Informed Health Choices Newsletter

March 2019

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Updates

The IHC project



The IHC team, May 2015

The Informed Health Choices (IHC) project started in January 2013 with a 5year grant from the Research Council of Norway. The aim of the project is to enable people to think critically about health claims and choices. The first step in the project was to develop a list of Key Concepts that people need to understand and apply when claims about the effects of treatments (and other interventions) are made, and when they make health choices. We then developed a database of multiplechoice questions to assess an individual's ability to apply the IHC Key Concepts. We designed and user-tested learningresources to enable primary school children and their parents to understand and apply some of the Key Concepts. Finally, we evaluated the learning resources in randomised trials.

<u>Elsewhere in this newsletter</u> we report on the process evaluations and one year follow-up studies of the IHC primary school resources and the podcast. Those findings further support the importance of encouraging critical thinking early. Starting with primary school children provides a foundation for future learning, as well as being immediately relevant. It is possible to teach critical thinking to primary school children and children who are explicitly taught these skills do better than those who are not. Young people and adults have increasing demands on their time and it becomes increasingly difficult to teach them to think critically about treatment claims if they lack a foundation. They have less time to learn and must learn more at once. Moreover, because misconceptions, attitudes and behaviours developed during childhood may be resistant to change later, as children grow older, it is important to encourage critical thinking early.



For these reasons, our main focus continues to be on school children. Much of what is reported in this newsletter builds on the IHC primary school resources. This includes translation of those resources to Euskara, Croatian, French, Farsi, Italian, Kiswahili, Kinyarwanda, Norwegian, and Spanish. It also includes testing the resources in other countries with plans to contextualise them, including Ireland and South Africa,

as well as countries where the resources are translated. This work is reported below under IHC around the world. Evaluation tools using multiple-choice questions from the Claim Evaluation Tools Database are also being validated in other countries and translated to other languages, including Chinese, German, Norwegian, and Spanish. Other work includes development and evaluation of learning resources for secondary school students in East Africa, in a new project funded by the Research Council of Norway, evaluation of a brief intervention for secondary school students in Australia. an intervention based on "behind the headlines" to teach IHC Key Concepts to university students, and a proposal for further development of primary school resources in Norway.

At the same time, we are continuing to develop the Key Concepts. A mapping review comparing the Key Concepts to other frameworks will be published later this year. People working in a number of other fields have recognised that largely the same Key Concepts apply to other types of interventions beyond health care. This has led to a promising interdisciplinary collaboration, as well as to adaptation of the IHC Key Concepts to other fields, and a new website for the Key **Concepts**. Students 4 Best Evidence (S4BE) have written a series of blog posts explaining the Key Concepts, which are being translated into several other languages.

Other resources related to IHC include transforming the <u>Critical thinking and</u> <u>Appraisal Resource Library (CARL)</u> to the Teachers of Evidence-Based Health Care (<u>TEBHC</u>) <u>Learning Resources Database</u>, further development of <u>Testing</u> <u>Treatments international</u>, and <u>GET-IT</u>. Lastly, although access to trustworthy information about the effects of treatments is not enough, it is essential for informed health choices. The last two reports included in this newsletter are about a review of free <u>online sources of</u> <u>information about treatment effects</u> for patients and the public, and a <u>checklist for</u> <u>reporting evidence-based information</u> <u>about the effects of treatments</u>.



Contact: Andy Oxman

The IHC network

Why a network?

Many people - educators, health professionals, engaged members of the public - have contacted us to ask if they can get involved in the IHC project. These people make up the IHC Network. What they have in common is a recognition of the importance of the aims of this work and a desire to make IHC resources broadly accessible. Members are for the most part involved in contextualising, (translating, adapting, and piloting) and evaluating and promoting use of IHC resources in their own settings, while some are also engaged in developing new resources.

We formed a Network to make it easier for people to collaborate, for instance on

grant applications or activities in the same region. Additionally, we wanted to provide a platform for collective support and sharing of ideas, and to keep track of who is doing what. Finally, we feel it is exciting to have a tangible community of people who are engaged in the same work, and we wanted to make that community – and its growth – visible.

Who are we?

The 57 current members of the IHC Network represent 26 countries and 15 languages: Austria, China, Croatia, France, Gaza, Germany, Iran, Ireland, Italy, Kenya, Mexico, New Zealand, Nigeria, Norway, Poland, Rwanda, South Africa, Spain, Switzerland, Syria, Uganda, UK, USA. We receive new inquiries from people in new settings a few times a month.

Meetings and resources

In October 2018, 34 people attended a Network meeting in Edinburgh, several via Skype. Opportunities to meet may vary from year to year, but we will try to meet at the Cochrane Colloquium or other similar conferences where many members are present for other reasons.

The Network shares a Dropbox folder that includes an overview of members and their planned activities, copies of grant applications, project presentations, and guides for contextualisation.

Administration

All work carried out by people in the IHC Network is self-governed and selffinanced. We don't have any funding or administration resources specifically for the Network. The IHC team in Norway functions as a point of contact - handling requests from people who are interested in getting involved, organising yearly meetings and collective information sharing, such as this newsletter.

Visibility

We are working on a new version of the IHC website to include an overview of the IHC Network and more visible access to translated resources.

If you want to get involved, please send us an email:

contact@informedhealthchoices.org

The IHC website

The scope of the IHC project has grown since we established the website a few years ago. Therefore we are making changes to the site so that it more accurately reflects the work and people involved now.

We will be contacting IHC Network members soon to provide us with content for the new pages that present Network activities and translated resources.

Some of what to expect on the new site:

- Addition of a top menu with country/language links leading to corresponding pages dedicated to each language or country. This will provide visitors with direct access to translated resources and information in other languages, without having to navigate the side menu in English.

- A new menu, so that items currently "hidden" under "Learning resources" will be visible in the main menu. We'll also be adding a menu item for "Secondary school resources" to reflect new work that begins in August.

- Addition of "Translations & adaptations" in the menu, to list all the ongoing resource contextualisation activities, including links to the country/language pages and resources. - Addition of information about the IHC Network, under "Who we are".

- Updating of the technical platform. Part of the updating involves getting rid of the sub-categories in the menu for technical reasons.

- Deleting content under the heading "Accessible Evidence". We plan to move that content to a new site that the Centre for Informed Health Choices in Norway is developing.

Informed Health Choices

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New side-menu structure

Contact: Sarah Rosenbaum

Key Concepts

The IHC Key Concepts

RESEARCH ARTICLE (1975) Key Concepts for assessing claims about treatment effects and making well-informed treatment choices [version 2; referees: 3 approved]

Andrew David Oxman ${}^{(\!\!\!D)}$ 1.2, Iain Chalmers $^{1,3},$ Astrid Austvoll-Dahlgren $^{1,4},$ Informed Health Choices group

F1000Research 2019

The IHC Key Concepts are standards for judgement, or principles for evaluating the trustworthiness of treatment claims and treatment comparisons (evidence) used to support claims, and for making treatment choices. The concepts are not, by themselves, a learning resource. They are a framework, or starting point, for teachers, journalists, researchers and others for identifying and developing resources to help people to understand and apply the concepts. Examples of such resources include the IHC primary school resources, the Australian Centre of **Research in Evidence-Based Practice** (CREBP) educational intervention for high schools, "bak overskriftene" (behind the headlines) and the Students 4 Best Evidence (S4BE) blog posts for university students, the IHC podcast for parents, and other resources that can be found in the Teachers of Evidence-Based Health Care (TEBHC) Learning Resources Database.

The <u>first version</u> of the framework was published in 2015. We developed the IHC Key Concepts by searching the literature and checklists written for the public, journalists, and health professionals; and by considering concepts related to assessing the certainty of evidence about the effects of treatments. We have revised the Key Concepts yearly, based on feedback and suggestions; and learning

from using the IHC Key Concepts, <u>other</u> <u>relevant frameworks</u>, and adaptation of the IHC Key Concepts to <u>other types of</u> <u>interventions</u> besides treatments.

We have made many changes since the Key Concepts were first published in 2015. The <u>2018 version</u> includes 44 Key Concepts compared to the original 32; the concepts have been reorganised from six to three groups; we have added higherlevel concepts in each of those groups; we have added short titles; and we have made changes to many of the concepts.

Higher-level concepts used to reorganise the Informed Health Choices (IHC) Key Concepts in 2018			
1. Bewa	1. Beware of treatment <u>claims</u> like these		
1.1	Beware of claims that are too good to be true.		
1.2	Beware of claims based on faulty logic.		
1.3	Beware of claims based on trust alone.		
2. Check the evidence from treatment comparisons			
2.1	Don't be misled by unfair comparisons.		
2.2	Don't be misled by unreliable summaries of treatment comparisons.		
2.3	Don't be misled by how treatment effects are described.		
3. Make well-informed treatment choices			
3.1	What is the problem and what are the options?		
3.2	Is the evidence relevant?		
3.3	Do the advantages outweigh the disadvantages?		

The IHC Key Concepts have proven useful in designing learning resources, evaluating them, and organising them. We are continuing to revise them in response to feedback, and we welcome suggestions for how to do this. Other ways in which we may further improve the IHC Key Concepts include reviewing related frameworks and learning from how those have been developed, evaluated, and used; developing a spiral curriculum with clear goals and a structure that outlines where learners should begin and how they should progress to reach those goals; and summarising the evidence supporting each of the Key Concepts.

Contacts: Andy Oxman, Iain Chalmers, Astrid Austvoll-Dahlgren



Are the IHC Key Concepts applicable to assess interventions beyond health care?

The results of the IHC controlled trials in Uganda have confirmed that teaching IHC Key Concepts (KCs) to primary school children and their parents improves their ability to apply the concepts when judging the likely trustworthiness of claims about the effects of treatments. Some educational trialists have been interested in our work over the past three years. At the first of a series of informal joint meetings of educational and health researchers which was convened by the **Educational Endowment Foundation** (EEF), Helen Wilson, a trialist assessing science teaching strategies in primary schools, suggested the IHC KCs seemed just as relevant to assessing claims about

Beyond health care

the effects of teaching strategies generally as they had been found to be for interventions in health care. This led Jonathan Sharples (at the EEF) and other educational trialists to assess and confirm that the IHC KCs were indeed relevant to assessing education strategies more broadly. For example, Sarah Pannell, a physics teacher, documented concordance between the IHC KCs and components of the primary school curriculum in England. These and other developments have led to <u>collaboration between health and</u> <u>educational researchers</u> and co-authored papers and joint conference presentations.

The success of the collaboration between the Centre for Informed Health Choices (CIHC) and educational researchers prompted Andy Oxman (CIHC) to convene a meeting at which researchers were invited to assess how relevant the IHC KCs are to judging the trustworthiness of claims about the effects of interventions not only in education, but also in agriculture, economics, environmental protection, informal learning, international development, management, nutrition, planetary health, policing, social welfare, speech and language, and veterinary medicine. A meeting was hosted by the James Lind Initiative in Oxford in December 2018 with people working in all of those fields. A consensus was reached that most of the IHC KCs were applicable across all of the fields represented at the meeting, and that we had much to gain by collaborating across disciplines. A summary of the consensus that was reached will be published later this year.

While the Key Concepts can be applied across disciplines, we recognized that the language used to teach and communicate them may vary by field. People working outside of health care have prepared Key Concepts that are tailored to interventions in their field. Those will be made available on a new <u>"That's a Claim" website</u>.



Meeting participants at the Oxford University Museum of Natural History

Contacts: Iain Chalmers & Andy Oxman

"That's a Claim" website



Home page for primary school version of "That's a Claim" for health

We hear claims about the effects of doing something all the time. We also make decisions about what to do all the time, often with little or no thought. This is true for individual decisions as it is for decisions on public policy matters. Unfortunately, people often fail to question claims about the effects of doing something (i.e. the effects of interventions). When they do question claims, they may struggle to understand whether the supporting evidence is trustworthy, and they may not make wellinformed decisions about what to do.

The Key Concepts for Informed Choices are standards for judgement or guides for evaluating the trustworthiness of claims about the effects of interventions and evidence used to support such claims, and for making informed decisions. They have been tailored to specific fields and audiences, to facilitate understanding and use in each field. Those adaptations will be accessible on a new website: thatsaclaim.org. Over time, we anticipate having translations of different versions of the Key Concepts. For example, a version of the IHC Key Concepts for primary schools has already been translated to Norwegian.

There will be a card for each concept (or 'guide'), like the one shown below.



Each card, when expanded, includes an explanation of the concept, with links to examples, resources, and a test yourself (Claim) question:



Clicking on SHARE creates a link that can be used in social media, for example to tag a bogus claim.

We also have made a poster that gives an overview of 28 guides for thinking critically about health claims for primary schools. It can be downloaded from the website and used as a helpful reminder and a handy reference.



Our plans are to complete implementation of the website in the next couple of weeks. We will then do some user testing, and hope to have the site ready to launch by the end of May.

Contact: Andy Oxman and Sarah Rosenbaum

S4BE blog posts

A blog series by Students 4 Best Evidence: to explain and promote 'Key Concepts' essential for assessing treatment claims



"Drinking coffee reduces your liver cancer risk by 50%" "Powerful new HIV drug... is hailed a success" "Eating plenty of salmon, mackerel and sardines protects against Alzheimer's"

These are just a handful of claims about treatments you might have come across recently. But every day – in the news, in conversations with friends and family, while browsing the internet – we're exposed to numerous claims like these. Making sense of treatment claims, whether they're about drugs or diet, can be difficult. Claims may be biased, unsubstantiated, or inaccurate.

As difficult as it may be to assess treatment claims, it's also essential. At best, making health decisions on the basis of unsubstantiated assertions is a waste of time and money. At worst, it can be harmful. But how can we make sense of it all?

To help us out, an Informed Health Choices (IHC) project team has developed, and continually reviews, a list of '<u>Key</u> <u>Concepts</u>' designed to help people assess claims about the effects of treatments.

Three groups of Key Concepts

The Key Concepts are divided into three groups, shown below with an example that falls into each group:



Discover the Key Concepts for yourself

The Students 4 Best Evidence (S4BE) community was keen to raise awareness of these vital concepts. As such, a group of 17 students prepared a series of 36 blogs, to explain and elaborate upon each of the Key Concepts.

Bloggers were encouraged to use two key sources for researching content for the blog: Testing Treatments international (TTi), which provides resources linked to each key concept and the James Lind Library. Each blog was reviewed by Iain Chalmers (TTi), who provided support and feedback, assisting us in producing a 'quality assured' blog series. Short videos explaining the concept were embedded into the blog, together with links to lots of useful resources to further help readers to think critically about treatment claims.

As of March 2019, the blogs have a combined viewing total of 165,000 and we are keen to continue this drive to promote critical thinking and discussion of treatment claims.

The IHC project team updates the Key Concepts annually. Since S4BE completed their blog series, the IHC team has been busy adding 8 more concepts and subgrouping them to ensure the list isn't overwhelming. You can find the September 2018 list <u>here</u>. Watch this space for the addition of these new concepts to the S4BE blog series!

Get involved!

If you are a student of any discipline, interested in evidence-based healthcare, and would be interested in getting involved with Students 4 Best Evidence, please get in touch by email general@students4bestevidence.net or tweet us <u>@Students4BE</u> – we'd love to hear from you!

Contact: Emma Carter

Critical thinking frameworks

The IHC Key Concepts are a framework for developing learning-resources to help people assess claims about the effects of treatments (and other interventions) and make health choices. The objective of this study is to systematically compare the IHC Key Concepts to other frameworks that are relevant to learning how to think critically about treatment claims and choices.

We will identify relevant frameworks from reviews of frameworks, searches using Google Scholar, citation searches, and contact with key informants. We will include frameworks that are intended to provide a structure for teaching or learning to think critically about the basis for claims, evidence used to support claims, or making informed choices. This includes frameworks for argumentation, causal inference, cognitive biases, critical appraisal, critical thinking, epistemic cognition, evidence-based practice, evidence-informed decision-making, health literacy, logical fallacies, research biases, science education, scientific literacy, scientific reasoning, and scientific thinking.

To be included, there must be a description of the purpose of the framework, a list of the framework's elements, and definitions of the key terms. The two authors will independently assess frameworks for eligibility and extract data from included frameworks using standardised forms. We will map the relationship of the included frameworks to the IHC Key Concepts.

So far we have identified 22 frameworks that meet our inclusion criteria. Screening and eligibility assessments are ongoing. We plan on completing the review and publishing a report later this year. The findings will inform further development of the IHC Key Concepts, development of related frameworks, and the use of such frameworks.

Contacts: Andy Oxman & Laura Martínez García

The Claim Evaluation Tools Database

Create your own Test: the Claim Evaluation Tools Database

Although a growing number of educational resources for improving people's critical thinking about treatment claims is available, few of these have been evaluated.

Consequently, we developed the Claim Evaluation Tools Database - a battery of multiple-choice questions (MCQs) that can be used to evaluate people's ability to assess treatment claims and make informed health choices.

If you are preparing a lesson to teach people about one or more of the Key Concepts you may be interested in evaluating your students' learning achievements after the lessons.

Available in several languages

The MCQs have been developed based on qualitative and quantitative feedback from methodologists and members of the public in several countries. Currently, the MCQs are available in Chinese, English, Luganda, Norwegian, and Spanish.

The Claim Evaluation Tools are open access as long as they are used for noncommercial purposes.

The database includes more than 150 MCQs. All questions within the database have been developed for use in children (from the age of 10) as well as for adults (including health professionals). This makes it possible to compare results between children and adults.

Although the MCQs were initially developed of use in the IHC trials, they can be used:

- to produce tests in school and other teaching settings
- in other randomised trials evaluating outcomes of educational interventions
- in cross-sectional studies to gauge ability in a population, and thus provide background information to help tailor interventions addressing people's educational needs.

How to create a test

We have developed the Claim Evaluation Tools Database so that teachers, researchers and others can select multiple-choice questions relevant for their purposes. This means that you can create your own test based on which Key Concepts you want to teach.

If you are interested in trying out the multiple-choice items, please take a look at our <u>manual</u> that will help you develop your own questionnaire in a few easy steps. If you would like to contribute or have any questions, feel free to send us an email. We are interested in collaborating with people who would like to create more MCQs, or who are interested in using or evaluating (validating) the existing MCQs.



Contact: Astrid Austvoll-Dahlgren

IHC around the world

Guides

People in many different countries have expressed interest in contextualising the IHC resources for use in their settings, and we receive new queries on a regular basis.

We produced a set of contextualisation guides to support this work.

Contextualisation includes any or all of the following:

- *translation* of resources to another language

- *minor or major adaptations* of the content

- *piloting* in classrooms or other settings - *exploring barriers and facilitators* related to implementing resources in a region or country

Based on our own and others' experiences carrying out contextualisation activities, we have tried to make it easier for people to understand what the work entails, what resources might be needed, and how the activity can be carried out, whether it is framed as a research project or not.

Following is an overview of the current set of guides. They are available also to people outside the IHC network.

See <u>IHC guides for contextualising and</u> piloting resources.

<u>Guides</u>	Description
<u>Market</u> analysis	This is an analysis of Norwegian primary and secondary schools, that can be used as a starting point for planning similar analyses in other settings. We explored: - the demand for learning resources for teaching students to think critically about health claims and choices; - where teaching these skills best fits in the curriculum; and - market conditions for introducing this into schools, including the availability of time, who the decision-makers are, and what influences their decisions.
Translating and adapting school resources	Step-wise plan for carrying out translations and/or adaptations of the primary school resources. Appendices include FAQs, examples of feedback collection methods, and a diffusion plan.

<u>Guides</u>	Description
<u>Resource</u> production	Technical details about using the PDF and InDesign files for creating translated primary school resources, as well as software considerations and other technical information, such as printer specifications
<u>Piloting</u> <u>school</u> <u>resources</u>	Protocol template that can be used for describing and planning pilots of school resources, or writing research applications. Large appendix folder, including templates for collecting feedback and detailed user testing instructions
<u>Claim</u> evaluation tool	Manual for preparing a test or questionnaire based on the Claim Evaluations Tools database
<u>Translating</u> <u>and</u> <u>adapting</u> <u>podcast</u>	Step-wise plan and materials for carrying out translations and/or adaptations of the podcast

Contact: Sarah Rosenbaum

Arabic speaking countries

The Arabic translation of the Informed Health Choices (IHC) resources

We translated the 2017 edition of the IHC key concepts (36 key concepts) into Arabic. The main challenge that we faced was deciding which type of Arabic (i.e. dialectic) that we should use in our translation. There are more than 30 dialectics of Arabic. We decided to use the standard Arabic (known as *al fusha*) to make sure that these concepts are understandable by all Arabic speakers (similar to the type of Arabic that has been used in translating Testing Treatments (http://ar.testingtreatments.org/). The Arabic translation of the IHC key concepts can be found <u>here</u>.

We plan to translate the updated version of the IHC Key concepts into Arabic and to distribute these concepts using social

media (using short videos and real-life examples illustrating each concept). We are also planning to translate a questionnaire with questions from the Claim Evaluation Tools Database, and to validate it in our local settings.

Yamama Bdaiwi, a Syrian medical doctor, currently doing a Masters at Oxford in Evidence-Based Health Care is coordinating a team from multiple disciplines (education, medicine, publishing, and design) from Arab countries to produce an Arabic translation to the IHC primary school resources. Medical students are being trained in evidence-based medicine through a voluntary online 3-month course provided by Syrian physicians in the US and the UK. Further training will be provided on translation. The main challenge we are facing is networking with publishers and stakeholders in the education field in the Arab world who are keen to adopt the curriculum after the translation phase.

We welcome feedback, suggestions, and help in translating IHC resources into Arabic.

The Arabic translation team members are Loai Albarqouni, Khamis Elessi, Yousuf Mokhallalati, Tarek Turk, Ibrahim Hanafi, Yamama Bdaiwi, and Adib Essali.

Contact: Loai Albarquouni

Australia

Under the guidance of Professors Tammy Hoffmann and Chris Del Mar, from the Centre of Research in Evidence-Based Practice (CREBP) in Queensland, we are close to completing the development and subsequent assessment of an educational intervention to improve Australian high school students' ability to identify and critically assess health claims in the media.

The educational intervention is of approximately four hours duration and has been designed to be delivered within high-school classes (grades 7-9) by the teachers. It is based on the <u>IHC Key</u> <u>Concepts</u> and was developed following a <u>systematic review</u> to identify gaps in the literature concerning critical appraisal in health literacy and a <u>qualitative study</u> to assess Australian high-school students' current understanding of health claims.

We intend to assess the impact of the intervention later this year through a randomised controlled trial. The outcomes will be measured through a set of questions from the <u>Claim Evaluation</u> <u>Tools Database</u>, which contain validated multiple-choice questions to assess an individual's understanding of and ability to apply the Key Concepts.

Based on past experience, our biggest challenge will be the recruitment of enough high-schools to ensure informative data.

Contact: Leila Cusack

Basque Country

We are a group of professionals at OSI Donostialdea (Osakidetza/Basque Health Service): two clinical epidemiologists and two medical librarians. Our professional approach to critical thinking has taken us towards the IHC project with the aim of implementing the resources in Euskara in the schools of the Basque Country; thus promoting health literacy and critical thinking from an early age.

The first meetings we have had with education officials have shown that they have a tremendous interest in this subject.

We have started searching for funds that will allow us to translate and pilot the materials.

There is a close relationship between this project the holds with one already approached and the Basque Testing Treatments group. Our translation of *Testing Treatments* into Euskara ("Nola Probatzen diren Tratamenduak") was awarded the Joannes Etxeberri Prize in December 2014.

Both initiatives, although targeting different audiences, aim to empower people. We are delighted to be on board the IHC network, and appreciate being welcome. We are sure this will be a fruitful collaboration.



The Basque team

Contact: Jose Ignacio Emparanza Knorr

China

From 2011, the faculty and students in the Evidence-Based Medicine (EBM) Center of Lanzhou University started to review and comment on the book *Testing Treatments: Better Research for Better Healthcare* before its publication. Subsequently, we translated the book to Chinese and joined the international network (Testing Treatments Editorial Alliance, TEA) to promote its spread all over the world. Also, we established a student club to help spread the book in China. At the 2015 Cochrane Colloquium in Vienna, we participated in a workshop on helping people understand claims about treatments. It was a good opportunity to learn about related projects and activities. Since then, we started to work closely with Andy and Astrid in the IHC project and its related activities (such as claim questions). Over the past eight years, more than 10 faculty, 20 graduate students and 150 undergraduate students have been involved in and are working on these projects in China.

What we have done?

The Chinese edition of Testing Treatments was published in 2016, and the online and audio version were available free in the same year. Within a year, 15,000 copies of the book in Mandarin were sold, and the Chinese translation team was inspired by hundreds of appreciative letters from readers.

We have translated most of multiplechoice questions from the IHC Claim Evaluation Tools Database into Mandarin and tested them in China. The paper Evaluating People's Ability to Assess Treatment Claims: Validating a Test in Mandarin from the Claim Evaluation Tools Database will be published in the Journal of Evidence-Based Medicine. In 2018, we participated in several IHC network meetings and we are interested in translations, contextualisation, and testing of IHC primary school resources in China.

We have published two papers and will publish one in 2019; and we have presented several oral and poster presentations in some important international conferences (such as the Cochrane Colloquium). Not only the Chinese team, but also the faculty and students have made important progress.

In 2018, Dr. Yaolong Chen took over the convenorship of the TEA. Based on the

ideas of TTi and IHC, Qi Wang won a China Medical Board (CMB) grant of US \$20,000 to test the effectiveness of online audio-visual resources for teaching key EBM concepts to medical students in China, and she now is studying at McMaster University in Canada as a PhD student.

What's next?

We are planning to validate more Claim questions in China, and are applying for funding from the Health Education Institute of Lanzhou to support more validations and to use validated questionnaires for conducting a provincial or national cross-sectional survey. Also, with help from Sarah and other international colleagues, we are conducting Chinese translations and will apply for funding for piloting and user testing Chinese versions of the IHC primary school resources. We are considering using current information and communication technologies to disseminate more key EBM concepts and to help the public critically appraise the health claims that surround them.



TTi Chinese team

Contacts: Qi Wang, Jingyi Zhang, Yaolong Chen

Croatia



Last year, Shelly Pranić, a Cochrane Croatia's member, conducted a project called #LittleMediaEducators. The project included interactive workshops at an elementary school in Split, Croatia. The goal was to encourage children to become conscientious healthcare consumers. This project made us understand the need in Croatia for an evidence-based curriculum for elementary school students that teaches concepts to facilitate interpretation of the information that comes from the media.

Soon after the Edinburgh Cochrane Colloquium, at which we found out about the Informed Health Choices Project, we joined the network. The Croatian IHC team consists of a group of enthusiastic colleagues with different backgrounds research assistants, clinicians, teachers, psychologists, pedagogues, and medical students - all contributing to the project goals with their expertise, and making this project fun.

We first started by translating the 36 <u>Students 4 Best Evidence Key Concepts</u> <u>blog posts</u>, which we plan to use as part of our research methodology teaching. The translated blogs have been proofread and will be given to students for testing.

However, our main target is primary school children. We have been focusing on

translating the <u>IHC primary school</u> <u>learning resources</u>, including the *Health Choices Book*, the *Teachers' Guide*, the exercise book, and the Claim questionnaire. Also, as part of our translation activities, the draft text for the ("<u>That's a Claim</u>") primary school website and poster has been translated along with the original, detailed list of the <u>Key</u> <u>Concepts</u>.

After getting involved in this project, we went through the Croatian education curriculum, as we were curious to see where we are in terms of critical thinking about health related topics and in relation to the IHC Key Concepts. Also, we wished to explore opportunities for implementing the IHC learning resources in our primary school curriculum. Also, having considered health literacy as a tool to strengthen active citizenship in health related issues, the idea that the Key Concepts could be well suited for use within Croatian civil education has also emerged.

We have been contacting schools to join the project, and we were invited to present the project at the County's Meeting for Pedagogues on February 15th. So far 12 schools have shown interest in joining the project, including participating in a qualitative study to explore teachers' experiences with the current education model, organising meetings with parents to investigate their perceptions of the IHC Key Concepts, and participating in a randomised trial that we plan to conduct during the next school year.

It is our pleasure and honour to be part of this project. We believe that critical thinking, once adopted for health claims, can be applied to different areas in life and, therefore, this project has the potential to change viewpoints and change the direction of future actions in education, contribute to bringing up generations that approach all information with responsibility and criticism, and add up to a healthier society.



Contacts: Tina Poklepović Peričić & Shelly Pranić

East Africa

We recently were awarded funding for a new five year project in Uganda, Kenya, and Rwanda. The project, which is funded by the Research Council of Norway, will start August 1st. The objectives are to develop and evaluate learning resources for secondary school students to help them make informed personal choices about caring for their health and to participate as scientifically literate citizens in informed debate about health policies.

We will prioritise IHC Key Concepts to be included in the resources based on consultation with teachers, students, and others. This will be informed by a systematic review of frameworks for critical thinking, and an analysis of curricula in Uganda, Kenya, and Rwanda. We will use multiple-choice questions from the Claim Evaluation Tools Database as the basis for evaluation tools. We will validate the tools using psychometric testing and Rasch analysis. We will

develop learning-resources in collaboration with teachers and students using an iterative process of brainstorming, prototyping, user testing, and feedback from teacher and student networks and advisory groups. We will randomise half of 80 to 100 schools in the three countries to use the resources and then compare the ability of the students in those schools to assess claims and make informed choices to that of the students in the comparison schools. We will use process evaluations to identify unintended consequences, and explore factors that might affect scaling-up use of the learning-resources.

The expected results of this project are freely-available and widely-disseminated learning-resources to help young people make informed decisions about their health and to participate as well-informed citizens in discourse about policies that affect health.

Contact: Andy Oxman

French speaking countries

Most of the IHC primary school resources were translated to French and proofread by a Swiss citizen scientist and a French researcher. The next steps are translating and proofreading the teacher's evaluation form and the CLAIM questionnaire, and getting feedback from children and teachers.

The first step will be done by the French translation team. For the second step, a school involved in the Spanish translation of the IHC material will support the review of the French version of the IHC material. That school has a program with a network of schools in Senegal. The team in charge of the Spanish translation will be in charge of collecting feedback. Based on the feedback, the French translation team will evaluate the need to have French or Swiss schools give additional feedback.

The team in charge of the French translation currently has no plans, resources or school networks to advance implementation of the IHC resources in schools. Anyone interested and willing to help is welcome to join.

Contact: Ignacio Atal & Martin Vuillème

German speaking countries

In 2016, the German working group* translated 68 items from the Claim Evaluation Tools database and conducted a validation study. The 68 items, addressing 22 key concepts, were randomly assigned to three item sets. The data collection was carried out online via Unipark as well as paper-based at schools and universities in Germany. The sample of 805 people included students from vocational grammar schools, trainees in healthcare occupations, nursing students, students in health sciences and citizens between 16 and 52 years (mean 22.4). Data analysis included reliability, item frequency and Q parameters. The study showed that some of the items were too easy. Therefore, item difficulty needed to be increased by adjusting task difficulty or changing distractors. Further item revision and validation will be performed later this year.

The aim of a second project is to adapt the item sets to the target group of secondary school students (grade 7 to 10, 12-16 years). The adaption includes changes concerning the language used and item topics so that the items fit to the target group as well as to the German context. Therefore, interviews using the think aloud method were conducted with

students and teachers in the target group. Teachers particularly made suggestions to improve readability. Interviews with students aimed to explore readability, comprehension and acceptance. Participants showed a good understanding and readability of the item sets.

At the moment, a validation study is underway at a German school and in cooperation with schools in Austria within the project *Health Literacy and Diversity for Students in Secondary School*. Results are expected this summer.

*The working group includes the following members of the German Network for Evidence-based Medicine and the Health Literacy Network: Anke Steckelberg, Jana Hinneburg, Julia Lühnen, Karin Riemann, Sascha Köpke, Eva Bitzer, Stephanie Stock, Marie Luise Dierks, Jonas Lander





Contact: Anke Steckelberg

Iran

We started translating the IHC <u>Health</u> <u>Choices Book</u> into Persian in August 2018. Our translation group consists of five dental students, four studying in Shahid Beheshti University of Medical Sciences: Ahmad Sofi Mahmudi (the leader), Hossein Mohammad Rahimi, Pouria Iranparvar, and Maryam Shakiba; and one studying in Hamedan University of Medical Sciences: Sara Moradi. The aim of the group is to provide evidence-based healthcare to the Iranian community. The group is called "Dahaan" (meaning "mouth" in Persian). We previously had translated the Key Concepts in Dahaan and put it on <u>our website</u>. We also put the Key Concepts in our <u>Twitter</u> and <u>Telegram</u> accounts (on Mondays, Figure 1).



Figure 1- Key Concept 1-1 in Persian

Currently, we have the first draft of the Persian Translation of the *Health Choices Book*. The editing process is ongoing and we expect to finish the process by the end of May. We plan next to translate the <u>Teachers' Guide</u> and the <u>Exercise Book</u>. We plan to conduct a randomised controlled trial in Iranian primary schools after we completed the translation of these books (Figures 2 & 3).



Figure 2- The Health Choices Book Persian translation cover



Figure 3 - The Health Choices Book Persian translation

Contact: Ahmad Sofi Mahmudi

Ireland

We, like all of you no doubt, are fans of the IHC initiative and were taken with its success in Uganda. The use of storytelling, active learning, group work and reinforcement exercises seemed an ideal way to engage primary school children. We were not aware of a programme, within the Irish primary educational system, which explored concepts to assess treatment claims. After time spent with the team in Oslo, we were keen to bring the IHC initiative to Ireland. However, with a different national curriculum and educational priorities in Ireland, we wondered if and to what extent contextualisation of the content and delivery of the programme would be required. The extent to which this contextualisation is needed in Ireland, and what those adaptations should be, is the focus on our on-going work.

We are lucky that the researcher, Dara Glynn, undertaking this work (as part of his MPhil studies) is himself a Principal Teacher in a primary school with extensive experience of working within the education system in Ireland. We think, (admittedly this is anecdotal in nature!), that this has influenced our ability to engage with teachers (or rather their willingness to engage with us!). Dara has given the rest of us a credibility that we believe would have been otherwise difficult to achieve!

So where are we at ... since September Dara, with the support of the wider team, has conducted interviews with 10 key stakeholders within the Irish primary school educational system. These interviews were guided by the IHC data collection resources and asked the participants to provide feedback on the IHC primary school resources, content and delivery. The programme has been delivered in two schools (three in total as Dara has also facilitated it in his own school). The teachers were interviewed before they started the formal teacher preparation. Data were collected via nonparticipant observation of some of these teaching sessions, focus groups with the children participating in the programme and interviews with the teachers facilitating the initiative. The CLAIM questionnaire was administered to the participants of the programme (thirty children).

It has been a busy couple of months but a lot of fun for us in that we got the opportunity to watch as the children's knowledge and confidence in applying the concepts developed. We now understand what Dara has been telling us about the busy world of primary schools!

So the next phase ... putting all the data together in a cohesive manner that will be useful for us in Ireland and for the wider IHC community. We will keep you posted. Thank you for including us in this group.

Contact: Linda Biesty (on behalf of the team - Dara Glynn, Declan Devane, Sandra Galvin, Sarah Chapman)

Italy

Translation and pilot testing

That good health depends on good choices is a cross-cutting concept for anyone involved in a healthcare profession, but also for anyone as a person, a citizen or a patient. At the same time, being able to perform good choices about health is not a trivial task as it requires a set of skills that has been observed to be neither widespread in the general population, nor sometimes even among healthcare professionals. In Italy, for example, it has been estimated that <u>only 37% of medical</u> <u>schools include Evidence Based Medicine</u> <u>in the core curriculum</u>.

The Informed Health Choices project is a high value answer, both in methods and in contents, to the need of absorbing these competencies since primary school.

In Italy, IHC educational resources have not yet been translated and implemented. Because of that, and given this project's high value, we have decided to contribute, on a voluntary basis, to the contextualization of the teaching resources in Italy.

We are two cardiologists based in Florence, working at the Don Gnocchi Research Foundation and in several facilities in the Florence area. We started our "IHC travel" by gaining support from the General Medical Council in Florence that appreciated the initiative and offered to patronize it through giving us support for printing book copies and through local press dissemination. Then, we identified a public primary school in Florence (Poliziano Institute , Viale Giovan Battista Morgagni, 22) to become a possible setting of a pilot IHC project. After introducing the IHC project to the school's principal, it has been presented to the school board in February 2019. Next steps will be us presenting the project in deeper detail to the school board in March and the project being discussed for the introduction in 2019-2020 school planning.

We have set our working schedule as follows. First, we will translate the educational resources, and we're going to start translation in March 2019. Second, after undergoing a first proof correction, the draft will be submitted to two primary school teachers, that we have already identified and involved. Third, we intend to extract a random sample of 5th grade children (3 to 5 children) from the same public school in which we aim to implement the project and gain feedback from them about the draft. And fourth, our objective is to have a pilot IHC project introduced in the 2019-2020 school planning. That would allow us to teach the 12 Key Concepts to fifth grade children starting in January 2020.

Our experience up to now has been positive, since we have received very good feedback from all the people we've being discussing with about the project's basis, aims and feasibility. We're also feeling very supported by the IHC group, and we hope we'll be able to discuss translating issues also with the French and Spanish groups, given the similarities of our languages.



Contacts: Camilla Alderighi & Raffaele Rasoini

Plans for a trial

Informed Health Choices Learningprogram to improve health literacy and informed choices in Italian primary school children

In response to a competitive call of the Ministry of Health last May 2018 we submitted the project entitled "Assessing the efficacy of the Informed Health Choices (IHC) Learning-program to improve health literacy and informed choices in Italian primary school children: a randomised controlled trial".

The project shares the awareness that to make informed health decisions people need to be able to assess claims about what might improve or harm their health. These claims are not always reliable and people who are not able to distinguish between trustworthy and untrustworthy claims are at risk of making poorly informed choices and of experiencing unnecessary suffering. In Italy, as in other countries, up to now little attention has been paid to developing strategies for teaching critical thinking skills for selfcare and informed decision-making.

Starting from evidence suggesting that it is possible to teach critical thinking about health choices to children, and that those who are taught these skills do better than those who are not, the project will involve primary school children.

The following phases are considered in the protocol.

First: Translate and adapt the IHC learning-program previously developed in other countries to the Italian context, in a way teachers and children find it useful, easy to use, understandable and desirable. This will follow <u>guides</u> for translating and adapting materials. A multidisciplinary working group will be organized including researchers, experts in communication, clinicians, teachers and parents.

Second: We will assess if the IHC learning-program effectively enables fifthgrade Italian children to think critically about health claims and choices. A cluster randomised controlled trial will be carried out, where intervention schools will receive the IHC learning-resource and materials, which will not be given to the control schools until the end of the study.

Third: We will disseminate and make available the translated IHC learningprogram to Italian primary school teachers. Materials and results obtained will be published on a website, with links to the website on the websites of involved schools and elsewhere. Selected parts of videos of workshops will be organised as a tutorial. Various information channels and tools - such as the website, a podcast, and video - will be used to inform officials and teachers who do not participate in the trial. The Italian experience will be reported on the Informed Health Choice website.

This project aims to increase dissemination of research-based knowledge by enabling children to recognize the value of research, to appraise research critically, and to use research to inform decisions.

BREAKING NEWS. The first of March we received communication that the project did not receive funding. We are waiting for the referees' comments in order to review the project and to look for other possible funding.

Contacts: Paola Mosconi, Roberto D'Amico, Simona Vecchi, Cinzia Colombo

Kenya



As in other populations in Africa, adults and children in Kenya are faced with choices on maintaining good health. In the midst of these choices, there are many claims on how to stay healthy. The IHC project in Kenya piloted learning materials during 2018 that aimed to test whether the materials were relevant and could be easily understood by primary school children aged 10 to 12 years.

Field-testing of the materials took place in two public schools, one of which had previously piloted the learning materials in English. The exercise involved meeting with pupils once a week for 9 weeks, for approximately an hour each week after the normal classes to go over the children's book, in the presence of their teacher who also had a teacher's guide.

The resource materials were written in simple Kiswahili and consisted of a children's comic storybook with eight chapters and a ninth review chapter, and classroom exercises. The children's exercise book contained take-home exercises. Posters on the wall and learning cards were provided which engaged the pupils in analysing simple concepts of health and health choices. The accompanying teachers' guide matched the children's learning materials and included lesson preparation notes, children's activities, and evaluation forms for assessing the lessons. Before using the resource materials, a 2day training session was provided to four teachers from the two schools, using the teachers' guide and the children's learning materials as training resources. The teachers were oriented on how the school materials were developed, including concepts, use of the materials, and the expected roles of the teachers during piloting of the materials.

The process for carrying out the pilot study was introduced to the teachers, after which the IHC learning resources were shown and discussed together as a group. The teachers were oriented on delivery of the lessons using the translated Kiswahili Teachers' Guide. At the end of the workshop, the teachers were asked to provide feedback on the training process and their views on using the resource materials.

Overall, the teachers found the training to be useful and highlighted areas that were important for effective use of the resource materials. The format of a comic storybook for the children was appreciated by both the teachers and pupils as a novel way of presenting new concepts in contrast to the traditional standard textbook style used in all the subject books in the schools. The use of cartoons was rated by the teachers as good reinforcement of the lessons. The format involving the comic book, exercises and games - provided an opportunity for a more engaging approach with primary school children on making choices.

Two weeks prior to the school sessions, the teachers received the Teachers' Guide to help them plan for lessons ahead of time. Despite the challenges of using the learning materials outside the regular class schedules and competing school activities, the teachers felt that the learning materials provided the children

and teachers with new learning experiences regarding health choices. The results of the piloting are currently being analysed and will be reported later this year.

Contact: Margaret Kaseje

Mexico

I found out about Informed Health Choices (IHC) through the Testing Treatments Editorial Alliance. As a paediatrician, the project immediately caught my attention because of a couple of claims used as examples to highlight the importance of critical appraisal: cow dung heals burns; vaccines cause infertility. Both, of course are false. But it was interesting that both examples, used in Uganda, had a counterpart in Mexico: refrigerated pig's fat cures burns; vaccines cause autism. Again, both false.

Our first participation with IHC was to validate a CLAIM questionnaire here in Mexico. We administered the translated questionnaire online to adults, and on paper to children 10-15 years old in both a public and a private school. Based on the findings of a Rasch analysis, we ended with a final set of 18 multiple-choice questions that had satisfactory fit. This was the first set of questions from the Claim Evaluation Tools Database available in Spanish to measure people's ability to assess claims about treatment effects.

After this study, we've been planning to use the questionnaire to do a cross sectional study in nutritionist schools. We are also exploring the possibility of running a summer camp for children to teach them the Key Concepts needed to assess claims. Finally, a group of medical students from the Autonomous University of Sinaloa and the University of Guadalajara have joined the Spanish version of Students 4 Best Evidence and have begun translating the blog posts explaining the Key Concepts. (See <u>Students 4 Best Evidence blog posts</u> above.)



Contact: Giordano Pérez Gaxiola

Norway

Translation of the Health Choices Book

A professional translator (Gaute Grønstøl) with a background in teaching natural science to teenagers translated the *Health Choices Book* to Norwegian at the end of 2018. We did not encounter any big problems with the translation. Children start learning English in primary school in Norway, so we decided to replace the Luganda and Kiswahili words and definitions in the original book with English words and definitions.

Feedback: Nine children between 10 and 13 years reviewed the translation. Two of them read each chapter. We asked them to tell us what they liked and did not like about the book. We gave them a list of 52 words that we thought might be difficult, and asked them to circle the words that they did not understand. We also asked them to circle anything they did not understand in the two chapters that they each read.

Things that one or more of the children liked about the book included the cartoon, the exercises, the activities, that there was not a lot of text, and that it was easy to read and understand. Things that one or more did not like included that there were a few long, difficult sentences; some of the examples that were used; that we called juice a "treatment"; and that there was too much repetition in the chapter about small studies being misleading. Several said that there wasn't anything they disliked, and that they thought the book should be used in schools. There were 19 words that one or more of them found difficult. We found easier words to replace some of those.

We were unsure what to call the book in Norwegian. We asked the children to vote on three alternatives. Two of the options scored better than the third, and we decided on one of those: *Boken om helsevalg: Lær å tenke nøye over hva som er sunt* (The Health Choice Book: Learn to think carefully about what is healthy).

Finalising the files and reproduction: After we finalised the text based on children's feedback, a professional proofreader copy edited all of the text and the translator put the final text into the Adobe InDesign files. The designer on our team edited all the images with English text embedded in the drawing, using Adobe Photoshop to change those texts to Norwegian (for instance "CREAM" changed to "KREM" on page 6). We printed 100 copies of the book, and will make the PDF file available on the IHC website. We brought some copies of the book with us to a research day at the Norwegian Institute of Public Health. Many of our colleagues asked if they could have a copy.



A new grant application

We plan to pilot the book in a couple of schools this fall, as a first step in a new project. The Norwegian Centre for Science Education and Asker Municipality, which is responsible for 16 primary schools, are partners in that project. We are applying to the Research Council of Norway for funds to develop and evaluate learning resources to teach the IHC Key Concepts in Norwegian primary schools. We hope to use the Health Choices Book as the starting point for creating a digital version and additional resources to teach other IHC Key Concepts. If our application is successful, the funding would start in January next year. The proposal is for funding for four years to design the resources and evaluate them in randomised trials with one year of followup and process evaluations.

Contact: Sarah Rosenbaum & Andy Oxman

Market analysis

Masters students at the Norwegian Business School (BI) undertook this research for us. They explored the following in Norwegian primary and secondary schools: the demand for learning resources for teaching students to think critically about health claims and choices; where teaching these skills best fits in the curriculum; and market conditions for introducing this into schools, including the availability of time, who the decision-makers are, and what influences their decisions.

They conducted a document analysis and semi-structured interviews. They analysed key documents related to current practice and the development of a new national curriculum in Norway that will be implemented in the fall of 2020. They interviewed 12 primary and lower secondary school teachers (grades 1 to 10), two principals, one policymaker, and one provider of Science learning resources. They used an interpretative description approach.

Key findings and implications for the design and implementation of IHC learning resources are summarised in the table below.

Findings	Implications
An important question that this study does not answer is how much time is likely to be allocated to teaching critical thinking about health.	The answer to this question has major implication for designing learning resources. Therefore, answering this question should be a priority.
There is limited classroom time for teaching and there are many demands on the time that is available.	Use of the learning resources should require as little classroom time as possible. They also should be designed to be used over more than one grade and to facilitate collaboration across grades.
Implementation of the new national curriculum offers an opportunity to introduce new learning resources.	It may be advantageous to have learning resources ready close to the time when the new curriculum is being implemented, although this may not be possible.
The new curriculum emphasises critical thinking and health.	Linking learning resources to core elements of the new curriculum may help to promote their use.
Teachers and other stakeholders desire interdisciplinary collaboration (teaching across subjects) generally and specifically for critical thinking and health. However, it is unlikely that classroom time will be allocated to this in two of the three subjects where critical thinking about health is a core element (Food & Health and Physical Education). It is more likely for Science.	Learning resources should be designed primarily for Science teachers. However, so far as possible, they should include activities for Food & Health and for Physical Education; and they should facilitate collaboration across subjects.
Teachers have little time to seek and test new learning resources. They also may lack competence and confidence in their own ability to assess health claims. They are unlikely to have experience teaching critical thinking about health.	The learning resources should be designed to be easy to find; e.g. by hosting them on <u>naturfag.no</u> and by informing Facebook groups of their existence. They should be easy to understand and use; e.g. by providing scaffolding for both teachers and students.

Findings	Implications
In the current Science curriculum, the ability to "critically assess" information is described as the ability to identify relevant information and assess the credibility of the source	Some teachers may confuse "source criticism" with critical appraisal of the basis for claims and the evidence supporting claims. This difference should be made clear in learning resources and promotional materials.
Primary and secondary schools use several different science textbooks, none of which are comprehensive and none of which cover critical thinking about health.	Consideration should be given to how best to link learning resources for critical thinking about health to the textbooks that are widely used in Norway.
There is variation in what is taught and how it is taught across schools, subjects, and teachers.	So far as possible, use of the learning resources should be flexible, so as to accommodate the needs of different teachers.
Teachers have a great deal of discretion and make many decisions about what and how they teach.	Teachers should be engaged in designing the learning resources.

Contacts: Andy Oxman and Sarah Rosenbaum

Bak overskriftene

Using treatment claims in the mass media to help university students master IHC Key Concepts

Can the deluge of unreliable treatment claims in the mass media be a resource?

Building on experience from developing the IHC Primary School Resources and the IHC podcast for parents of primary school children, we—students, educators, and researchers at Oslo Metropolitan University (OsloMet)—are developing an intervention to help university students learn to apply some of the same IHC Key Concepts.

"Bak overskriftene" is Norwegian for "behind the headlines", and the project is inspired by the British service named exactly that (www.nhs.uk/news). However, in our project, students are producing the content, and the primary outcome is their learning.

The intervention has two main components or phases: an introduction to the project and selected IHC Key Concepts, followed by a period of identifying and evaluating claims, and writing short, news brief-like texts that illustrate the concepts using those claims.

For example, in an ongoing pilot, a journalism student has illustrated why the results of single studies can be misleading, using the claim that ice cream improves concentration. And using the claim that fish for dinner can prevent dementia, a student from the applied computer technology programme has illustrated the difference between association and causation.

The pilot includes a small group of volunteer students from three faculties and six programmes. We aim to launch the website where their texts will be published by June 13, 2018, when we are hosting a conference on misinformation in the media, and interventions to address the problem.

Meanwhile, we are applying for funding to further develop the intervention and modify it so it can be used as part of a course, in particular a new introductory course on evidence-based practice, which will be mandatory for all first-year health sciences students at OsloMet. The rationale is that assessing claims in the mass media, which are simpler, more relatable, and more engaging than information in journal articles, can be a bridge to critical appraisal for inexperienced students.

The project is led by the Faculty of Health Sciences, in collaboration with the Institute for Journalism and Media

Studies, and the Institute for Information Technology. A working group with students and staff from all faculties and a wide variety of programmes—including nursing, public health nutrition and other health sciences, journalism, information technology, library and information sciences, and design—have helped develop the project.



The working group for Bak overskriftene generating ideas for the intervention



Ideas generated by the group, with different colours for different aspects of the intervention

Contact: Matt Oxman

A survey of Norwegian adults

Mapping the ability to assess treatment claims in Norway

Health literacy efforts in Norway and elsewhere have mainly been directed at providing reliable health information for the public through specific websites. There have been few community-based efforts to teach or evaluate critical health literacy, and we know little about the Norwegians' ability to assess treatment claims.

As in rest of Europe, the mapping studies that have been done have either focused on functional literacy, such as understanding medical terminology, or self-reported critical ability (such as the EU-study).

To our knowledge only one <u>survey</u> has attempted to measure the ability to understand and apply any of the IHC Key Concepts in a representative sample of Norwegian adults. This study, conducted in 2005 only addressed five Key Concepts, and was a precursor to the battery of multiple-choice questions (MCQs) now constituting the Claim Evaluation Tools Database.

In January 2019, members of the IHCteam in Norway - Astrid Dahlgren and Kjetil Furuset-Olsen - designed and undertook the second mapping study of the Norwegian public's ability to assess treatment claims. Drawing our sample from the National registry, 4500 people over 18 years received a postcard invitation to participate in an online study. This time we used MCQs from the Claim Evaluation Tools Database, allowing for comparison with other evaluations conducted internationally. In addition to providing an overview of the extent to which Norwegians are able to assess the trustworthiness of treatment claims, the survey will inform the development of learning resources and enable international comparisons.

Data collection will be closed in March and the results be reported later this year.



Contact: Astrid Austvoll-Dahlgren

knowledge about scientific evidence in everyday life.

On the basis of the IHC Key Concepts, working with a group of people professionally involved in developing and conducting workshops for children, we would like to prepare workshops for school kids (adolescents) about treatment claims, although this is in a very early planning stage.

Contact: Malgorzata Bala

Rwanda

Informed Health Choices primary school resources in Rwanda



Researchers in East Africa and Norway established the IHC project to develop resources for primary schools with the aim to teach children (10 to 12 years) some of the concepts that can be used to make informed health choices. The IHC primary school resources include a textbook and teachers' guide that introduce and explains Key Concepts, instructions for classroom activities, exercises, a list of key messages, and a glossary.

The IHC work in Rwanda started in 2015, where an MPH student, Michael Mugisha, from the University of Rwanda piloted teachers' and children's resources in one

Poland

Our work to disseminate the concepts of informed health choices is still mainly in the planning stage. We are looking for funding or cooperation that will make this work possible.

A group of students from Lodz Medical University translated into Polish 80% of the second edition of *Testing Treatments*. We are following up on this work, aiming to complete the translation, review it, edit it, and make it available in Polish. Our plan is to develop brief summaries for the general public about each chapter, directing them to the book on the <u>Testing</u> <u>Treatments interactive website</u>.

In our interactions with journalists we have been able to inform a wider audience about resources available on the <u>Informed</u> <u>Health Choices website</u> in English and about the book in English.

Our team also has applied for funds for a MOOC (massive open online course) project. If our application is successful, we will design an online course presenting basic knowledge about finding reliable information on treatments and about systematic reviews. The course will be for a lay audience, aiming to broaden

urban school. Around 40 children learned Key Concepts that can help them to make informed health choices. At first during the pilot, resources were perceived as guides to make right choices about what medicines to take. However, the teachers clarified the purpose of the lessons to children during lessons. Children shared the resources with their parents and felt that they needed them and that children in other schools needed them.

Based on the findings from pilot testing the resources in English, they were found to be useful, and easy to read and understand due to the comic story. However, the main challenge to using these resources for some children was that they were in English. Primary school children in Rwanda are taught in English starting from Primary 4. Primary 5, in which the pilot testing was done, was the second year of being taught in English. Consequently, the children were not yet familiar with English as a language of instruction.

In 2017, the same resources were piloted in Kinyarwanda by another MPH student, Ikirezi Aline, in another urban school. Children were able to understand the resources easily and experienced them as useful and relevant in their daily life. Children could easily identify examples of where the lessons could be applied in their daily lives. School teachers felt that similar resources should be developed for older children and adults, since choices and decisions about one's health becomes a challenge as one gets older.

The pilot testing was found to be useful in the Rwandan context. We have learned that it is important to collect suggestions and ideas from participants in order to ensure that resources that resources are well suited to the target audience. We found that the children and teachers were helpful in evaluating and revising the primary school resources, and they significantly contributed to improving the quality of educational resources that will contribute to health and education outcomes of Rwandan citizens.



Contact: Michael Mugisha

South Africa

Informing Health Choices South Africa – a work in progress

Since early 2018, we at the Health Systems Research Unit (HSRU) of the South African Medical Research Council (SAMRC) have been actively seeking funding for a demonstration project to replicate Informed Health Choices in schools in the Western Cape, a province of South Africa.

Our first step was to meet with the provincial Education Department who welcomed the project enthusiastically and agreed to be partners in developing the project further. There was a strong sense that science teachers would enjoy the training underpinning IHC and would find the materials useful for delivering the current curriculum. The Education Department encouraged us to adopt a demonstration approach rather than a trial design given the robust findings of

the Ugandan trial. Top of the Department's agenda is to think futuristically: despite many of our schools suffering significant disadvantage, the Department requests that new programmes be delivered digitally and in the local language. This immediately increases the projected costs of the project, but will potentially encourage local acceptance among science teachers and students.

Our second step was to build the brand of IHC. We rebranded it as an activity: '*Informing* Health Choices SA' (IHCSA), and began to present the concept at relevant organizational and scientific meetings. We have two clear aims: 1) to explore the local applicability of the current IHC programme and, 2) if applicable, to identify the steps necessary to optimise implementation for sustainable scale-up of IHCSA.

We have written a proposal for a 24 month demonstration project led by HSRU scientists experienced in knowledge translation and school-based research, and partnered with pedagogical colleagues from the Education Department and an experienced graphic design team. We will use an action research approach to the development and implementation process to ensure that appropriate feedback is immediately incorporated into revisions and activities. Contextualisation of IHC for South Africa will be informed by a formative evaluation comprising focus groups of teachers and children. We anticipate (and have budgeted for) revisions of the text and illustration to create IHCSA, suitable for our setting. IHCSA will then be translated and digitalised and 12 teachers will be trained to use and train other teachers in the IHCSA package delivered in their language of instruction: English, Afrikaans, and isiXhosa. Finally, 120

children, aged 11 to 13, from three schools will receive the package delivered in their mother tongue. Participating schools will be selected to ensure diversity of participants, settings, and teachers and to maximise the applicability evaluation and the lessons learned from delivery of IHCSA. We will test the knowledge and thinking skills of the learners before and after IHCSA using a validated questionnaire, and will evaluate the competence and confidence of teachers delivering IHCSA by participant-observer evaluation.

We have been supported throughout development of the above plan by the Norwegian-based IHC team and express our grateful thanks to Andy Oxman, Simon Lewin and Sarah Rosenbaum. When funding is secured we plan to establish a Steering Group comprising experienced IHC members from both Uganda and Norway to guide and advise us. Through IHCSA, we see great promise for children and teachers to become active citizen scientists by promoting and advocating for evidence-based healthcare policies and decision-making in South Africa.

Contacts: Nandy Siegfried & Cathy Mathews

Spain

In 2017 the IHC-Barcelona team launched the Informed Health Choices Project. We aim to explore and evaluate how IHC resources can be implemented in Spanish schools.

What has been the progress so far?

• We have translated the IHC resources into Spanish with the help of students and teachers (Virolai School, Barcelona), and

medical doctors (Hospital de la Santa Creu i Sant Pau, Barcelona).

- We have disseminated the Spanish IHC resources (tweets, news, and mailing).
- We have interviewed a school Principal (Virolai School, Barcelona) to get her views on IHC-Barcelona Project and how to approach other schools (see Box 1, Photo 1 and 2).



Photo 1. Interview with Coral Regí, Virolai School Principal (Barcelona)

To what extent is it relevant for children to evaluate the reliability of the information?

- "Children need to learn how to ask questions and how to answer them rigorously."
- "Nowadays, children have a quick access to information through Internet. It is imperative that we teach them how to search and select for relevant information. We have seen that teaching them critical thinking is better than restricting the access to Internet."

Within the current primary education curriculum, in which subject or field of knowledge would you include the training of students to evaluate the reliability of the health information?

- "Children don't have to learn many things in school. It is not about broadening the curriculum or creating a *health subject*. The point is to teach how to use *criteria* that can be then applied to any context."
- "How the resources are included in the curriculum depends on each school. For example, in our school, we could work with them in subjects like *Science*, *Ethics*, or even in *Language*."

Do you know any resource in our context that teaches how to evaluate the reliability of the information? And how to evaluate the reliability of the health information?

 "Students learn what is the Scientific Method, raising questions and a hypothesis, checking these through experimentation, and evaluating what has been learned. We work with children to make them able to improve their scientific knowledge, and establishing the basis of critical thinking."

The resources for primary school children provided by the Informed Health Choices project have been proved to be effective in children in Uganda. What do you think are the challenges for the introduction of these resources into the schools in our context?

Facilitators

•

- "Personally, one of the aspects that I like most about the IHC resources is that they were developed in Africa. We have many things to learn too, maybe here we do not put our finger on the cow dung, but people don't get vaccinated without thinking carefully about this decision."
- "I think it is very important to involve parents in the project. For this reason, I find the IHC podcasts a very interesting resource."
- "This health program is evidence-based."
- "IHC resources are well developed, facilitating a quick access for the children, loving, very friendly, and with beautiful illustrations."

Barriers

- "Schools do not have time to address all the challenges that they are facing or to respond to all situations that arise."
- "Each school prioritises the projects in which they want to participate. Sometimes this is done without formal strategies for example, the projects that first arrives, those disseminated through social networks, or those with the highest reliability."

How do you think the students in our context could apply the knowledge of the Informed Health Choices project in their daily activities?

- "The relevance of the IHC project is the topic, health, and the skills that are taught, critical thinking, which are applicable to any area of knowledge."
- "For a person to be happy it is important to be in good health. It is for this reason that any health program is important."
- "It is vital that people learn to use rigorous information because we live in an easily

manipulated society at all levels, including the social, economic, or political level."



Photo 2. Virolai School children pose with Spanish text book (Barcelona)

What are we up to right now?

- We are developing the pilot study protocol to explore children's and teachers' experiences using the Spanish version of the IHC resources in three schools in Barcelona.
- We are producing the Spanish children's textbook to have a printed version available for the pilot study. This has been possible thanks to the support of Fundación Dr Antoni Esteve.
- We are preparing publications to further disseminate the IHC Project in our context (Gaceta Sanitaria [http://www.gacetasanitaria.org/] and SINC Agency [https://www.agenciasinc.es/]).
- We are collaborating with Dr Andrew Oxman to review frameworks for critical thinking.

What are our plans?

• This year we will apply for funding in a call from the Spanish Ministry of Health to conduct: 1) A document analysis to identify, describe and map the educational documents used to support the teaching of the IHC Key Concepts in our context, 2) A qualitative study to explore the perceptions of relevant stakeholders in relation to teaching critical thinking about healthcare, and to identify factors that facilitate or hinder the implementation of IHC resources, 3) A validation of the Claim Evaluation Tools to assess in the future the effect of IHC resources in our context.

- We will collaborate with OSI-Donostialdea (Donostia, Spain) to pilot the IHC resources in our country.
- We will collaborate with the French translation team to get feedback from students and teachers (Virolai School, Barcelona) on French IHC recourses.

Contacts: Laura Martínez García, Montse León García, Pablo Alonso Coello

Uganda



First prototype of the IHC primary school resources

Allen Nsangi and Daniel Semakula have submitted six articles reporting the research that they completed in Uganda following the randomised trials that were published in *The Lancet* in 2017. The first two articles we report the development of primary school resources to teach children to think critically about treatment claims, and a podcast to teach their parents some

of the same concepts. The second two articles report the primary and secondary outcomes measured again one year after the results reported in The Lancet. After one year, 80% of the children in the intervention schools achieved a predetermined passing score compared with 52% of those in the control schools (adjusted difference 40%, 95% CI 30% to 48%). In the podcast trial, after one year, 47% of the parents in the intervention group compared to 40% of those in the control group had passing scores (adjusted difference 10%, 95% CI 3% to 20%). These results show that the children in the intervention schools retained what they learned, with the proportion of children with a passing score increasing from 69% to 80%; whereas the proportion of parents with a passing score in the podcast group decreased from 71% to 47%.

The last two articles report process evaluations that explored factors that may have affected the implementation and impact of the interventions, and could affect scaling-up their use; and potential adverse and beneficial effects of the interventions. The findings showed that children, their teachers, and parents all found the content of the learningresources to be new, important, and empowering. They found them to be understandable, interesting, and enjoyable. Their positive experience of the learning resources played a key role in their effectiveness. Parents and teachers had some concerns about the potential for conflict between adults and children resulting from children challenging their authority. However, although children challenged both their teachers and their parents, no actual conflicts were reported.

Key messages from these six articles are:

- It is possible to teach primary school children and adults to think critically about claims about the effects of treatments.
- Children are more likely to retain what they learn than adults. It is also more difficult to reach and engage adults in learning new concepts.
- After one year, compared to students in the control schools, students in the intervention schools were also more aware of treatment claims and more sceptical about them, and more likely to assess the trustworthiness of the last claim that they had heard correctly.
- Use of a human-centred design approach resulted in learning resources that children, teachers, and parents experienced as useful, easy to use, understandable, credible, desirable, and well-suited to them.
- How they experienced the resources played a critical role in determining their effectiveness.
- Children, teachers and parents found what they learned to be empowering.



Third (final) version of the IHC primary school resources

Contacts: Allen Nsangi, Daniel Semakula, Nelson Sewankambo

United Kingdom

Generation R

Young people getting actively involved in research

<u>Generation R</u> is an alliance of Young Persons' Action Groups (YPAGs) based in the United Kingdom. The YPAGs are groups of young people, aged 8 to 24, who are interested in health care and health research. The groups get together to learn about health care and research, and to work with researchers on studies involving young people. Each YPAG is facilitated by specialist National Health Service (NHS) staff located in a teaching hospital.

How the YPAGs help research

The groups get involved in research in a number of ways. For example, in January 2019, the London YPAG worked with researchers to improve the experience of children with eye diseases who are taking part in trials. They also advised a new centre for rare diseases on how to lay out the waiting room in their new unit. They even had time to give feedback to a researcher looking into the effects of hearing loss on mental health.

YPAG member Maisie <u>wrote up her</u> <u>experiences in her blog</u>, and there are many more <u>similar stories</u> on the website.



What young people say about Generation R YPAGs

It's not just the researchers who benefit from working with YPAGs. The young people enjoy learning about research and many of them see their involvement as being helpful towards their future careers:

"I decided the join the East Midlands YPAG because I am interested in medicine and wanted to learn more about clinical research. I enjoy the YPAG sessions because in each one we learn something different and the activities we do are fun and interesting."

YPAG Member Katherine, aged 15

Read more about the YPAGS here.



What's on the Generation **R** website?

The website has the distinction of having been designed by the young people themselves, and most of the content is added by young people. It now contains a wealth of information about the groups and what they get up to. There are videos, games and other activities that they have used or produced during their meetings. Parents and Carers are not forgotten, nor are Researchers.

• <u>Check it out to find out more</u>

The YPAGs are currently working on a version of the <u>GET-IT Glossary</u> for young people, so watch this space!

Generation R is supported by the UK National Institute for Health Research

Contact: Douglas Badenoch

A webpage for GPs

I was elected to the Royal College of GPs almost six years ago, and one of the first things I did was to set up the RCGP Overdiagnosis group. This is now an active online group of over 300 GPs, hospital specialists, nurses, and lay people. We have done many things - from changing the guidelines on how guidelines are used, to a '5 tests' policy paper, approved and adopted by the RCGP, which means that all new policies have to be considered against their potential to do unintended harm. We have also held conferences in Scotland, and Birmingham in England, and have a sub group with a particular interest in evidence based laboratory testing, All the work the group did was voluntary until 2018, when the RCGP agreed to fund myself and my colleague Sam Finnikin - a GP academic in Birmingham - as Fellows in Evidence and Values. We now have a half day a week for a couple of years to work on this. Concurrently, Realistic Medicine in Scotland, Prudent Practice in Wales, and Rethinking Medicine in England have raised similar concerns about the way medicine is practiced. We think there is a consensus that shared decision making is an ethical good, but there are also systemic challenges about the way medicine often overpraises interventions, inadvertently harms people, and makes it hard to share those decisions.

We have two projects that we are working on, both in partnership with the Patients and Carers Group of the RCGP. The first is a visual project recording what it is that patients value about general practice. The second is a an online course to introduce some of the concepts that we know are often hard in shared decision making. GP consultations are often time pressured and multifaceted, and for doctors it can often feel risky 'not' to do things, even though it's what the patient wants. We also know there are many terrific projects already blossoming and we do not want to step on any toes or recreate what has already been better done elsewhere. Our vision is for a very basic (but layered) online course which patients, families, carers, healthcare students and professionals can use as a precis, a launchpad, or a guide to all the other great work that already exists. We also want to create a webpage for GPs which links to the resources already existing, hosted on the RCGP website.

We welcome discussion, thoughts and criticism - please feel free to get in touch.



Photo by SiRAstudio

Contacts: Margaret McCartney & Sam Finnikin

United States

Development and testing of the effects of an educational podcast to improve parents' critical appraisal of health services claims in the United States

Most research on the use of evidencebased practices in mental healthcare has focused on increasing supply through providers and organizations rather than on consumer factors that could upsurge demand. This study intends to expand

research on parent consumers of health information by investigating an educational media method for increasing their ability to critically appraise health practices claims for both physical and mental health conditions. The overall aim is to adapt the Informed Health Choices podcast, which successfully taught critical appraisal to parents in Uganda, for a U.S. parent audience. Development and testing of the U.S. parent podcast includes the following phases:

1) Conduct an online critical appraisal needs assessment to establish podcast content using items from the Claim Evaluation Tools. This phase was completed in November 2018 (n = 179 internet-using parents).

2) Adapt podcast scripts to prioritize Key Concepts that emerged as most difficult to parents during needs-assessment phase, and include physical and mental health claims relevant to U.S. parents. This phase is 95% complete as of March 2019.

3) Record and mix the podcast.

4) Carry out user-testing and a focus group with ten parents to collect feedback.

5) Conduct an internet-based pilot randomized trial with a sample of 200 internet-using parents. Prior to the pilot trial, we will conduct a pre-pilot with 20 parents. We will test the effects of the educational podcast on critical appraisal skills, intended behavior, and attitudes toward evidence-based practices.

We plan on completed the last three phases of the project in April 2019.

Contacts: Vanesa Mora Ringle & Amanda Jensen-Doss

Other resources

TEBHC Learning Resources Database

TeachingEBHC.org – Home of the CARL Database

The Critical thinking and Appraisal Resource Library (CARL) was originally developed by Testing Treatments international, but is now housed in a new website, <u>TeachingEBHC.org</u>.

The searchable database contains over **500 learning resources** for everybody from self-directed members of the public to professors of research. Our friends at Minervation have taxonomized and usercentred-designed it into a handy tool for anyone who has ever thought "**Hmm**, where can I get some inspirational teaching material for this stuff?"

Evidence Based HEALTH CARE	Teachers of Evidence-Based Health Care	
Learn	ning Resources Database	3
Q Fi	nd Resources	Search
Filter by:	EBM Stage	
Sort by:	Target audience Language Format Difficulty Relevancy Display as: List	Clear

The site has been designed with mobile browsing in mind and, of course, features a **Trip Advisor-style** rating scheme so you can tell us which resources you like best. You can even create **Bundles** of resources and share them with your students.

Who is behind it?

TeachingEBHC.org was funded by the James Lind Initiative and supported by the <u>International Society for Evidence</u> <u>Based Health Care</u>. Content is edited by Patricia Atkinson, Douglas Badenoch and Paul Glasziou. The initial search for

resources was done by John Castle (<u>Castle</u> 2017).

We must also acknowledge the encouragement and support of the Sicily group of Teachers and Developers of EBHC. When we met in October 2017, this germ of an idea received a thorough watering with encouragement and ideas. As the design and conception developed, the group provided feedback to help keep us on track. And now they help us to keep the content in hand.

How can I help?

Joining this august body is as simple as signing up to the Teaching EBHC Network. From there, you can do any or all of the following:

- Rate and comment on learning resources you've tried
- Create Bundles for others to use
- Suggest new learning resources, especially in areas where our cover is thin
- Review suggestions for new resources to add

Contact: Douglas Badenoch

Testing Treatments

The second edition of *Testing Treatments* was published in 2011. By the end of 2018, translations were available or in preparation in 20 languages - Arabic, Basque, Catalan, Chinese, Croatian, Danish, Farsi, French, German, Italian, Japanese, Korean, Malay, Norwegian, Polish, Portuguese, Russian, Spanish, Swedish, Thai, and Turkish. Texts of the book and its translations are all available free, both through the Testing Treatments interactive (TTi) sibling websites www.testingtreatments.org and through the <u>Cochrane Collaboration's learning</u> <u>programmes</u>. The numbers of annual visits to the book ranges from 62 and 281 (Basque and Catalan) to 3,361, 32,918 and 37,629 (Chinese, English and Spanish, respectively). Audio versions of the book in Chinese, Spanish and English are also freely available on the relevant websites.

In his foreword to Testing Treatments, Ben Goldacre, a researcher and science writer, wrote "I genuinely, truly, cannot recommend this awesome book highly enough for its clarity, depth, and humanity." The book's strengths were summed up succinctly by a Norwegian physician who judged the book to be "Important, scary, and encouraging". Others have written that Testing Treatments is "a terrific little book" (BMJ); "...the best available introduction to the methods, uses and value of fair testing (Health Affairs); and that it "...will inform patients, clinicians and researchers alike" (Lancet), and "should be required reading for everyone interested in healthcare (J Clin Res Best Practices). The European Writers' Association noted that the book "... encourages users and providers of healthcare to question assumptions, detect biases, and raise questions about the quality of the evidence if they find it unconvincing".

Perhaps the best endorsement of the enduring value of *Testing Treatments* is that people continue to go to the trouble of translating it into other languages. These positive reactions to the book are likely to reflect, in part, extensive pre-publication piloting of its text with lay and professional readers.

In 2013, Iain Chalmers convened a TTi Editorial Alliance to share experiences of using translations of the book in different

languages (<u>Chen and Chalmers 2015</u>). Opportunities have been taken subsequently to have meetings when circumstances permitted. At a meeting at the end of 2018, the role of convenor of the Editorial Alliance passed from Iain to

The former Chinese Vice Minister of Health, Dr. Longde Wang said that *Testing Treatments* is a priceless book. I believe the book will be popular for decades and will benefit patients and the public globally.

Contact: Yaolong Chen

me.

The GET-IT Glossary

The GET-IT (Glossary of Evaluation Terms for Informed Treatment choices) Glossary was established to provide plain language definitions of health research jargon terms.

How we built GET-IT

A team was established to identify and collate existing glossaries, review their scope and definitions and write plain language versions of these definitions.

A list of 242 health research terms were identified, and all the existing definitions compared and consolidated. Where a new definition was warranted, it was written and reviewed. You can read more about how we developed GET-IT in <u>Moberg et al</u> 2018.

How you can get GET-IT

The glossary can be found here: <u>getitglossary.org</u>.

Users can browse or search for definitions, explanations and examples. Links are provided between entries to allow exploration. Each entry has a Definition, Synonyms, Full Explanation and See Also fields. The Content Management System (CMS) also supports additional materials, such as cartoons and illustrations, which are provided for some definitions. The CMS also provides version control functionality.

Search

— The process of assigning <u>participants</u> in a study to treatment comparison groups using a chance process, like

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

۹

Sign in

Not getting it?

random allocation

drawing lots, to protect against bias.

GET-IT Glossary

Browse the glossary:

GET-IT has an in-built tracker for how well the definitions work. We count the proportion of readers who click the "I Don't Get It (IDGI)" character, presented as a visual call-to-action. This feature



This allows us to prioritise the improvement of definitions in our annual review, and also measure whether our improvements have worked!

Get GET-IT on your website

GET-IT can be embedded in other websites as a sidebar widget and pop-up boxes, with content drawn through from the glossary database. Any changes to the glossary are automatically deployed to any third party website users.

GET-IT can also be cloned to provide a bespoke glossary tool. This includes translations into languages



other than English and versions for different audiences, such as young people (currently being developed by <u>Generation</u> <u>R</u>) or practitioners of Evidence-Based Health Care (<u>cebm.getitglossary.org</u>, embedded in the <u>Catalogue of Bias</u>).

If you are interested in using GET-IT in your website, <u>please get in touch</u>.

Contact: Douglas Badenoch

Treatment information on the web

Who can you trust? A review of free online sources of "trustworthy" information about treatment effects for patients and the public

Information about effects of treatments based on unsystematic reviews of research evidence may be misleading. However, finding trustworthy information about the effects of treatments based on systematic reviews, which is accessible to patients and the public can be difficult. The objectives of <u>this study</u> were to identify and evaluate free sources of health information for patients and the public that provide information about effects of treatments based on systematic reviews.

We reviewed websites that we and our colleagues knew of, searched for government sponsored health information websites, and searched for online sources of health information that provide evidence-based information. To be included in our review. a website had to be available in English, freely accessible, and intended for patients and the public. In addition, it had to have a broad scope, not limited to specific conditions or types of treatments. It had to include a description of how the information is prepared and the description had to include a statement about using systematic reviews. We compared the included websites by searching for information about the effects of eight treatments.

Three websites met our inclusion criteria: Cochrane Evidence, Informed Health, and PubMed Health. The first two websites produce content, whereas PubMed Health aggregated content. A fourth website that met our inclusion criteria, CureFacts, was under development. Cochrane Evidence provides plain language summaries of Cochrane Reviews (i.e. summaries that are intended for patients and the public). They are translated to several other languages. No information besides treatment effects is provided. Informed Health provides information about treatment effects together with other information for a wide range of topics. PubMed Health was discontinued in October 2018. It included a large number of systematic reviews of treatment effects with plain language summaries for Cochrane Reviews and some other reviews. None of the three websites included links to ongoing trials, and information about treatment effects was not reported consistently on any of the websites.

It is possible for patients and the public to access trustworthy information about the effects of treatments using two of the websites included in this review. However, these websites could be improved and made more useful and easier to use by consistently reporting information about the size of both the benefits and harms of treatments and the certainty of the evidence, and by making it easier to find relevant information.

Searching the websites frequently yielded much irrelevant information. Users can limit searches by using Boolean logic inserting AND between terms (e.g. for the condition and for the treatment) and quotation marks to indicate that words need to be next to each other; e.g. "back pain". However, this is unlikely to be obvious to novice users. Some users may want to use sources that are not intended for patients and the public, such as *Epistemonikos*, if they are unable to find information on one of these websites. They also might want to consider searching for ongoing trials, if there is important uncertainty about the effects of relevant treatments.

There are many other websites that claim to provide evidence-based or reliable information about treatments, but it is difficult to assess the reliability of the information about treatment effects provided on those websites since they do not explicitly base that information on systematic reviews.

Contacts: Andy Oxman & Elizabeth Paulsen

Evidence-based information checklist

Many individuals and organisations provide information about treatment

effects for the purposes of informing decisions about healthcare. For instance, government authorities and professional organisations host web sites with health advice to the public. Much of this kind of information is not evidence-based. But even information that *is* based on systematic reviews may still be unclear, incomplete, and misleading.

At the Centre for Informed Health Choices, Norwegian Institute of Public Health, we are creating guidance for people who produce this type of evidencebased information, for instance targeted summaries based on systematic reviews.

Based on research relevant to communicating evidence-based information, including existing systematic reviews, and our own experience and research, we have produced a set of draft recommendations. We then compared this to guidance produced by others. Lastly, we sought structured feedback from people with relevant expertise, including people who prepare and use information about the effects of interventions for the public, health professionals, or policymakers.

The result is a checklist with ten recommendations:

- Three recommendations are about making it easy to quickly determine the relevance of the information and find the key messages.

- Five recommendations are about helping the reader understand the size of effects and how sure we are about those estimates.

- Two recommendations are about helping the reader put information about intervention effects in context, and to understand why the information is trustworthy.

These ten recommendations summarise lessons we have learned from the literature and our experience over the past

20 to 30 years developing and evaluating ways of helping people to make wellinformed decisions by making research evidence more accessible to them. When the checklist is finalised, we will submit it for publication and create a video that provides examples and instruction.

Make it easy for your target audience to quickly determine the relevance of the information and find the key messages.

- State clearly the people for whom the information is relevant, the options that were considered, and the outcomes that were considered – so that people can determine if the information is relevant to them.
- Present information in layers using language that is appropriate for your audience – so that they can easily and quickly get the key messages and dig deeper if they want.
- Report all potentially important benefits and harms, including ones for which no evidence was found – so that there is no ambiguity about what was found for each outcome that was considered.

For each outcome, help your target audience to understand the size of the effect and how sure we can be about that; and don't mislead them.

- 4. Explicitly assess and report the certainty of the evidence.
- 5. Use language that is consistent and "plain".
- Present both numbers and words, and include summary of findings tables.*
- 7. Report absolute effects with confidence intervals.
- 8. Avoid misleading presentations and interpretations of effects.
 - Avoid implying that everyone will experience an average effect.
 - Always include scales, and explain unfamiliar scales.
 - Avoid misleading reports of subgroup effects.
 - Avoid confusing "statistically significant" with important.
 - Avoid confusing "no evidence" with "no effect".

Help your target audience to put information about the effects of interventions in context, and to understand why the information is trustworthy.

- Provide relevant background information and help people weigh the advantages against the disadvantages of interventions, taking into consideration their baseline risk or the severity of their symptoms, and what's important to them.
- 10. Tell your audience how the information was prepared, what it is based on, when it was prepared and who prepared it.

*A summary of findings table is a table that shows the size of the effect and the certainty of the evidence for each important outcome.

Draft checklist, March 2019

Contact: Sarah Rosenbaum

Contributors

Ahmad Sofi Mahmudi ahmad.pub@gmail.com

Aline Ikirezi <u>dadika90@yahoo.fr</u>

Allen Nsangi <u>allennsangi@gmail.com</u>

Andy Oxman <u>oxman@online.no</u>

Anke Steckelberg anke.steckelberg@medizin.uni-halle.de

Astrid Austvoll-Dahlgren astrid@rbup.no

Camilla Alderighi camilla.alderighi@gmail.com

Cathy Mathews <u>catherine.mathews@mrc.ac.za</u>

Cinzia Colombo cinzia.colombo@marionegri.it

Daniel Semakula semakuladaniel@gmail.com

Douglas Badenoch douglas.badenoch@minervation.com

Emma Carter general@students4bestevidence.net

Giordano Pérez Gaxiola giordanopg@gmail.com

Iain Chalmers ichalmers@jameslindlibrary.org

Ignacio Atal ignacio.atal@cri-paris.org

Jingyi Zhang jingyizhang1394@163.com

Jose Ignacio Emparanza Knorr ignacio.atal@cri-paris.org

Laura Martinez laura.martinez.garcia@cochrane.es

Leila Cusack leila.cusack@student.bond.edu.au

Linda Biesty linda.biesty@nuigalway.ie

Loai Al Barqouni <u>lnb6des@daad-</u> <u>alumni.de</u>

Malgorzata Bala malgorzata.1.bala@uj.edu.pl

Margaret Kaseje <u>mkaseje@gmail.com</u>

Margaret McCartney margaret@margaretmccartney.com

Martin Vuillème martin.vuilleme@gmail.com

Matt Oxman matt@mattoxman.com

Michael Mugisha michaelmgsh@gmail.com

Monserrat León García <u>mleong@santpau.cat</u>

Nandi Siegfried nandi.siegfried@gmail.com

Nelson Sewankambo sewankam@infocom.co.ug

Pablo Alonso Coello PAlonso@santpau.cat

Paola Mosconi mosconi@marionegri.it

Qi Wang wangq87@mcmaster.ca

Raffaele Rasoini raffaele.rasoini@tiscali.it

Roberto D'Amico damico.roberto@unimore.it

Sam Finnikin <u>sfinnikin@gmail.com</u>

Sarah Rosenbaum <u>sarah@rosenbaum.no</u>

Shelly Pranic <u>spranic@mefst.hr</u>

Simona Vecchi <u>s.vecchi@deplazio.it</u>

Tina Poklepovic tinapoklepovic@gmail.com

Vanesa Abigail Ringle vanesa.ringle@miami.edu

Yaolong Chen chenyaolong21@163.com

Yamama Bdaiwi yamama.bdaiwi@kellogg.ox.ac.uk