



Informed Health Choices

Update - 9 January 2018

Supporting informed healthcare choices
in low-income countries

FINAL REPORT

Summary

The Informed Health Choices (IHC) project started in January 2013 with a 5-year grant from the Research Council of Norway. In this update we summarise what we have accomplished with that support and what we see as the next steps in this work. Our aim is to enable people to think critically about health claims and choices.

During the past five years we have:

- Developed 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
- Developed and validated [evaluation tools](#) to assess an individual's ability to apply the IHC Key Concepts
- Designed and user-tested [learning-resources](#) to enable primary school children and their parents to understand and apply some of the Key Concepts
- Evaluated the effectiveness of those learning-resources in [randomised trials](#)
- Prepared a [database of learning-resources](#) intended to help people understand and apply one or more of the IHC Key Concepts
- Prepared a [plain language glossary](#) of health research terms

In addition, we have:

- Collected [in-depth qualitative data](#) from observations, interviews and focus group discussions to investigate ways of scaling up effective use of the resources, potential adverse effects and other potential benefits of the interventions
- Collected [one-year follow-up data](#) to assess the extent to which participants in the trials have retained and applied what they learned
- [Translated, piloted, and user-tested](#) the IHC primary school resources in Kenya and Rwanda

We are collaborating with colleagues in other low, middle, and high-income countries and plan to continue to develop the IHC Key Concepts, the Claim Evaluation Tools Database, and learning-resources to enable children, young people, and their parents to assess the trustworthiness of health claims and make informed health choices.

Background

We want to enable people to think critically about health claims and choices.



Claims about what improves or harms health are ubiquitous. Many of these are unreliable and many people are unable to distinguish reliable from unreliable claims. This leads to poorly informed choices, unnecessary suffering, and waste. This problem is worse for people in low-income countries because they can least afford to waste resources. We aim to address this problem by enabling people to think critically about health claims and choices, to make informed personal choices, and to contribute to informed health policy decisions.



Supporting informed healthcare choices in low-income countries (SIHCLIC) was a research project supported by the Research Council of Norway from January 2013 to December

2017 (GLOBVAC project 220603/H10). The objectives of this project were to develop and evaluate resources for primary schools and mass media resources designed to improve the ability of children and adults to assess claims about the effects of treatments. Our focus was on low-income countries. By treatments, we mean any action intended to maintain or improve health.

The key partners in the SIHCLIC project were the Norwegian Institute of Public Health, Makerere University in Uganda, Great Lakes University of Kisumu in Kenya, the University of Rwanda, and the James Lind Initiative in the UK. The primary focus of our work was in Uganda where two doctoral candidates, Allen Nsangi and Daniel Semakula, were responsible for implementing the project. Our approach to achieving our objectives included:

- Establishing an advisory group, a network of teachers in Uganda, and a network of journalists in Uganda, and engaging these groups in the research
- Mapping the key concepts that people need to understand and apply when assessing claims about treatment effects and making health choices
- Developing evaluation tools to measure people's ability to assess health claims and make informed choices
- Designing resources to enable them to do this
- Evaluating the effects of using those resources

What we have done

The Informed Health Choices (IHC) Key Concepts

The [IHC Key Concepts](#) serve as standards for judgment, or principles for evaluating the trustworthiness of treatment claims, comparisons, and choices. The list is intended to be universally relevant. The concepts can help people to:

- Recognise **claims** about the effects of treatments which have an unreliable basis
- Understand whether **comparisons** of treatments are fair and reliable
- Make informed **choices** about treatments



The IHC Key Concepts serve as the basis for developing learning-resources to help people understand and apply the concepts when claims about the effects of treatments (and other interventions) are made, and when they make health choices. They are also the basis for a database of multiple-choice questions that can be used for assessing people's ability to apply the IHC Key Concepts.

We started to develop this list of concepts at the start of the project in 2013. We published the first version of the list in 2015 [1], with 33 concepts in six groups. We published a revised list with 34 concepts in three groups in October 2016 [2]. The current list, published in October 2017, has 36 concepts in the same three groups [3]. A paper describing the current status of the IHC Key Concepts and some of its uses will be published in January 2018 [4].

Evaluation tools

The [Claim Evaluation Tools Database](#) consists of multiple-choice questions that assess an individual's ability to apply the IHC Key Concepts.



1 Habibah has pain in her ear, and she asks her brother Hassan what to do about it. He says that once, when he had a pain like that, he rinsed his ear with hot water. The next day, his ear pain was gone. Based on his experience, he says rinsing with hot water is helpful for ear pain.

Do you agree with Hassan?

A. Yes, because this is Hassan's experience, it is likely to be true

B. No, Hassan's experience is not enough to be sure

C. Yes, Hassan rinsed his ear with hot water, and the next day his ear pain was gone

Astrid Austvoll-Dahlgren, led this work as a postdoctoral fellow. Astrid, together with the two doctoral candidates, systematically reviewed existing instruments that measure an individual's understanding of or ability to apply at least one of the Key Concepts [5]. They found 415 studies that met their inclusion criteria, but the instruments only covered a handful of the concepts. Only four covered 10 or more. Rather than develop another single instrument, we developed the Claim Evaluation Tools Database. It contains multiple-choice questions that assess an individual's ability to apply the Key Concepts. We iteratively developed questions for each concept, based on extensive feedback from methodological experts, health professionals, teachers, children, and members of the public [6]. We conducted Rasch analyses to validate sets of questions [7,8]. The questions are currently available in several languages, including: Norwegian, Chinese, English, German, Luganda, and Spanish. Rasch analyses of translated sets of questions have been conducted in China and Mexico, as well as in Uganda, and are underway in Germany. The questions can be used for self-assessment, or by teachers to assess students, or by researchers to evaluate interventions or map abilities in a population.

[Learning-resources](#) for primary school children and their parents



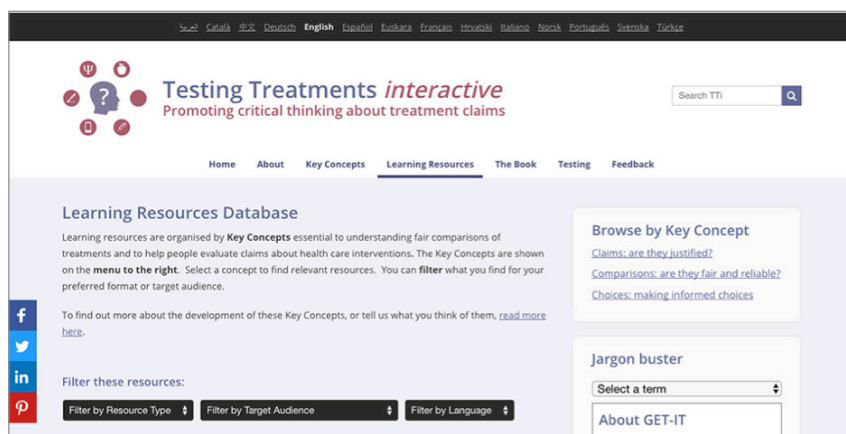
We used human-centred design methods to develop these learning-resources. This entailed multiple cycles of development: idea generation, prototyping, testing, analysis and refinement. We piloted, and user-tested resources in Uganda, Kenya, Rwanda, and Norway. The resulting learning-resources for primary schools include a [textbook](#), a [teachers' guide](#), an [exercise book](#), a [poster](#), and a [song](#). The textbook consists of a story told in a comic book format, instructions for classroom activities, exercises, a checklist summarising the concepts in the book, and a glossary of key words with definitions in English and translations to Luganda and Swahili. The activities, exercises, poster and song reinforce the Key Concepts and main messages introduced in the story.



Similarly, together with journalists in Uganda, we prototyped, user-tested and piloted mass media resources for facilitating critical appraisal of claims about treatment effects. This resulted in an educational [podcast](#) for teaching nine of the concepts to parents of primary school children, produced in both English and Luganda. The podcast complements the primary school resources, which include 12 concepts. We also developed a [checklist](#) for parents, summarising the concepts and main messages in the podcast.

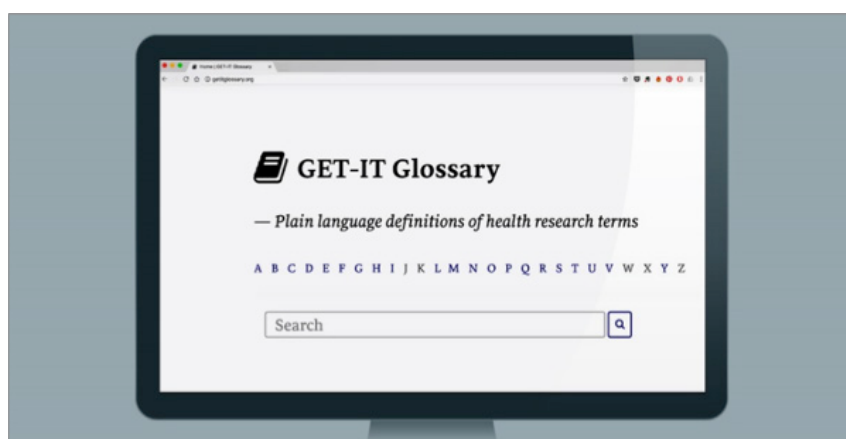
The Critical thinking and Appraisal Resource Library (CARL)

In addition to the interventions described above, we have developed the Critical thinking and Appraisal Resource Library (CARL) [9], an inventory of learning-resources for those responsible for teaching school children, undergraduates, and graduates. One aim of this inventory is to encourage formal evaluations of learning-resources to assess their effectiveness in promoting the skills needed to assess treatment claims. CARL currently contains over 500 open-access learning-resources in a variety of formats: text, audio, video, webpages, cartoons, and lesson materials. Only eight of these resources have been formally evaluated.



A plain language Glossary of Evaluation Terms for Informed Treatment choices (GET-IT)

We have also developed a glossary to provide plain language explanations and illustrations of 242 commonly used health research terms [10].



Randomised trial of the IHC primary school resources



In a cluster-randomised trial of the primary school intervention, published in *The Lancet*, we included primary schools in the central region of Uganda, which taught year-5 children (aged 10–12 years) [11]. We randomly allocated a representative sample of eligible schools to either the intervention group (n=60, 76 teachers and 6383 children) or control group (n=60, 67 teachers and 4430 children). Intervention schools received the Informed Health Choices primary school resources. Teachers attended a two-day introductory workshop and gave nine 80-minute lessons during one school term. We did not intervene in the control schools. The primary outcome, measured at the end of the school term, was the mean score on a test with two multiple-choice questions for each of the 12 concepts and the proportion of children with passing scores [12] on the same test. In the intervention schools, 69% (3967/5753) children achieved a predetermined passing score (≥ 13 of 24 correct answers) compared with 27% (1186/4430) children in the control schools (adjusted difference 50%, 95% CI 44–55; $p < 0.00001$).

[Randomised trial of the IHC podcast](#)



We evaluated the podcast in a linked randomised trial in central Uganda, which was also published in *The Lancet* [13]. We recruited parents of children at 35 schools that were participating in the trial of the primary school resources. The parents were randomly allocated to listen to either the Informed Health Choices

podcast (intervention group; $n=334$) or typical public service announcements about health issues (control group; $n=341$). The primary outcome, measured after listening to the entire podcast, was the mean score and the proportion of parents with passing scores [12] on a test with two multiple choice questions for each of nine Key Concepts essential to assessing claims about treatments (18 questions in total). In the podcast group, 71% (203/288) parents had a predetermined passing score (>11 of 18 correct answers) compared with 38% (103/273) parents in the control group (adjusted difference 34%, 95% CI 26–41; $p<0.0001$).

Process evaluations, follow-up and piloting the learning-resources in other settings

No adverse events were reported in either trial. We measured outcomes again after one year, including actual treatment decisions, based on self-report. In process evaluations, we have collected in-depth qualitative data from observations, interviews and focus group discussions [14,15]. We are using these data to investigate factors that might have influenced the effect of



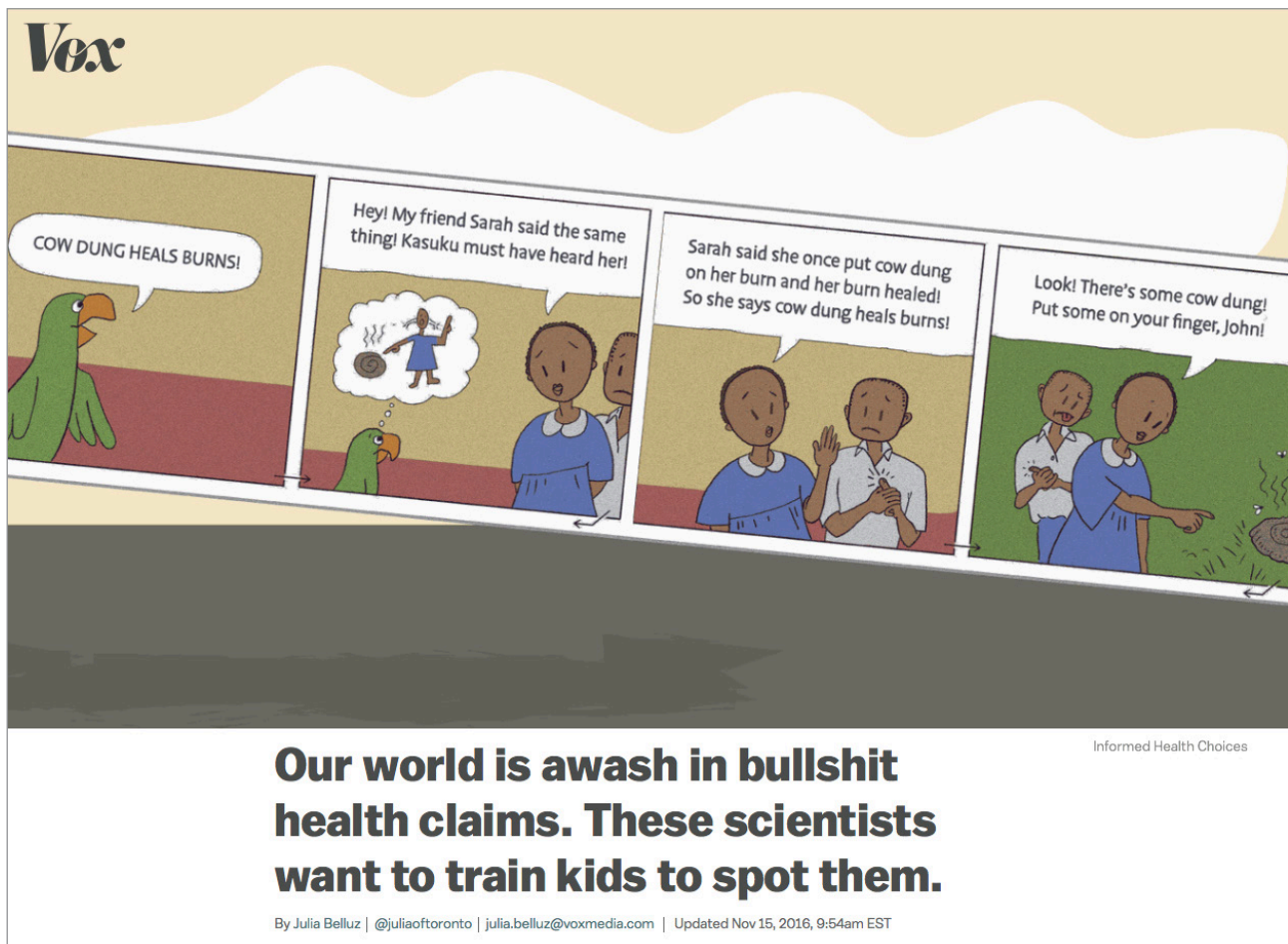
the interventions, ways of scaling up effective use of the resources, and potential adverse effects, in addition to other potential benefits of the interventions. We are also evaluating the extent to which, after one year, participants in the trials retained and applied what they learned. We are investigating the transferability of the interventions in Kenya and Rwanda, using primary school resources that have been translated to [Kiswahili](#) and [Kinyarwanda](#).

Dissemination and use of the results



In his [President's Address](#), 28 June 2017, Sir David Spiegelhalter, President of the Royal Statistical Society, said about our work: "It's a new science that is being developed, and very important indeed." Both our approach and our outputs are ground-breaking. Although, most of the methods that we use are well established (e.g. human-centred design methods, randomised trials, and process evaluations), we are not aware of other groups using this combination of methods. We have also contributed to the further development of these methods. For example: using a systematic and iterative method to develop a framework for critical thinking about treatments and informed health choices; exploring multidisciplinary, human-centred design approaches to engage children, parents, educators, and researchers in developing learning-resources; and further developing methods used to determine criterion-based cut-offs for tests.

The two educational interventions that we have already developed and evaluated are both the first of their kind. As noted by Bermudez and colleagues in The Lancet [16], commenting on our randomised trials: *"The implications for these papers are relevant to multiple stakeholders - those interested in health promotion, evidence-based healthcare, and health literacy. First - as Nsangi, Semakula, and colleagues mention - the ability to assess and refute health claims creates a more informed citizenry that will make better family health decisions while also holding governments accountable for health policy."*



Our Lancet article reporting the randomised trial of an intervention in primary schools was in the top 1% of [Altmetric Attention Scores](#) compared to outputs of the same age. While there are important uncertainties, which we intend to address in subsequent research, we have demonstrated that this work is feasible and that there is widespread interest in it and recognition of its importance. [Links to media coverage of the project can be found here](#). Our work will be featured in a programme currently being made for broadcast by BBC World.



The resources that we have developed are freely available and we are using a variety of strategies to disseminate them and our findings. We are promoting dissemination and use of the results through [mass media](#), social media, our own [website](#) and other websites, and presentations. The school resources and multiple-choice questions from the Claim Evaluation Tools Database are being translated to other languages, and piloted and validated in other countries. Two major challenges that we plan to address in future research are ways of reducing the cost of the intervention in schools in low-income countries and ensuring that the learning-resources are adapted to curricula.

Next steps

Colleagues in other countries, including Spain, Switzerland, Ireland, and the U.S.A. are translating, adapting, and testing the IHC learning-resources in their contexts; and we have prepared guides for piloting the IHC school resources [17] and podcast [18]. In China, Germany, and Mexico [19], colleagues have translated and validated questions from the



Claim Evaluation Tools Database; and we have prepared a guide for doing this [20]. [Contact us](#) if you would like to translate, adapt, or pilot the IHC learning-resources or questions from the Claim Evaluation Tools Database in your setting.

Research is needed to address how best to scale up use of the learning-resources, their suitability and effects in other countries, and how to build on these resources with additional primary and secondary school resources. Few studies have investigated the effects of interventions to teach critical appraisal skills to children, patients or the public in any country. Key challenges that we plan to address in future work include:

- Continuing to develop the Key Concepts list and use that as the basis for a spiral curriculum for teaching primary and secondary school children to think critically about treatments and make informed health choices. A spiral curriculum is an approach to education that introduces the concepts to students at a young age and covers these concepts repeatedly, with increasing degrees of difficulty and reinforcement of previous learning.
- Developing a fully functioning online database of multiple-choice questions and sets of validated questions that can be used for self-assessment, assessment of students by teachers, and evaluation of interventions by researchers; including questions that can be incorporated in learning-resources for formative assessment and resources for generating summative assessments, including computer-adaptive testing.
- Developing and evaluating sets of learning-resources that build on each other to help children and young people learn to apply all the concepts in the spiral curriculum.
- Market and stakeholder analyses to learn how best to ensure that we develop resources that will be used in schools

We plan to make all the learning-resources that we develop open access, and designed for translation, working with an international collaboration to ensure that our learning-resources are flexible and can easily be used or adapted for use in other contexts.

We are looking for funding to support this work and welcome suggestions and collaboration.



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* For a complete list of over 30 IHC publications see www.informedhealthchoices.org/publications/

