



## Public Reviewer Guidance: Part 2

# How members of the public can comment on research for the Health Technology Assessment programme

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This document has been adapted for the NIHR Health Technology Assessment programme from work prepared for the Cochrane Collaboration by the Social Science Research Unit, Institute of Education, University of London ([www.ioe.ac.uk/ssru/perspectives](http://www.ioe.ac.uk/ssru/perspectives))

## 1. Glossary and abbreviations

### **Themed Call Board, Commissioning Board and Clinical Evaluation and Trials Board:**

These HTA Boards assesses the scientific merits of research proposals submitted to the programme.

**Designated Board Members (DBMs)** are Board members designated to assess an application and to report back to the full board for discussion.

**Health Intervention:** See health technology.

**Health Technology** are methods used to promote health, prevent and treat disease and improve rehabilitation and long term care including: drugs (e.g. antidepressants, contraceptives, antibiotics), devices: such as pacemakers, dialysis machines, hearing aids), procedures (e.g. surgical techniques, acupuncture, counselling); settings of care (e.g. general practice, hospitals, care homes), and screening (e.g. for cancer, sexually transmitted diseases, or stroke). Health technologies are also known as health interventions.

**Health Technology Assessment (HTA)** tries to find out whether these technologies work, for whom, at what cost, and how it compares with the alternatives.

### **Health Technology Assessment Programme (HTA Programme):**

Based at the University of Southampton, the HTA Programme is managed by the NIHR Evaluation, Trials and Studies Coordinating Centre, on behalf of the NIHR.

### **INVOLVE:**

The national advisory Group, funded by the Department of Health, which aims to promote and support active public involvement in NHS, public health and social care research ([www.invo.org.uk/](http://www.invo.org.uk/))

**National Institute for Health Research (NIHR):** The National Institute for Health Research is a virtual organisation established by the Department of Health to deliver the Government's R&D strategy ([www.nihr.ac.uk](http://www.nihr.ac.uk))

**NIHR Evaluation, Trials and Studies Coordinating Centre, (NETSCC):** Based at the University of Southampton, the NIHR Evaluation, Trials and Studies Coordinating Centre manages a number of research programmes, including the HTA programme, on behalf of the NIHR.

**Peer Referees and Peer Reviewers** are individuals who are invited to comment on proposed or completed research because they share an interest in the research topic but are not directly connected with the research project or team. Sometimes comments are invited to improve research and this is often called peer reviewing. At other times comments are invited to help decide whether to fund or publish a piece of work and this is often called peer refereeing.

### **'Public':**

The HTA programme has adopted and adapted INVOLVE's definition of the public.

We define 'the public' as patients; unpaid carers; parents/guardians; users of health services; disabled people; members of the public who are the potential recipients of health promotion/public health programmes; groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services; groups asking for research because they believe they have been denied products or services from which they believe they could have benefited; organisations that represent service users and carers.

<http://www.hta.ac.uk/public/definition.shtml>

The HTA programme involves the public in our programme to ensure that our funding applications are more relevant to people's needs and concerns, reliable, and likely to be used.

**Public Perspective:**

A public perspective is one that is from a non-medical or non-health practitioner background. Therefore, it is inappropriate for medical or health care professionals to comment on behalf of their patients.

**Public Referee/Advisor:**

To maximise public input into the HTA programme, a public advisor should be linked to relevant service user/carer networks. They should be able to draw on a wide body of service user opinion and be able to provide a public perspective to help at the stage requested in the HTA process. A public advisor should not normally be a health practitioner, manager or researcher, and should bring fresh perspectives rather than rely on conventional professional attitudes or knowledge.

## 2. Introduction

This document has been prepared to help members of the public provide *public perspectives* on research proposals. It is important for health services research to be influenced by people who use the relevant services.

This is the second of a pair of documents:

- Why the Health Technology Assessment programme asks members of the public to comment on research
- How members of the public can comment on research for the Health Technology Assessment programme

This document has been arranged in sections to give practical advice to members of the public who have decided they want to comment on research. It is designed for people who already know something about the HTA programme and research proposals. It is recommended that it be read after 'Why the Health Technology Assessment programme asks members of the public to comment on research', which provides more background information about the work of the HTA programme (available from the HTA programme - see section 7).

### 3. Why comment is invited

Inviting comment from people not directly connected with proposed or completed research is a critical part of ensuring quality. Sometimes comments are invited on a piece of work to improve it (often called reviewing). At other times comments are invited in order to make a decision, such as whether to fund or publish a piece of work (often called refereeing).

When comment is invited by other health professionals or researchers, it is commonly called 'peer reviewing' or 'peer refereeing'. As all those invited to comment are interested in the topic, public advisors and health professionals can be considered 'peers'. Some members of the public believe they have a contribution to make that is distinct from that of doctors and other health professionals who have studied and trained for many years. Therefore they don't consider themselves 'peer' reviewers, but public reviewers. The HTA programme considers all reviewers as external experts who are essential for guiding decisions about what research to fund.

### 4. Bringing public perspectives to research

We ask members of the public, familiar with research, to comment on research in their area of special interest. We have found that when these individuals comment on research they:

- **know a lot about their subject**, (often based on their personal experience and that of other service users), commenting on health conditions, current practice and research questions;
- **seek information**, asking personal questions as patients or carers;
- **value clear communication**, seeking to understand, and comment on technical language, presentation, abbreviations, readability and illustrations (or lack of them);
- **think of service users**, considering their needs and concerns, to comment on access, information, equity, choice, dignity, safety and support. In doing so they are applying ethical principles such as human rights and civil rights;
- **think logically**, bringing a fresh perspective, testing the logic, commenting on the aims, rationale, flow of argument, bias and conclusions;
- **think creatively**, not only reacting to other people's ideas, but tapping into their own experience, visualising situations that are relevant to the topic and bringing fresh ideas;
- **encourage the authors**, highlighting valuable aspects of a piece of research, making practical suggestions for change and explaining the value of possible improvements;

Public referees offer fresh perspectives and ideas for researchers to consider in their work. Individual members of the public may comment on research proposals in many ways.

Sometimes they find the work a little difficult at the beginning, because some words and ideas are unfamiliar, but many find it rewarding nonetheless. Individual public referees don't need to address every aspect of the research. They can offer their public expertise and let other experts offer their specialist expertise, so that a comprehensive range of comments is contributed. Each experience of commenting

on a research proposal involves learning and contributing. If you get involved, we hope you enjoy it.

We describe in more detail below how some public referees have approached commenting on research, we also suggest ways of developing these skills and offer some practical tips.

#### 4.1 Using your expertise

People who **know the topic well** comment on research from a strong knowledge base. Knowing about how the public experience health and health care is particularly valuable because it complements the professional knowledge of other people working for the HTA programme. Public referees can draw on their knowledge to comment on health conditions, current practice and research questions. Some people are concerned that the more knowledgeable public referees become, the more like professionals they grow. However, members of the public who become more knowledgeable, but continue to be influenced by other members of the public, are able to challenge clinicians and researchers perspectives in greater detail.

**For example**, when reading a study of iron supplementation, a public referee with personal experience wrote *“All the information is about the problems of anaemia (and the benefits of iron therapy) but nothing about the problems of iron therapy which I believe can be considerable...”*

**To build your own skills**, continue to learn from service users, patients, carers, lay writers and bring their views to bear when you are considering technical work. Read popular media reports on your subject of interest as well as technical reports.

**When commenting**, remember the authors are writing from their perspective. Your perspective is also important.

#### 4.2 Asking patients' questions

People who **seek information** ask personal questions as if they were patients or carers.

**For example**, *“service users would like to know whether they will be in pain, is the surgery done under local/general anaesthetic, will they have to stay in hospital (if so, for how long?)”*. The information might be found in the list of outcomes, or in a detailed description of the intervention.

**To build your own skills:** When you read technical reports, get into the habit of putting yourself in the place of the patient. Would you know what to expect? What would you ask about? What might worry you? If this topic is new to you, do you have any pre-conceptions?

**When commenting:** When asking questions about health problems and their treatment, patients typically want to know: What would happen if nothing were done about it? What is the likely course, outcome, prognosis and danger? What options are there for treating the condition? These are all issues that could be considered in a study of effectiveness.

### 4.3 Checking the clarity of the message

People who communicate well seek to understand, comment on technical language, presentation, abbreviations, readability and illustrations (or lack of them), and make practical suggestions.

So how can members of the public help? When commenting on research it may help to think of the primary readership as individual health professionals about to discuss treatment options with a patient. These readers will find it easiest to assimilate facts and ideas if the report uses technical language with which they are familiar, but they will need to discuss these facts and ideas with their patients largely in plain language. If lay terms or simple explanations are added (possibly in brackets) alongside the technical language, the clinician is introduced to phrases suitable for a patient discussion at the same time as accessing the information about effectiveness they are seeking from the HTA. Public referees can highlight terms which clinicians would need to explain to patients during a consultation, and suggest lay alternatives which can be incorporated into the report and into a glossary.

**For instance:** A public referee may ask *“How well does the research explain the words and scientific terms it uses? I thought they worked hard to explain terms, but scientific terms crept in which could have done with a mini dictionary somewhere in the text. So in [the research] which was admirably explained for the most part, words such as ‘papular’, ‘vesicular’, ‘coagulase-positive’ crept in unexplained.”*

**To build your own skills** you can get into the habit of using technical and lay language interchangeably. This is particularly helpful when discussing health care in a mixed group where some terms may not be familiar to everyone. Look out for phrases you regularly use amongst friends and colleagues. Such phrases often hide layers of assumptions and invoke different ways of thinking. For instance, ‘informed consent’ and ‘informed choice’ tend to be used by different groups of people who visualise completely different scenarios. If other people use phrases you tend not to use yourself, explore the different meanings they may have and the assumptions behind them.

**When commenting:** Are there words which need explaining, perhaps in brackets? Are sentences long and unwieldy? Can you work out the likelihood of a patient benefiting or suffering from the intervention being tested? Mark technical words and phrases which could be usefully included in the glossary and offer lay translations. Pay particular attention to the abstract because this is most widely available and most widely read.

Suggest plain, non-technical wording to help service users and to help clinicians explain evidence to patients.

Even if you can’t suggest an improvement, it is still helpful to highlight sections which are difficult to read or understand.

### 4.4 Speaking for the public

People who apply such principles bear in mind public protection and rights to information and choice. They can comment on choice and ethics.

**For instance**, one public referee felt “... *what is being said here is fine, but the way it is expressed implies that once the benefits and risks can be estimated with greater certainty then [patients’] choice should be removed.*”

**To build your own skills**, when reading newspaper editorials or listening to the news on the television or radio, compare how the stories are reported according to which service you are listening to or which newspaper you are reading. Notice how journalists and lawyers give very partial reports depending on whose perspective they are representing. In bringing a public perspective you need to be aware of your own principles and biases, and to notice other people’s principles and biases too.

**When commenting:** Some research proposals include a conflict of interest statement detailing any conflicts that the authors might have. You may find other potential conflicts of interest such as sponsorship of the included trials or commercial interests in the products being tested. Are all potential conflicts of interest openly acknowledged? Do authors use emotive language? Of course everyone (including members of the public) has particular interests and we must be vigilant to the many possible sources of bias.

#### 4.5 Thinking logically

People who **test the logic** of a study do not necessarily share the same assumptions as the authors. Rather they may bring a fresh perspective and comment on the aims, rationale, and flow of argument, bias and conclusions.

**For instance**, one public referee wrote “*I did like those [proposals] which said what hypotheses they would be testing. This would have helped to focus the eventual analysis, but in the full [report], the discussion did not return to the hypotheses! So, although the [report] was very interesting and educative, I would have benefited from... discussion in the same order as set out in the objectives. In fact, I think the information is there, but it is difficult to unpick.*”

**To build your own skills**, look for opportunities to exercise your logic. Does a film plot make sense? What does an advertisement actually claim (compared to what it wants you to believe)?

**When commenting:** At first sight research may look puzzling. When you think you understand it, you could try:

- rewriting the ideas in plain language
- drawing a diagram to illustrate the work done,
- imagine trying to explain it to a friend over a cup of coffee.

Does it still make sense?

#### 4.6 Tapping your own experience

People who **think creatively** not only react to other people’s ideas, but tap into their own experience (and that of their family, friends, and colleagues). They are also informed by their personal reading. They visualise situations that are relevant to the topic and bring fresh ideas.

As a public referee you are bringing an important perspective to a HTA research proposal. You do not want to let other people’s perspectives overwhelm your particular expertise. You could try bringing to mind what you already know about a topic, before thinking about how the researchers have tackled the question they are addressing.

**For instance:** When reading a research proposal about neonatal care a public referee explained *“I picture the mother and baby, and apply what’s written to her. Does it make sense? How does the intervention affect everything else that’s happening?”*

Another public referee imagined some sight screening tests and wondered whether a difference in where the tests were done might have an effect upon the results. For example, *“Patients may be less relaxed in a clinic.”*

**To build your own skills:** Take every opportunity to make use of your expertise as a member of the public and keep in touch with other service users. Listen carefully to people talking about their experiences. Notice what they are talking about, and how they are talking about it. When accepting health care for yourself or your family, notice how you react to situations.

**When commenting:** Try reading the title of research proposal first, then stop to think about it. Jot down your own ideas about the topic. What do you think is the problem? Can you visualise people experiencing this problem? Where might they be? Who with? How might the problem affect them? What questions might they have? In what ways might people be different? What personal experience do you have? What have you heard from other members of the public? Do you have books on your shelf addressing this topic by service users? What issues concern them? What terms do they use? What questions do they ask? What treatments might they be considering? What outcomes might they be hoping for?

Asking yourself particular questions may help: What does the title mean to you? What information do you expect in the background? What is the theoretical reason for trying an intervention? What might you expect to happen, for better or for worse? What aspects of the experience might be particularly important to patients?

#### **4.7 Encouraging authors**

People who **encourage others** highlight valuable aspects of a report, make practical suggestions for change and explain the value of possible improvements. Research teams have worked hard to prepare a proposal, and they have had to be brave to let their work out for comment for the first time. No one expects their work to be received without suggestions for improvement. Criticism is easier to accept if it is accompanied by an appreciation of the better points of a piece of work. As a consistently perfect piece of work is rare, compliments and criticisms may alternate to keep the authors spirits up!

**For example:** *“This is a good, well-written research proposal. It’s easy to understand, concise and to the point... [but] what pre-existing pathology might influence the outcome? Does this include people with previous detachments/ retinal tears, and/or those with other ocular conditions such as macular degeneration, cataract, glaucoma, retinitis pigmentation etc?”*

*“This is wonderful stuff! The patient is obviously on the research team’s mind; not only is quality of life mentioned, but reference is made to patient satisfaction, which is vitally important. When patients are treated as people, rather than a pair of eyes, the surgical procedures become easier to bear on an emotional level. The psychological well-being does much to promote the healing process. Seems to present a holistic approach for treatment.”*

*“[We] were very impressed by the extent of the search undertaken for this [study] and felt confident that a thorough job had been done. We were also impressed by*

*the detail with which the [researchers] explained how they had chosen the outcomes to be measured ... We also felt that it was refreshing to see the reviewers openly acknowledging their individual part in the research process.... [but] It would help to have more information on... outcomes which relate to quality of life..., and have some consistency in the use of American or European terminology, and drug or generic names... and subgroup analyses by whether participants were smokers or not, and...It would be good to have the 'Numbers needed to harm' result in the abstract."*

**To build your own skills** you can get into the habit of noticing and commenting on the positive aspects of any experience, as well as the disappointments.

**When commenting:** What can you find in the authors' work which pleases you? The explanation of the problem, or choice of outcomes? The language used? Or a particular turn of phrase?

Give positive feedback first, give it as often as possible, and give it even if you have been asked to fill in a standard checklist which doesn't request positive feedback.

## **5. Commenting on research: step-by-step**

Commenting on research can be done individually or by a small group working together. Research **proposals sent for expert comments are confidential**. This is because research proposals are competitive and people's salaries and careers depend on their success. **If you would like to share the work of commenting on research with other service users or members of the public, contact the person at the HTA who sent you the work, to make sure that it will not present particular problems.** For instance, sharing the task with service user organisations who are involved in a competitive research proposal would not be appropriate, and needs to be guarded against. However, there are benefits from working as a team, not only in terms of generating more ideas, but also in terms of looking after yourself (see section 5).

Whether you are working alone or with others, we suggest that you take a step-by-step approach to commenting on research. We make some practical suggestions below.

Throughout the task of making your comments, remember that your most valuable contribution is your *public perspective*.

### **Step 1                      Gathering your own ideas**

To begin, try reading only the title of the research proposal, and jot down your own ideas about the topic. You may prefer to flick through to get a general idea of the whole document first. Whichever method, notice what thoughts and questions you have.

Remember, you have been invited to comment because you know this subject well (3.1 above). You are likely to ask questions important to patients (3.2 above).

## **Step 2                      Thinking about the research**

Read the research carefully and consider it in the light of your own experience and expertise. You may scribble notes on the text itself, or on a separate sheet of paper. Notice how you react as you read through it. Are there some sections that you particularly like or particularly don't like? What do you think is good and what do you think is bad? Can you explain how and why you think this? Are you reacting to the ideas or the style of presentation?

Who might want to use the findings of this work, and when? Does this give you ideas about information they might like to see come from the research?

This is the stage when you should check how clear the text is (3.3 above), how well patients will be informed and supported (3.4 above), and whether the plans make sense (3.5 above).

## **Step 3:                      Ordering your thoughts**

Look back at the notes you made in step 1. Are all the questions that arose from your initial thinking answered? Might you suggest changes in how the research is done or how it is reported?

Look at the notes you made in step 2. Can you separate your responses to the ideas in the research and your responses to how they are presented? Would your suggestions allow the authors to keep those sections you liked and change the sections you did not like?

What can you find in the authors' work that pleases you? The explanation of the problem, or choice of outcomes? The language used? Or a particular turn of phrase? Researchers like to hear the positive feedback as well as the negative.

Using a checklist after you have had ideas of your own may help you see if there is anything else you could think about. You may like to read through the proposal again in light of the checklist. But reading the checklist first to provoke your thinking may not help you work more efficiently. Instead it may restrict your thinking and stifle your imagination.

## **Step 4:                      Making your comments**

Comments on research proposals are used to inform discussions at HTA Board meetings. Where research has been commissioned the research question has already been decided at an earlier stage – often with the input of public advisors. Challenging the choice of question at length will take up your time and is unlikely to influence any decisions. It is more useful to comment on how well the research team plans to answer the research question. Suggestions for major changes at this stage are impractical, but comments on the teams' proposal may be passed onto them. These comments may explain why a team has not been commissioned to do the research, or they may (very briefly) suggest how the successful team may improve their plans.

Give positive feedback as often as possible and, whenever possible, suggest changes which could improve the text. List your suggested changes. Explain why you recommend doing it differently and how important it is. List who might find the findings from this work useful and in what circumstances.

**Step 5a): Scoring the research proposal/s**

The Public Referee's assessment form asks you to score each proposal (using a summary score table). It is important that you give each research proposal a score. The Designated Board Members use the score as an indication from the external experts of the quality of the proposal and whether it is worth funding. The scoring is also important if there are competing proposals as the HTA Boards will use the scores to decide which proposal to fund. Please score the research proposals from a public perspective.

**Step 5b): Comparing research proposals**

The commissioned programme often attracts more than one proposal for a single research question. In this situation it is important to compare the research proposals. Would one be more acceptable to participants than another? If so, why? Are the technologies being tested in one slightly more acceptable than in the other? Or are the outcomes and how they are measured better? Will one of the research projects be easier for participants, or appear more worthwhile?

A summary sheet (see next page for a worked example) is included with your proposals to help you compare and score the proposals. Take each section of the Referees' Assessment Form in turn, and compare your comments on each proposal before assigning a score for each section:

- Proposed 'health technologies' being evaluated
- Proposed patient groups included in the research
- Proposed outcomes of the intervention
- Recruitment of trial participants
- Service user representation on the research team
- Ethics and Trial Management Arrangements

When you have scored each section for a proposal, choose an overall summary score. This should be a score for your overall impression – not necessarily an average of the scores for each section.

## HTA Commissioned Research Service User Referee Summary and Comparison Form

<b>Name of lead applicant:</b>	<i>Prof Brown</i>	<i>Dr Green</i>	<i>Dr Black</i>		
<b>1. Proposed 'health technologies' being evaluated</b> Are the interventions selected likely to be acceptable to participants?	4	6	5		
<b>2. Proposed patient groups included in the research</b> Have the researchers chosen the right patient group(s) for assessing these interventions?	4	5	5		
<b>3. Proposed outcomes of the intervention</b> Are the outcomes selected relevant to trial participants and to service users in general?	3	6	6		
<b>4. Recruitment of trial participants</b> Have the researchers chosen the best way to recruit participants in a study of this nature?	3	5	6		
<b>5. Service user representation on the research team</b> Is the service user representation on the research team appropriate?	2	3	4		
<b>6. Ethics and Trial Management Arrangements</b> Are the ethics and trial management arrangements appropriate?	5	5	5		
<b>7. Overall score</b> What is your overall judgment? This is not necessarily a numerical average score.	4	5	5		

This overall score, 5, means 'Good' Proposed research acceptable with minor changes' (see table below). This is the number you will transfer onto the Public Referee Assessment Form, section 10, page 8.

Score	Description of application	Justification
<b>6</b>	<i>Excellent</i>	Proposed research acceptable as it stands
<b>5</b>	<i>Good</i>	Proposed research acceptable with minor changes
<b>4</b>	<i>Good potential</i>	There is much merit in this proposal, but it could only be considered acceptable after resubmission, perhaps with additional external support.
<b>3</b>	<i>Some merits</i>	There are significant weaknesses in this application, but these could in principle be addressed.
<b>2</b>	<i>Poor</i>	Weak application
<b>1</b>	<i>Extremely poor</i>	Unsupportable application

## 6. Looking after yourself

Contributing to research as a public advisor means thinking hard about issues that are personally very important. You might be taken by surprise by the strength of your emotional reactions, as was found by members of staff at a national charity who were reviewing a research report:

*“[The research topic] is an extremely important but sensitive issue for each of these users. They found reading the report an emotional experience and have each taken time to think through their comments which are presented here in a reasoned form. The strength of feeling aroused by this report amongst users should not be underestimated”.*

Before you start, please be aware that it's not unusual to get upset when the work touches on issues that are important to you. Ask yourself how you will make time to talk about your feelings and who you can turn for help. Can you call on a personal support network of family, friends, self-help groups, colleagues or specialist health help lines?

This is particularly important for members of the public working in isolation. Indeed you may prefer to work in a team if this is possible, or develop a system of mutual support with other members of the public.

Other members of the public may turn to you for help and support with their personal health concerns if they hear of your involvement in research. Beware of trying to deal with complex enquiries from other service users. It is a great responsibility. There is a big difference between befriending and peer support, and a trained counseling service with structured supervision sessions. Perhaps you know of a counseling service, either as part of the NHS or as part of a service user group, which could help.

Take seriously your potential need for support when commenting on research in areas which can touch you personally, and consider how you can encourage others to be similarly gentle with themselves.

## 7. Getting more help

We hope that this document has been a useful introduction to commenting on research for the HTA programme.

A **companion document** “Why the Health Technology Assessment programme asks members of the public to comment on research” is also available. It provides general background information and can be obtained from the HTA programme – see below.

To help us assist members of the public commenting on research, please send us your comments on this document and tell us about your experiences.

A **glossary of research terminology** frequently used in health care research, specifically written for members of the public, has been developed by the Cochrane Service user Network. It is freely available, along with access to an **online medical dictionary**, at:

<http://www.cochrane.org/resources/glossary.htm>

If you do not have access to the internet and would like a paper copy of the glossary, please contact:

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## **8. Your ideas...**

We have learnt about members of the public commenting on research from public referees and advisors themselves, however, we would like to learn more.

Please tell us what you think of this document, what you think about members of the public commenting on research and whether you have any advice for us or for other members of the public.

Jennifer Cook  
External Review Programme Manager

(email: [htapublic@southampton.ac.uk](mailto:htapublic@southampton.ac.uk))

Revised December 2011

File Ref: \\soton.ac.uk\home\windows\jmc1u08\Desktop\Review of Funding Docs\Reviewed Docs\Guidance\merged guidelines\PeerReview\_Guidance2\_HOW - October 2010.doc