Developing Plain language Summaries for Diagnostic Test Accuracy (DTA) reviews

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Collaboration for Leadership in Applied Health Research and Care West
What is a plain language summary?

MECIR Standard

Prepare a summary of the review containing all the crucial information in plain language that will be understood by the general public.
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Challenges for DTA PLS

Methodology less familiar
Paired accuracy measures
Accuracy measures poorly understood
Large degree of heterogeneity
Quality difficult to communicate
Potentially larger target audience than PLS
Focus group 1: Consumers (n=8)  
PLS 0.1

Focus group 2: Journalists (n=9)  
PLS 0.2

Focus group 3: Clinicians (n=2)  
PLS 0.2

One-on-one  
User testing  
PLS 0.3

Web-based survey:  
Multiple rounds  
PLS 0.3-0.?

PLS template and guidance  
PLS 1.0
Starting point: Evidence

<table>
<thead>
<tr>
<th>In-service training for healthcare professionals to improve care for severely ill newborns and children in low-income countries</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is the aim of this review?</strong></td>
</tr>
<tr>
<td>The aim of this Cochrane review was to find out whether additional emergency care training programs could improve the survival of infants and children who are admitted to hospitals. The review was conducted by the Cochrane Collaboration and is aimed at determining whether training programs could be effective in improving outcomes for these vulnerable groups.</td>
</tr>
</tbody>
</table>

| **What is the evidence for?** |
| The evidence for this review was based on a systematic search of the literature for randomized controlled trials (RCTs) and other types of studies that compared different training programs with no training or with other training programs. The evidence shows that training programs can lead to improvements in survival and other measures of healthcare outcomes. |

| **What was studied in the review?** |
| In general, the studies were focused on healthcare professionals, including doctors, nurses, and midwives, who work in settings where there is limited access to healthcare services. The interventions included in the review were targeted at improving the skills of these professionals so that they could provide effective care for severely ill newborns and children. |

| **What was the main result of the review?** |
| There were some limitations to the studies included in the review, such as small sample sizes and variations in the quality of the interventions. However, the overall conclusion was that training programs could lead to improvements in survival and other measures of healthcare outcomes. |

| **Interpretation** |
| The results of this review suggest that training programs can be effective in improving outcomes for severely ill newborns and children in low-income countries. However, more research is needed to determine the ideal training programs and the most effective ways to implement them. |

| **Conclusion** |
| The review findings indicate that training programs can lead to improvements in survival and other measures of healthcare outcomes. However, more research is needed to identify the most effective training programs and to ensure that they are implemented in a way that is sustainable and replicable. |

| **BMJ Open** |
| How to improve health outcomes for newborns and children? A systematic review of interventions. |

| **Introduction** |
| The survival of infants and children who are admitted to hospitals is a crucial outcome for healthcare systems. The aim of this review was to identify interventions that could improve outcomes for severely ill newborns and children. |

| **Methods** |
| The review was conducted using a systematic search of the literature for randomized controlled trials (RCTs) and other types of studies that compared different training programs with no training or with other training programs. The evidence shows that training programs can lead to improvements in survival and other measures of healthcare outcomes. |

| **Results** |
| The review identified several interventions that could be effective in improving outcomes for severely ill newborns and children. These interventions included training programs that were targeted at improving the skills of healthcare professionals. |

| **Discussion** |
| The results of this review suggest that training programs can be effective in improving outcomes for severely ill newborns and children in low-income countries. However, more research is needed to identify the most effective training programs and to ensure that they are implemented in a way that is sustainable and replicable. |

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Focus groups: PLS version 0.1

The aim of this Cochrane review was to find and appraise evidence for the diagnosis and management of childhood non-tuberculous mycobacterial (NTM) disease, especially in low-income and middle-income countries. The results were presented at a WHO Global Conference on Tuberculosis (TB) in 2014.

Among the key findings:

- NTM is a major public health problem, affecting millions of people worldwide.
- NTM can cause a variety of infections, including skin, lung, and bone infections.
- Diagnosis can be challenging, often requiring a combination of culture, radiology, and clinical findings.
- Treatment options vary depending on the site of infection, with medications such as clarithromycin and ciprofloxacin commonly used.
- Prognosis can vary significantly, with some patients experiencing spontaneous remissions.
- Research is ongoing to improve diagnostic accuracy and treatment efficacy.

The review was published in PLoS Medicine in 2016.
The IQCODE had a sensitivity of 95%, this means that most people with dementia would be identified by the IQCODE. It had a specificity of 89% meaning that 11% of those without dementia would also have a positive result.

Option 2
Using the IQCODE for diagnosing dementia in the general hospital setting:
- Of every 1000 people tested using the IQCODE, an estimated 612 will have a negative result and of these 13 will actually have dementia.
- Of the 388 people with a positive IQCODE result, 141 will be incorrectly classified as having dementia.

Option 4
The IQCODE can help in 'ruling out' dementia in the general hospital setting. This means that if a person has a low IQCODE score, they are unlikely to have dementia. Yet if a person has a high score, that person does not necessarily have dementia.
Focus group: Topic guide

What is your overall feeling?

Are there sections of the document that you like? Any sections that you don’t like?

Looking at the two PLSs side by side, how do they compare?

What are your first impressions of the 4 [results] presentation options?
Risk of Bias

So to say that, “We decided they had a low risk of bias,” if you’ve got no idea what it means, there’s no point in having it in there.

I assumed that that sort of implied that the studies aren’t done by drug companies or aren’t funded by them in some way, but I wasn’t really – but I don’t really know.
I think there are often cases where a positive result is actually bad news, so the word ‘positive’ is questionable.

If I had a test result and was 89% something, is that good or is that bad? There’s no context to explain.

Yeah, you could use the 95% and the 11% on their own…. Without saying ‘specificity and sensitivity’ at all.
Changes made to PLS based on us groups

Made text short and concise
Removed reference to how “good” the test is
Removed section on “summary of findings”
Introduced downstream consequence of test early on (new heading) and to the flow diagram
Restructured flow diagram to go from left to right
Using the IQCODE questionnaire at detecting dementia in people with memory problems in hospital?


Introduction

The aim of this review was to find out how accurate a questionnaire-based assessment for the IQCODE, is for detecting dementia in different hospital settings. These include memory clinics, old-age psychiatry units, general hospital clinics and wards, and older people’s facilities. Researchers in the Cochrane Collaboration collected and analysed all relevant studies and found thirteen studies.

The diagnosis of people who may have dementia is a health and social care priority. Missing a diagnosis means opportunities for early help such as support for patients and carers are lost. Incorrectly making a diagnosis of dementia may result in anxiety and stress as sources because of unnecessary further investigation and treatment.

In the review?

Tests that can help identify people with memory and thinking problems that suggest dementia are sometimes used in hospital settings. There is no agreement on which tests are best.

A simple questionnaire designed to diagnose dementia. There are two versions, a “long” version 26 questions and a “short” version that includes 16 questions. Both are completed by a person close to the person being assessed for dementia. Each question assesses a person’s ability to perform certain everyday tasks has changed. Questions are rated from “has become much better” to 5 “has become much worse”. Dementia is more likely with higher scores.

The figure below shows the expected results in a group of 1000 patients tested for dementia using the IQCODE:

The IQCODE produced more false positive and false negative results (more people in the “oval boxes”) in specialist memory clinics and psychiatry wards than in general hospital clinics and wards. There was no difference in results between long and short versions of the IQCODE or for languages other than English (similar numbers in each box above).

How up-to-date is this review?

The review authors searched for and used studies that had been published up to January 2013.
Per testing

Clinician

Commissioner

Cochrane author

Clinician

Journalist

Clinician

Patient representative
Survey round 1

Targeted dissemination

Broad dissemination

Currently 58 responses
The IQCODE questionnaire at detecting dementia in people with memory problems in hospital?


Of this review?

The Cochrane review was to find out how accurate a questionnaire-based assessment for the IQCODE, is for detecting dementia in different hospital settings. These include clinics, old-age psychiatry units, general hospital clinics and wards, and other people's referrals. Researchers in the Cochrane Collaboration collected and analysed all relevant studies relating to the question and found thirteen studies.

Is dementia important?

Diagnosis of people who may have dementia is a health and social care priority. Missing a diagnosis means opportunities for early help such as support for patients and carers or drug treatment may be lost. Incorrectly making a diagnosis of dementia may result in anxiety and stress as well as unnecessary further investigation and treatment.

What is in the review?

Tests that can help identify people with memory and thinking problems that suggest dementia. There is no agreement on which tests are best.

A simple questionnaire designed to diagnose dementia. There are two versions, a “long” version supplied by somebody close to the person being assessed for dementia. Each includes 26 questions and a “short” version that includes 16 questions. Both are completed by a person’s ability to perform certain everyday tasks has changed. Questions are rated from 1 “not more difficult” to 5 “has become much worse”. Dementia is more likely with higher scores.

The figure below shows the expected results in a group of 1000 patients tested for dementia using the IQCODE:

- Hypothetical cohort: IQCODE result
- Actual diagnosis
- Consequence

<table>
<thead>
<tr>
<th>IQCODE indicates dementia not present</th>
<th>IQCODE indicates dementia present</th>
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<tbody>
<tr>
<td>1000 people tested for dementia using the IQCODE</td>
<td>1000 people tested for dementia using the IQCODE</td>
</tr>
<tr>
<td>975 Dementia (55)</td>
<td>475 Dementia (55)</td>
</tr>
<tr>
<td>Miss early intervention &amp; support</td>
<td>Appropriate intervention</td>
</tr>
<tr>
<td>Anxiety, stress, wasted resources</td>
<td>No intervention, consider other diagnoses</td>
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(a) true negative: test is negative (indicates dementia not present) and patient does not have dementia; (b) true positive: test positive (indicates dementia) and patient has dementia; (c) false positive: test a positive but patient does not have dementia; (d) false negative: test a negative but patient does have dementia.

The IQCODE produced more false positive and false negative results (more people in the “oval boxes”) in specialist memory clinics and psychiatry wards than in general hospital clinics and wards. There was no difference in results between long and short versions of the IQCODE or for languages other than English (similar numbers in each box above).

How up-to-date is this review?

The review authors searched for and used studies that had been published up to January 2013.
Stewart NIHR:

Important to ensure that in the future that everyone can understand what is being said and explained about the treatments

The Mental Elf added, "Important work. Please take part in the survey if you can. The Mental Elf added, about Science @senseaboutsci improve plain language summaries! Researchers would love your feedback: http://bit.ly/29i82St @cochrane_collab dementia"
I like the layout of the summary

Strongly Agree
Agree
Neutral
Disagree
Strongly Disagree
How should additional information be included?

In the main text of the summary?
As footnotes
As hyperlinks to the main Cochrane review
IQCODE indicates dementia not present: 470

445 no dementia (tn)
- No intervention, consider other diagnoses

25 Dementia (fn)
- Miss early intervention & support

IQCODE indicates dementia: 530

475 Dementia (tp)
- Appropriate intervention

55 no dementia (fp)
- Anxiety, stress, wasted resources
Conclusion of "consequences" in the diagram helps understand the results

Strongly Agree 48%
Agree 38%
Neutral 5%
Disagree 0%
Strongly Disagree 10%
The following would improve the diagram:

- Use of colour
- Going from top to bottom instead of left to right
- Inclusion of %
- Inclusion of tp, fn, tn, fn
- Smiley face next to good consequence, sad face next to bad consequence
The diagram is a good way of summarising the results of the review.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
Challenges for DTA PLS

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Accuracy measures poorly understood
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Further challenges

Should we try and incorporate confidence intervals?

What to do with reviews that include multiple index tests?
Next steps

Please fill in our survey:
– https://sscm.onlinesurveys.ac.uk/cochrane-pls

Future rounds of survey
Development of final version of PLS with accompany guidance
Launch at Cochrane, October 2016
thank you!

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