ENHANCING PUBLIC UNDERSTANDING OF HEALTH RESEARCH

Conference Report

Kellogg College, Oxford 7-8 April 2011

Executive Summary

Introduction

A two-day *Conference on Enhancing Public Understanding of Health Research*, held at Kellogg College on 7-8 April 2011, was attended by 35 participants from across the world. The aim was to look at the development and evaluation of methods and materials to enhance public understanding of health research and explore the creation of an international Network to collaborate and promote progress in this area.

Format

There were plenary sessions with formal presentations and parallel workshops on participant-chosen themes to explore issues and challenges in enhancing public understanding of health research.

Formal presentations

Drs Woloshin and Schwartz presented a sample of products identified in an inventory of what is currently available and an overview of the topic. They also reported two randomized trials evaluating the impact on knowledge of *Know Your Chances,* a book written to help the public understand numbers in health research. Dr Burls demonstrated an interactive, flash-based package to help people interpret confidence intervals and described an internet trial being undertaken to see whether the package is acceptable and effective. Dr Oxman presented six projects related to promoting understanding of health research: BackInfo; Consumer Use of Research Evidence; Summary of Findings Tables for Cochrane Reviews; SUPPORT summaries; plain language summaries; DECIDE.

Participant-led small group and plenary discussions

Issues raised in discussions were mapped to nine key areas: target groups and scenarios; intermediaries; evaluation; research and development (R&D); Wikipedia, YouTube, and Web 2.0; context and personal motivation; making messages better; mapping what is being done; critical appraisal skills and understanding risk. Three themes were chosen for in-depth parallel workshops:

Theme 1 - Target groups and context

The target audience was judged to be any interested person, from teenage onwards. It was noted that materials need to reflect to what people feel they want to know and be available in a variety of languages. The key proposal from the workshop was to develop a humorous, interactive website called *Certified Bullshit*. This would use topical news stories and Web 2.0 functionality to engage the public in distinguishing between trustworthy and untrustworthy evidence and would link to further learning resources.

Theme 2 - Intermediaries

Intermediaries were defined as people who provide information about health care to the public, such as journalists, community based organisations, health professionals, and school teachers. Intermediaries can be engaged in many ways, including through a web portal, and can help promote access to explanatory resources and encourage critical thinking.

Theme 3 – Evaluation, Research and Development

This group proposed that an international Network should be established to develop a website of evaluated resources, and to facilitate collaboration, evaluation, dissemination and translation of resources. They proposed that a taxonomy be developed to help organise this material.

Moving forward

Sir Iain Chalmers chaired the final plenary session. The meeting had created a lot of energy and enthusiasm.

It was agreed:

1. to submit a bid to the Wellcome Trust to create an interactive website, CertifiedBullshit.org
2. to form an international Network to collaborate on the development, evaluation, adaptation, translation and dissemination of materials and projects to promote healthy scepticism and help people become discriminating users of health research
3. to set up a website and/or online group to support the Network
4. to seek funding to support the website and Network in the future
5. to agree and circulate a report of the conference.

Report of the Enhancing Public Understanding of Research Conference – Kellogg College Oxford 7-8 April 2011

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About the Conference

The "Enhancing Public Understanding of Health Research" Conference 2011 drew together thirty-five individuals from around the world with experience of developing and evaluating materials to help people become discriminating users of health research and to promote healthy scepticism – the reflex to ask *"Why should I believe these results? What do they mean?"*

Conveners
The conference was convened by Amanda Burls, Iain Chalmers, Lisa Schwartz and Steve Woloshin in Oxford, with input from Paul Glasziou in Australia, Ben Goldacre in London, and Andy Oxman in Oslo. The meeting was hosted by Kellogg College, University of Oxford, and received funding from the Wellcome Trust and the National Institute for Health Research.

Aims
To learn from the practice of others who have developed and evaluated methods to enhance public understanding of health research.

To explore the creation of an international Network to advance the development and evaluation of tools, and other initiatives, to enhance public understanding of health research.

Objectives
1. To share information about projects undertaken by participants to enhance public understanding of health research.
2. To present the current findings of a search for interactive tools and learning materials to help people develop skills to make sense of scientific evidence.
3. To consider opportunities for the development of further tools or projects.
4. To consider how tools/programmes can be evaluated and promote an evaluative culture.
5. To explore the feasibility, desirability and logistical requirements for setting up an international Network to enhance public understanding of health research.
6. To develop concrete proposals for future collaborative working.

Focus
To enhance the public understanding of health research, we need to develop and evaluate efforts to improve:

The public's skills
- How can we help people develop the skills needed to become more discriminating when seeking and using health research?
- How can we generate awareness of the need to be discriminating?

The messages people receive
- How can we promote policies to create better messages routinely?
- How can we educate communicators to understand better what is needed?

Conference Programme

Thursday 7th April

11:00   **Welcome** – Professor Jonathan Michie, President of Kellogg College

11:10   **Introductory session** (Iain Chalmers and Amanda Burls)

11:45   **The bigger picture and what is out there?** (Steve Woloshin, Lisa Schwartz)

13:00   **Lunch**

14:00   **Problems and Solutions** (Chaired by Amanda Burls)
           Small group discussions and plenary session to identify issues and prioritise themes

16:00   **Tea and coffee**

16:30   **Are our efforts any good?** (Chaired by Andy Oxman)
           Evaluation of a book - Lisa Schwartz and Steve Woloshin
           Evaluating a flash-based interaction on confidence intervals - Amanda Burls
           Summary of findings tables- Andy Oxman

18:15   **Close of plenary session**

19:00   **Conference dinner** (After-dinner speaker, Ben Goldacre)

Friday 8th April

08:45   **Group working on the top three themes prioritised by conference participants**
           (Doug Badenoch, Louise Locock and Gill Gyte were group facilitators)

11:00   **Coffee**

11:30   **Plenary session** (Chaired by Paul Glasziou)

12:30   **Lunch**

13:30   **Aims and Activities of a possible International Network** (Chaired by Iain Chalmers)
           Small group discussions
           Plenary session

15:00   **Taking things forward**

15:30   **Next Steps** (Chaired by Iain Chalmers)

16:00   **Close**

Conference Participants

Organisers

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4. Ben Goldacre: bengoldacre@gmail.com;
5. Andy Oxman: oxman@me.com
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Participants (attendance was by invitation only)

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Summary – Day One

Welcome – Professor Jonathan Michie, President of Kellogg College

Professor Michie welcomed a high quality and diverse group of international experts to Kellogg College. He highlighted the commitment of the College to supporting students engaged in part-time study and in postgraduate continuing professional development, noting that the Kellogg College's vision shared much with the aims of the Conference.

Introductory session – Sir Iain Chalmers and Dr Amanda Burls

Iain Chalmers explained the background to his interest in the topic of the conference. Early in his career, while a clinician, he realised that some of the things that he had been taught at medical school were lethally wrong. This led to a lasting interest in the quality of evidence about the effects of treatments. While working subsequently as a researcher assessing the effects of care given during pregnancy and childbirth he appreciated the mutual advantages of women and researchers working collaboratively to identify important unanswered questions and to discuss how to obtain reliable answers to them. Women's groups lobbying for maternity services to be informed by reliable research evidence were effective because they became expert in critically appraising treatment claims made by professionals. It was in the light of this encouraging example that, ten years ago, he convened a meeting to discuss how to increase public understanding of health research. This led to his work with others to create the James Lind Library website (http://www.jameslindlibrary.org/), and to co-authorship of a 100-page book written for the public entitled 'Testing Treatments' (http://www.jameslindlibrary.org/pdf/testing-treatments.pdf).

These are just two of the many initiatives taken by participants in the conference with similar objectives. However, Iain Chalmers mentioned that he had been disappointed by the lack of material in museums, exhibitions and other places which had been designed to help people understand how biases in health research can result in dangerously misleading treatment claims. For example, a recent Wellcome event entitled "Quacks and Cures" provided no guidance to visitors about how to distinguish between quack remedies and real cures. After writing to the Director of the Wellcome Trust to comment on this, the Trust expressed interest in considering how the problem might be addressed. This had led it to support the meeting, along with the support given to the James Lind Initiative by the National Institute for Health Research.

Amanda Burls described her interest in questioning the evidence from an early age and described having to provide medical care as a House Officer according to each consultant's preferences rather than the patient's needs. She founded the International Network for Knowledge about Wellbeing (Thinkwell) (www.ThinkWell.eu), which aims to help people to understand what makes for good evidence when taking health decisions and be active partners in health research

The bigger picture and what is out there? –Dr Woloshin and Dr Schwartz

Steven Woloshin summarised the problems from the use of poor information and the exaggeration of messages. To make good decisions, people need facts. Typically, public health messages lack sufficient meaningful data. Messages are often exaggerated, using "hype" to create fear, increase people's feelings of vulnerability and create exaggerated hope about the effectiveness of treatments. Steven Woloshin illustrated his point by showing health care advertisements and examples of companies offering the general public brain scans and abdominal aneurysm screening, without providing information about the chances of disease or realistic outcomes of treatment.

Lisa Schwartz discussed two questions that need to be asked when using health information:

- Why should I use these results?
- What do they mean?

She proposed two areas of focus for investigation:

1. *People*
    - Generating awareness of the problems that can arise from using poor evidence or no evidence so that people are engaged and want to know the truth
    - Improving skills seeking and using health research
2. *The message*
    - Making messages better – use standardised templates to make information more accessible
    - Educating communicators
    - Highlighting and correcting messages

She summarised the results of a review looking for interactive tools to help people make sense of health research. Among 3,148 abstracts identified, there were 63 that discussed interactive tools, of which only 20 were publicly available.

Points from the plenary discussion

There is a real public hunger to understand research about health care

- People often feel overwhelmed by information and can become sceptical and disempowered.
- People are not homogeneous – their needs are individual.
- Sometimes telling a story may be a good way of communicating.
- People often search for health information when they have a health problem and these situations can focus their searches.

Some common challenges were identified:

- There is a balance between giving enough information to explain complex concepts and making content too dense.
- People often need disease-specific information. Can this be used to help people develop skills to understand it?
- People often do not find reliable information when they search for it.
- How do you teach people to be questioning?

- It is important to promote scepticism rather than cynicism by helping people develop the skills to recognise what can and what cannot be trusted.
- Teaching children science – it is easier to teach and assess facts than processes of learning. This can lead to neglect of the latter.
- What is the minimal level of training or skill required to detect 'bullshit'?
- Being able to understand and use health care research is a problem that health care consumers face all over the world. An important challenge is therefore to ensure that tools and resources to enhance understanding of health research are developed and made available in different countries and different languages.

Discussion of role in educating journalists
- Importance of the role of news editors versus medical journalists.
- Importance of finding out what the public want to know.
- There is a conflict for journalists between being good at telling the truth and selling newspapers.
- There is a need to provide alternative and authoritative sources of information.
- Do the public pay newspapers to do their thinking for them?
- Different countries may have different access to reliable information.

Medical students report getting their information from Wikipedia
- How evidence-based is the information they are getting?
- Can we help ensure that high quality information is available in Wikipedia?

Small group discussion – problems and solutions
Amanda Burls asked participants to discuss in small groups whether the two categories given in the conference overview captured the most important issues within enhancing the public understanding of health research? And, if not, what was missing? Each group was asked to identify the three or four themes they felt should be discussed in more depth the following day. Key points from the small group discussions were reported back to the whole conference and discussed in a plenary session. The issues raised were wide ranging and included the following:

What will be different in 10 years?
- People, skills and motivation
- Messages – regulation versus process
- Behavioural change
- Research and development

People tend to look for information on health conditions rather than statistics or research methods
- Resources – what is manageable? We need milestones.
- Priorities – who are we aiming at and where do we reach them?
- How do we convey uncertainty yet maintain trust?
- Should we use and develop Wikipedia?

A bottom up approach is needed

- We should not assume we know what people need. We should go to the public and ask them what they want.
- We need to evaluate what we do to assess whether it meets the public's needs.

Different tools are needed for different purposes

- Target audience – information givers and receivers.
- Brand/kite marking – to identify what is good evidence.
- Collaborative tools –patient and GP interaction, answering questions together.
- Resources need to be adapted for the local context and in different languages.

People and messages - we need to practice what we are teaching

- Context, personal motivation, clinical situation, individual concern.
- Intermediaries - key role for carers, advocates in passing information from science research to members of public.
- Mapping exercise –to identify what is out there, what works well and how to match people's motivations with their needs.
- Strategy - why are we doing this? How will we know we are successful?

Teachable moments - how to teach people useful skills

- Using intermediaries by offering a central depository of useful resources.
- Evaluating materials – make it clear how resources have been evaluated and to what level, where they can be used, and how intermediaries can choose resources to use depending on audience and need.

The plenary session grouped the key themes identified by each small group into nine main categories (see below). Participants then voted for the themes they wanted to discuss the following day (votes given in brackets).

1. Target groups and scenarios (23 votes)
2. Intermediaries (21 votes)
3. Evaluating materials intended to enhance people's understanding of health research (17 votes)
4. Research and development (15 votes)
5. Wikipedia, YouTube, and Web 2.0 (15 votes)
6. Context and personal motivation (8 votes)
7. Making messages better (6 votes)
8. Mapping exercise (6 votes)
9. Skills – understanding risk (3 votes)

Following further discussion, it was agreed to combine topics 1 & 6 and 3 & 4 to give the following three themes for in depth discussion the following day:

(1) Target groups and context

(2) Intermediaries

(3) Evaluation and Research and Development

Presentations – Are our efforts any good?

1. Evaluation of a book (Lisa Schwartz and Steve Woloshin)

A book, "Know your Chances" by Woloshin, Schwartz and Welch, (http://www.jameslindlibrary.org/testing-treatments.html), designed to teach readers *"what numbers to look for in health messages and how to tell when the medical statistics don't support the messages"*, was tested in two randomized trials (RCTs).

Summary of the evaluation (*http://www.annals.org/content/146/4/256.short*)
- There were 2 RCTs – one in high and one in low socioeconomic status (SES) groups.
- Controls received a general health booklet developed by the U.S. Department of Health and Human Services Agency for Health Care Research and Quality.
- Primary outcome measure was score on a medical data interpretation test, a previously validated 100-point scale, in which 75 points or more was considered "passing."
- Result: In the high SES trial, 74% of participants in the primer group "passed" compared to 56% in the control group (P = 0.001). Mean scores were 81 and 75, respectively (P = 0.0006). In the low SES trial, 44% in the intervention group "passed" compared to 26% in the control group (P = 0.010). Mean scores were 69 and 62, respectively (P = 0.008).

2. Evaluating a flash-based interaction on confidence intervals (Amanda Burls)

Amanda Burls had converted an interactive teaching session into a flash- based reusable learning object. Following the suggestion of Iain Chalmers it was decided to test its effectiveness in a randomized controlled trial (RCT):

- *Design*: An internet-based RCT
- *Population*: Anyone 16 or over, anywhere in the world, who speaks sufficient English to be able to participate
- *Intervention*: Use of flash-based reusable learning object
- *Comparators*:
  (i) the Critical Appraisal Skills Programme's teaching example, as used in the first edition of *Testing Treatments*;
  (ii) extract from the NHS Choices glossary;
  (iii) no information.
- *Outcome*: Test of understanding of information reporting confidence intervals. (The instrument for the latter had been developed specifically for this trial and was piloted with the public at an event hosted by Science Oxford.)
- *Recruitment*: Self-enrolled with the link to the trial disseminated by snowball email and a link from NHS Choices and other websites.

There was a group discussion of whether it is important for the public to understand the confidence intervals and, if so at what level. It was suggested that *regression to the mean* is a basic concept people need to know about. Some participants offered to provide a link to the trial from their websites.

3. Summary of Findings tables (Andy Oxman)

Andy Oxman presented a summary of six pieces of research that the Norwegian group had completed to enhance public understanding of health research.

(1) **BackInfo** – What challenges do people face when trying to extract and present relevant, consistent, and accessible information from systematic reviews?
Claire Glenton et al. Summaries of findings, descriptions of interventions, and information about adverse effects would make reviews more informative. JCE 2005.

(2) **CURE (Consumer Use of Research Evidence)** – How well does the public understand effectiveness research?

(3) **Summary of Findings Tables for Cochrane Reviews** What should be presented? Why?
Sarah Rosenbaum et al. User testing and stakeholder feedback contributed to the development of understandable and useful Summary of Findings tables for Cochrane reviews. JCE 2010.

(4) **SUPPORT Summaries** – How should findings be presented to policymakers?
Sarah Rosenbaum et al. Evidence summaries tailored to health policy-makers in low- and middle-income countries. Bull. World Health Org. 2011.

(5) **Plain language summaries** – How should the findings be presented to consumers?
Claire Glenton et al. Presenting the Results of Cochrane Systematic Reviews to a Consumer Audience: A Qualitative Study. Medical Decision Making 2010.

(6) **DECIDE**: How should evidence-based information be communicated to clinicians, the general public and policymakers?
Developing and Evaluating Communication strategies to support Informed Decisions and practice based on Evidence: a 5-year project from 2011 funded by the European Commission's Seventh Framework Programme. http://decide.test.cochrane.org/welcome

Key themes from discussion

- improving public understanding and use of health research is likely to require several different types of effort targeted at different types of problems
- lack of research, access, interest, ability
- examples of strategies discussed for each issue
- the need for this to be international

Summary – Day Two

The day began by participants selecting which of the three themed discussion groups to join. The groups then discussed their themes for about 2½ hours before reporting back and discussing their conclusions in a plenary session.

Theme 1: Target groups and context

This group had participants from a wide range of backgrounds (patient organisations, lay representatives, the media, learning technology, funding organisations, the Science Museum) and two academic researchers. The group emphasised the need for initiatives to be undertaken in partnership with the public and to use modern technologies to increase public engagement.

Who are we targeting?
- There was a discussion about whether we should be targeting nurses and other health professionals in preference to the public as they were intermediaries in understanding health research. It was generally agreed that these groups need to be targeted as well as the public and the target group for the rest of the discussion was considered to be interested people age 14 years and above.
- It was recognised that this needs to have an international impact and not be duplicated in every country.
- Products and materials needs to be available in languages other than English.
- It was important that this be a partnership with the public, rather than the idea that this is something "*we* do for *them*".

Proposal

The suggestion that caught the imagination and enthusiasm of the group was to create a website, "CertifiedBullshit.com**",** directed at the people aged 14 and over.

The general idea was that this website would (or could)
- use health stories in the media as a basis for engaging the public in deciding whether the information was trustworthy or bullshit, which could be linked to, or use information from, the NHS Choices "Behind the Headlines" pages
- use Web 2.0 functionality (e.g. allowing people to post examples of poor or good news coverage, to vote on the best stories or worst bullshit, give feedback about what others voted etc.)
- use humour to make the site engaging and attract repeat visits ("edutainment")
- link to explanations of bias and increase understanding
- link to further resources identified in the inventory and materials produced by members of the nascent international Network
- link to suitable YouTube videos
- be evaluated initially via process measures such as hits, bounces, postings, revisits, completed resources
- start with a *Declaration*– "What we want to do or aspire to"
- invite key people/celebrities to sign up or endorse the site
- allow people to vote for a "Bullshit of the Week" award
- be targeted and suitable for everybody, including schools, nurses, doctors
- identify individual "heroes" of evidence-based health care or healthy scepticism and award a certificate or other form of recognition (analogous to a Blue Peter badge).

Other suggestions from the plenary
Regular "Certified Bullshit" slot on the "One Show" (Ben Goldacre was suggested as an ideal person to represent this) linked to the activities on the website.

Steps
- Apply to the Wellcome Trust for funding to support the development of a "Certified Bullshit" website as a proof of principle.
- The Science Museum and Science Oxford offered to organise user testing to help develop the website.
- Encourage members of the Network to contribute to the website and also to identify their resources that could be linked to.
- Check IP and legal issues – fair use of advertisements, newspapers, and segments of TV programmes.

Theme 2: Intermediaries

Definition of intermediaries
People who provide information about health care to the public.

Categories of organisations
Community based organisations, NGOs, carers, media, scientists, health information providers, health professionals, school teachers.

Need to engage with other organisations engaging with the public
- Professional associations
- Umbrella organisations
- Organisations in different countries

Ideas for engagement
- Journalists - protect yourself from criticism by being a critical thinker
- Broadcasters – possible shift in demand towards more sophistication in science reporting
- Schools – may be an opportunity to develop a package "how science works"
- Opportunity for a web portal – but needs to include a simple and clear vision

Key components of a *Vision Statement*
- Promote access to the tools
- Hold decision makers to account
- Produce and share the best healthcare knowledge
- Create and nourish a knowledgeable society
- Critical thinking
- Knowledge is a renewable resource
- Sustainable growth

Wheels in Motion Diagram for Intermediaries
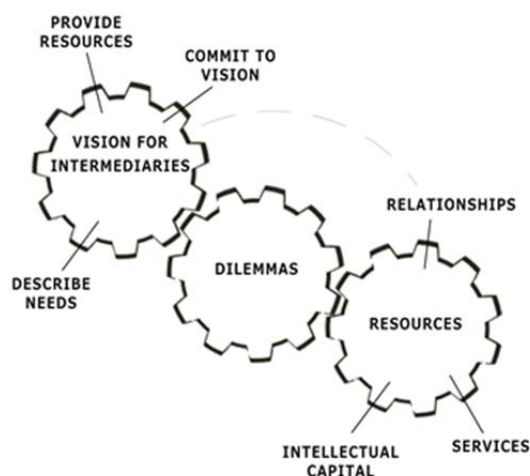
Theme 3: Evaluation, research and development

Develop a website of evaluated resources

The target audience for the website would be lay people, intermediaries (teachers, journalists) and researchers.

Objectives of a website

1. To provide access to evaluated resources
2. To facilitate evaluation, e.g. RCT of teaching materials, web trials, difficulties
3. To facilitate collaboration through an interactive website, with comments, discussion list
4. To flag uncertainties
5. To help intermediaries
6. To reach hard-to-reach groups – use the website to identify materials for these groups
7. To include translated resources

The development of the website will be informed by the findings of the overview reported by Steven Woloshin and Lisa Schwartz and by the taxonomy of products supporting the understanding of health research. The inventory of interactive tools produced by Kendall Krause and colleagues would be available through the website. Extending this review to include non-interactive tools was discussed; it was agreed that the scope for this would be large and require substantial external support.

The criteria for selecting products for inclusion on the website, and the method of categorising these, have to be developed. One suggestion was to categorise the products as evaluated and unevaluated.

Taxonomy

It was noted that there is a need to produce a taxonomy to classify information and resources relevant to promotion of understanding of health research.

Discussion of ideas about creating a website

- Needs more market research
- May need to plan a series of events to engage people and build relationships
- Harness political influence of attendees to influence policy makers
- Run workshops to train people who work in research
- Tailored agency for people working in evidence-based health care – work with the Science Media Centre.

There was discussion about the possibility of using the James Lind Alliance (http://www.lindalliance.org) - DUETS approach to finding the public's unanswered questions, alongside those of clinicians/researchers, about how to engage the public in better understanding health research.

Afternoon plenary - Summary of small group discussions

Proposed manifesto

1. Everyone CAN be empowered to ask useful questions about health research claims.
2. TOO OFTEN, the results of studies are presented as more certain than they really are. Sometimes this information is deliberately misleading. This is unacceptable.
8. WE WILL highlight where this is happening, and offer people the skills to ask questions and make informed choices.

Suggestions for an acronym

AUQWARD: Asking Useful Questions Which Answer Real Dilemmas
Alternatives:

- Exposing quacks and lies
- Expert questions for all
- Empowering questions for all
- Explore, question and learn
- Empowering to question, understand and learn

Discussion concerning a web presence

- Set up Google groups for Network members to work together (NING – alternative platform – social blog space).
- Media training instructions.
- Crowd source Network wiki – to grow and accumulate resources.
- Front end – pop principles, stories and organisations involved.
- Real strength USP – great tools and content, deeper layered understanding.
- Needs an Editor with IT and media skills – therefore funding is needed.

Other issues

- Roving reporter to create stories?
- Name and site structure, tools for different audiences?
- Copyright and terms of use statements.
- Term "bullshit" could be blocked in schools. Suggestions to get around this included a mirror site called "Certified Baloney" or using the title "Quack or Cure" instead.
- Do we need to stratify content depending on audience?

Next Steps – Germany and Norway

It was noted that it was important for this to be an international network and initiative and we needed to identify individuals or organisations in other countries, e.g. China, Spain, and France, to become involved.

Taxonomy group

Needs a project grant to fund this, using a survey process which will

- ask what sort of situations/decisions will focus the taxonomy
- identify what is needed to understand
- a part-time research assistant would be required for a minimum of one year.

It was noted that Australians are developing a taxonomy of interventions for communication.

Funding discussion

- Meeting participants from the Wellcome Trust expressed interest in possible support for an international Network, and a "Certified Bullshit" website.
- Iain Chalmers proposed that Amanda Burls should lead the development of the proposal to Wellcome Trust for funding for this latter website to produce a "proof of concept" website. This was agreed by the conference.
- It was noted that further funding sources would need to sustain such a website in the longer term.
- Need to bring all aspects together in a final draft proposal.
- To be eligible for funding by Wellcome this needs to start as a UK-led exercise – but it can have international input and support.
- Iain Chalmers offered some limited financial support from the James Lind Initiative budget over the next 2-3 months so that some of the plans could begin to be put into action while a grant application is being prepared for submission.

Discussion about building on the link with Kellogg College

It was noted that the aims of the proposed Network align with Kellogg College's activities and philosophy. The idea that Kellogg College might be a home for the international Network was discussed and met with a generally favourable response from the meeting.

Actions for all Network members

- Provide feedback about suggested name for the Network, further acronyms, possible logos etc.
- Provide feedback on the draft conference report.
- Participants of the conference and future members of the Network need to indicate what they would hope to get out of the Network and what they would be willing to contribute to the Network.

Thematic Summary

Summarised by Sharon Mickan

Thirty-five international experts interested in enhancing public understanding of health research met at Kellogg College, in Oxford for a two- day networking conference. This conference was designed to share and critique current activities in this broad area and to explore the creation of an international network to enhance public understanding of health research.

Through a combination of prepared presentations, brainstorming sessions and focused discussion groups, a shared perception of the realities of enhancing public understanding of research emerged. Several themes were clear:

- There is a real public hunger to use and understand research about health care. However most people access research when they have a specific health care condition or concern. They are looking for specific information and often do not know how to think critically about the research information presented. They would like to be able to discuss information with health care practitioners.
- The skills for understanding health research information cannot normally be learned at the time that people are seeking this information. Therefore there is an important role for intermediary organisations to assist the public to understand health research.
- In the overwhelming amount of information available about health research, there is a need to identify which resources have been sufficiently evaluated to be useful to the person or group searching for the information. The skills of critically evaluating research are unique life skills, which could be taught more broadly to the population, beginning in formal school education.

It became apparent during this conference that informal international networks already exist. There was a strong and shared commitment to create an inclusive international network with a focus on enhancing public understanding of health research. The key activities of this network would include:

- formalising communication between the attendees, to encourage the continued development and sharing of information
- creating a website to store information and encourage engagement with the public
- providing a taxonomy of evidence to assist the public understand health research; this may include objectively evaluated content and the skills to understand and use it
- developing a funded secretariat and administration hub to manage and coordinate these activities.

The challenge for all members of this newly formed network will be to continue to develop these activities, with the high levels of motivation that were apparent during this conference, once in attendees had returned to their demanding work environments. The challenge for this new Network (which has yet to be named) is to coordinate and communicate between all members so they can stay connected and share expertise and relevant new and existing resources.

Production of conference report

The first draft of this conference report was produced by Sharon Mickan and edited by Amanda Burls. It was circulated to all course participants who had the opportunity to feedback suggestions for improvement or make corrections. Amanda Burls wrote the executive summary and edited the final report to incorporate participant feedback.