td>
<td>125049</td>
<td>Advanced</td>
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<td>4</td>
<td>early diagnosis/</td>
<td>20117</td>
<td>Advanced</td>
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<td>5</td>
<td>((early or earlier) adj3 (diagnos* or identif* or test or tests)).ti.</td>
<td>18534</td>
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<tr>
<td>6</td>
<td>4 or 5 [Early Diagnosis]</td>
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<td>7</td>
<td>exp *primary health care/</td>
<td>71414</td>
<td>Advanced</td>
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<tr>
<td>8</td>
<td>*general practice/</td>
<td>8025</td>
<td>Advanced</td>
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<td>9</td>
<td>*general practitioner/</td>
<td>4021</td>
<td>Advanced</td>
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<td>10</td>
<td>(primary or gp or &quot;general practi**&quot; or &quot;family practi**&quot;).ti.</td>
<td>299398</td>
<td>Advanced</td>
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<tr>
<td>11</td>
<td>or7-10 [Primary Care]</td>
<td>347320</td>
<td>Advanced</td>
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<td>12</td>
<td>3 and 6 and 11</td>
<td>51</td>
<td>Advanced</td>
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<td>13</td>
<td>limit 12 to yr=&quot;2010 -Current&quot;</td>
<td>28</td>
<td>Advanced</td>
</tr>
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</table>
Click to show your search history and hide search results. Remember you can use the quick search page instead.

Search: (dementia or alzheimers) and "early diagnosis"

The default is to search the whole of PROSPERO without restriction. Change how PROSPERO is searched by clicking Show Filters button then editing the sections to add one or more search filters. All filters you select will be applied to the next search you perform and will stay in place until you change them.

6 records found for (dementia or alzheimers) and "early diagnosis"

<table>
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<tr>
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<th>Title</th>
<th>Review status</th>
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<tr>
<td>23/08/2016</td>
<td>18F-PET ligands for the early diagnosis of Alzheimer's disease dementia and other dementias in people with mild cognitive impairment (MCI) [Cochrane Protocol]</td>
<td>Ongoing</td>
</tr>
<tr>
<td>18/08/2015</td>
<td>Automated tests for cognitive impairment</td>
<td>Ongoing</td>
</tr>
<tr>
<td>06/01/2015</td>
<td>Individual and group psychotherapy with people affected by dementia</td>
<td>Ongoing</td>
</tr>
<tr>
<td>22/05/2015</td>
<td>Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) for the early diagnosis of dementia across a variety of healthcare settings [Cochrane Protocol]</td>
<td>Ongoing</td>
</tr>
<tr>
<td>30/10/2015</td>
<td>Multi-disciplinary team approaches to screening and early diagnosis of dementia in primary care - costs and consequences</td>
<td>Ongoing</td>
</tr>
<tr>
<td>04/06/2013</td>
<td>Observational assessments of task performance in complex everyday activities to estimate functional cognition in older adults: a systematic review and evaluation of measurement properties</td>
<td>Ongoing</td>
</tr>
</tbody>
</table>
Evaluation, Trials and Studies

Search our portfolio of projects

Search terms: Dementia early diagnosis

Advanced Search [+] Browse projects

Results for: Dementia early diagnosis

Filter by project status:
- All statuses
- Waiting to start
- Research in progress
- Waiting to publish
- Project complete

Recent portfolio projects

Number of projects: 7

**HS&DR Project: 14/70/96**

*Project title:* Dementia undetected or undiagnosed in primary care: the prevalence, causes and consequences

*Chief Investigator:* Dr George Savva
*Organisation:* South Norfolk CCG
*Status:* Research in progress

**HTA Project: 14/140/80**

*Project title:* Journeying through dementia; randomised controlled trial of clinical and cost effectiveness

*Chief Investigator:* Professor Gail Mountain
*Organisation:* Sheffield Health & Social Care NHS Foundation Trust
*Status:* Research in progress
Example Query @ Leeds RDS
Dr Ken refines the question

**Searches show**
- Range of current tools and techniques are in use and being researched around the world
- ‘Early’ diagnosis is a research priority
- Outcomes of early diagnosis is under-researched
- GPs and patients play a role in success of tools and techniques for diagnosis

**Follow-up RDS meeting**
- Dr Ken discusses lit search results with RDS team.
- Research question may be modified in light of evidence

**Improved proposal**
- Dr Ken’ proposal: Has relevant up to date references
- Demonstrates good knowledge of the research area
- Provides robust rationale for the research
Costing a librarian into a research project

- Ask to see proposal even if its ‘very draft’

- Scoping & draft searches help to get idea of size of searches, complexity (do search concepts have MeSH that fit well?)

- Manage expectations, offer alternatives, negotiate
Adding it all up

• Cost the time requirements based on
  – Expertise and salary of the searcher
  – Number of databases
  – Complexity of searches
  – Likely duplication / reference management
  – If document acquisition is required
  – Writing search methods
  – Update searches
  – Time in meetings

• Remember any travel, consumables, Inter-library loan costs

• Add 10%? Always takes longer than you think

* https://www.flickr.com/photos/felixidan/2162733310 (CC BY-NC-ND 2.0)
How can you support research proposals?

• Refer your researchers to the RDS service*
  
http://www.rds.nihr.ac.uk/

• If capacity, undertake some proposal searches

• Advise researchers on starting their own searches

• Check that research idea really is novel
  
http://youtu.be/WLmhNNdYntQ (Claire Beecroft, ScHARR)

*NHS & academics are eligible if applying for national funded schemes
Benefits of proposal work

• Interesting

• Widen your network of contacts, greater engagement

• May lead to funded project work for Info team

• Develop your own skills in grant applications

• Reduces waste and improves value of research
Conclusions & Issues

• Growing potential/obligation to help tackle research waste
• Low profile of librarians in supporting research proposals?

• How to measure impact of proposal work?
  – # successful proposals?
  – amount of proposal work prevented by identifying when a researcher is attempting duplicate or unviable research?

• Greater sharing of search methods and evaluation of methods will improve our best practice.

• Next…co-authoring paper for Supporting Researchers special issue of the New Review of Academic Librarianship (Mary Edmunds Otter RDS E Mids)
Acknowledgements

- Natalie King (RDSYH) and Mary Edmunds Otter (RDS E Mids) – RDS Information Specialist survey
- Claire Beecroft (ScHARR) - RDS Scoping Search training materials
- RDS Information Specialists and Advisors providing supporting information and survey results

- Emoji provided free by http://emojione.com
- Vector images by https://Pixabay.com
1. Matthews D. Success rates: surge in application to ‘struggling research councils’. Times Higher Education Supplement. 29th October 2015


Links

- NIHR Research Design Service  [http://www.rds.nihr.ac.uk/](http://www.rds.nihr.ac.uk/)
- Top 10s of priorities for research  [http://www.jla.nihr.ac.uk/top-10-priorities/](http://www.jla.nihr.ac.uk/top-10-priorities/)
- ClinicalTrials.gov  [https://clinicaltrials.gov/](https://clinicaltrials.gov/)
- International Clinical Trials Registry Platform (WHO)  [http://www.who.int/ictrp/en/](http://www.who.int/ictrp/en/)
- PROSPERO  [http://www.crd.york.ac.uk/PROSPERO/searchadvanced.php](http://www.crd.york.ac.uk/PROSPERO/searchadvanced.php)
- NIHR Evaluation Trials and Studies  [http://www.nets.nihr.ac.uk/](http://www.nets.nihr.ac.uk/)
- Check that research idea really is novel  [http://youtu.be/WLmhNNdYntQ](http://youtu.be/WLmhNNdYntQ) (Claire Beecroft, ScHARR)