



Public Reviewer Guidance: Part 1

Why the Health Technology Assessment programme asks members of the public to comment on research

NETSCC, HTA
Alpha House
University of Southampton Science Park
Southampton
SO16 7NS

Tel: 023 8059 5586
Fax: 023 8059 5639
www.hta.ac.uk

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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)

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/)

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)

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 interested in reading and commenting on research that the HTA programme is considering funding. It is important for health services research to be influenced by people who use these services.

This is the first 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 is in sections explaining the work of the HTA programme; how members of the public may contribute, and some of the more technical and scientific. You might want to read this right through, or you could dip into the sections in any order.

3. What is health technology assessment?

The term 'health technology' covers a range of methods used to promote health, prevent and treat disease and improve rehabilitation and long term care including:

Drugs: such as antidepressants, contraceptives, antibiotics

Devices: such as pacemakers, dialysis machines, hearing aids

Procedures: such as surgical techniques, acupuncture, counselling

Settings of care: such as general practice, hospitals, care homes

Screening: e.g. for cancer, sexually transmitted diseases, stroke

Health Technology Assessment asks important questions about these technologies such as:

- when is counselling better than drug treatment for depression?
- what is the best operation for aortic aneurysms?
- should we screen for human papilloma virus when doing cervical smears?
- should aspirin be used for the primary prevention of cardiovascular disease?

It answers these questions by investigating four main factors:

- whether the technology works
- for whom
- at what cost
- how it compares with the alternatives

We describe below some of the approaches to answering questions about health care technologies.

Does the treatment work?

To test whether a treatment works, one group is given one treatment and another is given another treatment or a "dummy" treatment (known as a placebo). A placebo looks identical to the new treatment (for example, if it was a tablet, like a head-ache pill, it would be the same shape and colour) but the placebo contains no active ingredients.

By assessing the health of the two groups after treatment, we can tell which treatment is more successful – but only if the two groups of people were very similar before treatment began. Otherwise we might be misled. For instance, after the study one group may be healthier, not because their treatment was better, but because they were younger, or not so ill, or at less risk of ill health before treatment began.

Researchers might try to match the two groups of people so that each group has a similar age range, sex ratio, good or ill health or risk of ill-health. Although they can match for some of the characteristics likely to be important, they can't match for important factors that haven't been identified or recorded. The only way of dealing with this problem is by allocating each person to one or other of the groups at random, as if tossing a coin.

The first step in a randomised controlled trial is to randomly assign each individual to one of two groups, the comparison groups. As randomised controlled trials compare similar groups, they are particularly reliable for testing the effects of treatment. The results of randomised controlled trials may be published in an international journal or indeed not published at all, and studies found most easily tend to have over-optimistic results.

Finding reliable information about the effects of care is therefore difficult, and often decisions about treatments are made without referring to the evidence from the relevant trials. To find out what works, it is worthwhile to search research literature thoroughly to see if the answer is

already known. This may require considerable work over many months, but it will be much less effort than conducting a new randomised controlled trial.

Is the treatment appropriate?

Whether a treatment is appropriate depends on whether it is needed, feasible and acceptable to all those involved in giving and receiving it. Finding out requires asking everyone involved and observing what happens during treatment. People may be asked for their views through questionnaires, interviews (face-to-face or by telephone), or in discussion groups. Getting accurate and useful answers depends on how questions are asked, what time is available for people to think about and discuss their answers, and how important they consider the research.

What do we know from past assessments?

If someone decides to look at and comment on articles that have appeared in the medical or health literature on a particular topic they are 'reviewing the literature'. They may review, say, all the drug treatments available for one type of heart disease. The review might be specific and set out to find what evidence there is for prescribing one particular drug.

They may set about their task very methodically. This requires following step by step an advance plan which covers:

- the way the existing studies are searched for,
- the ways in which, once relevant studies have been found, they are judged, in terms of their usefulness in answering the question the reviewers are interested in,
- the ways in which the results of the separate studies might be brought together.

Following such a clear plan to identify and bring together all relevant studies, is known as 'systematically reviewing the literature'. Some results may be presented statistically, in various ways, and statistical techniques can be used to combine results from more than one study (a 'meta-analysis').

In technical terms, a systematic review is:

A review of a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant research, and to collect and analyse data from the studies that are included in the review. Statistical methods (meta-analyses) may or may not be used to analyse and summarise the result of the included studies.

(The Cochrane Library, Issue 3, 2000. Oxford: Update Software.)

What are the economics of treatment?

Finding out what treatments cost requires listing both obvious and hidden costs. These include costs of drugs, accommodation and nursing costs for hospital patients, and costs to patients and their families, such as travel costs for visitors, and sick pay or income lost through days off work. With this information economists calculate the net benefits or costs of a treatment (cost benefit analysis). They may also compare alternative approaches to care (cost effectiveness analysis) by drawing on randomised controlled trials or systematic reviews of effectiveness.

4. The work of the HTA programme

The HTA programme seeks to answer the questions that patients and the NHS need addressing in four different ways:

- 1. Commissioned research:** Through the commissioned research funding stream, the HTA programme identifies gaps in NHS knowledge and commissions research to fill them.
- 2. Researcher-led:** Through the researcher-led funding stream, researchers are invited to submit outline research proposals on an ongoing basis. The HTA programme provides grants for researchers for clinical trials and evaluation studies that address questions of direct relevance to clinical practice in the NHS. These questions must have outcomes that matter to patients.
- 3. Themed calls:** Researchers are invited to submit research proposals in specific themed areas, where there is a particular identified need for evidence.
- 4. Working with policy customers:** The programme commissions research for a number of policy customers, including the National Institute for Health and Clinical Excellence (NICE) and the National Screening Committee, providing scientific evidence to inform their decisions.

5. Public involvement in the HTA programme

Involving members of the public whose primary interest in health care is for their own health, or the health of people they care for, is important to the HTA programme. They are active in all stages of the HTA programme, from helping to set and prioritise the research agenda to commenting on research proposals. Their role is continuing to develop as the programme progresses.

What do we mean by 'public involvement'?

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

We define 'the public' as:

- patients, unpaid carers, parents/guardians, or 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
- likely to be used.

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

How are members of the public involved?

A formal approach to public involvement was introduced into the HTA in 1997 and members of the public are now engaged throughout every stage. For each task we have developed job descriptions and person specifications. The HTA programme invites the public to become involved, and offers those involved encouragement and practical support.

Feedback about public involvement has been invited from individuals who are providing public perspectives to the HTA programme. Key developments in response to this feedback have included:

- Establishing a mentor scheme for new 'public' panel members.
- Amending guidelines and forms for referees to make them more "lay friendly".
- Training HTA programme staff to seek and support public expertise.

6. Inviting comments from advisors

The HTA programme carefully considers what research should be done before deciding whether a research team, or which research team, should be funded to do it.

For the **commissioned programme**, external advisors are invited to comment on research topics before those considered important are advertised. Research proposals submitted in response to advertisements are circulated for expert comment to decide which, if any, of the research teams should be funded to conduct the research.

For the **researcher-led** funding stream Advisory panels which include public members, consider *what* the researchers plan to address before deciding the details of *how* they intend to do the research. If the Advisory panel supports what is proposed, a full proposal is circulated for wider comment before considering how the research will be conducted.

For the **themed calls** stream, an Advisory Board, which includes public members, consider *what* the researchers plan to address before considering the details of *how* they intend to do the research. If the Advisory Board supports what is proposed, a full proposal is circulated for wider comment before considering how the research will be conducted.

To consider the merits and problems of research proposals, the HTA programme invites comments from external advisors, including:

At least two professional advisors with special clinical interest in the topic who assess:

- the quality of the research proposed,
- how justifiable are the costs,
- the adequacy of the composition of the research team and their capacity to undertake the work.

A number of methodologists who are invited to advise on the quality of the proposals, depending on the nature of the topic, for example:

- health economists
- statisticians
- clinical trials experts

A public advisor who is invited to assess issues important to the public, such as:

- the types of patients to be included in the research
- how they will be recruited
- their information and support needs
- patients' views about health care
- the choice of patient outcomes
- patients' relevant experiences in health care and everyday life.

Comments are invited on a standard HTA referee's assessment form. 'Open' comments are anonymised and sent to the applicants. The Boards are greatly assisted by recommendations from the referees and DBMs' when deciding which applications to fund.

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.

7. Why are public advisors' comments so valuable?

Members of the public can make many useful and important contributions to health care research because they tend to highlight aspects of the research that are relevant to them, such as:

- outcomes important to patients,
- how these outcomes are measured
- the importance of long term outcomes,
- public views about health care, in particular, the acceptability or appropriateness of particular technologies
- potential benefits and risks of the research
- taking account of social relationships within healthcare and everyday life,
- how patients might be invited to participate in the research
- public views about research procedures, their acceptability, and
- public needs for information and support during the research.

Professionals are also asked to focus on other different aspects of the research work, such as the staffing and economic aspects.

Members of the public refereeing HTA research have provided positive, reassuring comments and suggested changes. Some have raised issues not mentioned by other referees and given useful opinions on the ranking of research recommendations. Some have given sensitive interpretations of the results from the service user perspective, with suggestions on how the text might be made more accessible and informative to patient choice. Some public referees have been critical, for example questioning how outcomes are measured.

Person specification: Public contributor commenting on research

Factor	Essential attributes	Desirable attributes
Experience	Having good links through service user networks/ associations/ organisations/ societies/ groups.	
Special skills	Willingness to familiarise yourself with medical and research language.	Keeping up to date with current service user issues via service user networks/media.
Specialist knowledge	Special understanding of particular aspects of health. Knowledge of service user perspectives and able to consider the questions that patients may ask.	Be research aware. Understand the purpose of research within the NHS but do not necessarily have skills in research methods.
Personal qualities	Good communicator. Ability to express own views in writing.	Willingness to give feedback to the HTA programme and help develop this area of work.

8. What to do next

We hope that this document has been a useful introduction to contributing as a member of the public commenting on research for the HTA programme. If you have decided that you would like to become involved in the HTA programme or have any queries, please contact:

NETSCC, HTA
Patient and Public Involvement
Alpha House
University of Southampton Science Park
Southampton
SO16 7NS

Tel: 023 8059 5756

Fax: 023 8059 5639

Email: htaid@soton.ac.uk

A companion document “How members of the public can comment on research for the Health Technology Assessment programme” is also available. It explains how to get started and offers practical advice.

9. Your ideas...

We have learnt about public refereeing from public referees and members of the public. However, we would like to learn more.

To help us try to improve public involvement, send your comments on this document and tell us about your experiences working with the HTA programme 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)

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