



The plain language Glossary of Evaluation Terms for Informed Treatment choices (GET-IT) at www.getitglossary.org

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Abstract

Well-informed choices about how to improve health outcomes depend on access to reliable information, including research evidence. Many people (the public, health professionals and policymakers) have problems understanding some of the terminology used in describing evaluations of treatments. In this article, we describe the development of a glossary to provide plain language explanations of commonly used terms. We identified terms for inclusion in the glossary by screening multiple sources, including 14 other glossaries. Using an iterative process that included feedback and user testing, we designed an online glossary that is freely available at <http://getitglossary.org>. The glossary includes 242 commonly used terms. For each entry there is a suggested preferred term (plain language term), a short definition that can be accessed as a 'pop-up' within text, synonyms, a longer explanation and links to related terms. We also flag 11 terms that we advise against using because they are ambiguous or misinterpreted, with explanations of why we advise against using them. The glossary can be incorporated into documents, providing support for evidence-informed health-care decisions, and embedded in other websites serving a wide variety of functions.

Keywords: glossary; keywords; research jargon; plain language; treatment evaluation; research methods

Key messages

- Well-informed health-care decisions depend on research evidence, but many people do not understand terminology that is used, including the public, health professionals, and policymakers.
- The Glossary of Evaluation Terms for Informed Treatment choices (GET-IT) includes short definitions, synonyms, and longer explanations for 242 commonly used terms.
- It is freely available online and can be adapted for specific user groups, translated into other languages, and embedded in other websites.

Introduction

Well-informed choices about treatments to improve health depend on being able to access and understand reliable information, particularly research evidence. Jargon, and the inconsistent use of terms, can be a barrier to understanding and using research evidence.

This glossary – which we have named GET-IT (Glossary of Evaluation Terms for Informed Treatment choices) – aims to facilitate informed choices about treatments by: (1) promoting consistent use of plain language; and (2) providing explanations of the concepts and terms that may be needed to assess claims about treatments.

The glossary is intended to be useful to people with no research background, particularly those who want to make a choice about a treatment, communicate research evidence to the public, or teach others about how to assess treatment claims.

Jargon-laden claims about treatment effects may arise from summaries of research evidence (systematic reviews of comparisons of treatments) or evidence-informed recommendations (for example, from evidence-based clinical practice guidelines). Because we have failed to find a suitable plain language alternative to the term ‘treatment’, we have used this word to refer to any preventive, therapeutic, rehabilitative or palliative action intended to improve the health or well-being of individuals or communities. This includes, for example, drugs, cells and other biological products, surgical procedures, radiological procedures, physical therapies, devices, psychological or behavioural treatments, screening and other types of preventive care, public health actions, and changes in how health care is delivered or financed.

The GET-IT glossary was developed collaboratively by three international projects:

DECIDE (Developing and Evaluating Communication Strategies to Support Informed Decisions and Practice Based on Evidence; www.decide-collaboration.eu/) was a five-year project (from 2011 to 2015) co-funded by the European Commission under the Seventh Framework Programme (Trewick *et al.*, 2013). It aimed to improve the dissemination of evidence-based recommendations by developing and evaluating methods that address the targeted dissemination of guidelines.

Informed Health Choices (IHC; www.informedhealthchoices.org/) is a project with funding support from the Research Council of Norway. It aims to develop and evaluate resources to teach children and parents how to assess claims about treatment effects.

Testing Treatments interactive (TTi; www.testingtreatments.org/) is a website developed by the James Lind Initiative, with funding support from the English National Institute for Health Research. It contains the Critical thinking and Appraisal Resource Library (CARL) for teachers, promoting critical thinking and appraisal of claims about the effects of treatments (Castle *et al.*, 2017).

GET-IT is intended to facilitate the understanding and use of a variety of resources about the effects of treatments, including:

- plain language summaries of comparisons of treatments, evaluations of health technologies, health economic evaluations, reviews and guidelines (Glenton *et al.*, 2010)

- summaries of findings from systematic reviews (Rosenbaum et al., 2010a; Rosenbaum et al., 2010b)
- explanations of how evidence has been used to arrive at a recommendation or decision (evidence-to-decision frameworks) (Alonso-Coello et al., 2016a; Alonso-Coello et al., 2016b)
- databases of systematic reviews, recommendations or information for patients, carers and the public
- websites and tools that support careful appraisal of claims about the effects of treatments, or the understanding of what constitutes a fair comparison of the effects of treatments.

Methods

We designed and implemented the glossary iteratively, guided by a review of other glossaries and consultation with end users.

Identification of terms for inclusion

We identified terms for inclusion in the glossary by screening:

- the index of the second edition of *Testing Treatments* (Evans et al., 2011) (IC)
- terms used to code learning resources in TTI English (DB)
- explanations of key concepts that people need to understand to assess claims about treatment effects, developed by the Informed Health Choices project (Austvoll-Dahlgren et al., 2015) (AA-D)
- terms used to code resources identified in the European Communication on Research Awareness Needs (ECRAN) project (Mosconi et al., 2016) (IC)
- Cochrane Diagnostic Test Accuracy Working Group Glossary (<http://methods.cochrane.org/sdt/welcome>) (JM)
- explanatory essays in the James Lind Library (www.jameslindlibrary.org/) (Chalmers et al., 2008) (IC)
- a sample of existing glossaries (see below) (IC, PA)
- summaries of findings of systematic reviews (JM)
- evidence-to-decision frameworks (<https://ietd.epistemonikos.org/#/login>) (JM)
- patient versions of guidelines (RH)
- indexes of books written for the public, including *Smart Health Choices* (Irwig et al., 2008), *Know Your Chances* (Woloshin et al., 2008), and *Bad Science* (Goldacre, 2010) (IC, PA).

Drawing on a sample of four existing glossaries

To create a first-draft glossary of terms relevant to the assessment of treatment effects, we selected, from many alternatives (see Box 1), four existing glossaries created specifically to support websites concerned with trials of treatments:

- EU Clinical Trials Register Glossary (www.clinicaltrialsregister.eu/doc/EU_Clinical_Trials_Register_Glossary.pdf)
- US National Library of Medicine ClinicalTrials.gov Glossary (<http://clinicaltrials.gov/ct2/about-studies/glossary>)
- Clinical Trials Toolkit Glossary (www.ct-toolkit.ac.uk)
- CONSORT Glossary (www.consort-statement.org/resources/glossary/).

Of these four glossaries, only the Clinical Trials Toolkit makes explicit its target user group, and provides some information about how it has been developed: it was launched in 2012 by the National Institute for Health Research to help clinical triallists and research and development managers to understand the regulations and requirements for conducting clinical trials.

As a first step to developing our plain language glossary we alphabetically listed terms contained in each of these four glossaries, then tabulated the definitions from the different glossaries side by side, so that they could be compared conveniently. When a term only appeared in one glossary, we adopted its definition for the first iteration of GET-IT; when more than one definition was available for a topic, whichever definition was judged by us to be the most lay-friendly was adopted for the composite glossary. We listed synonyms, for example, 'blinding' and 'masking'. We edited the entries in the glossary to exclude words outside our focus on supporting choices about treatments, or to provide additional clarification.

Box 1: Links to glossaries relevant to health research assembled for the ECRAN Project (Mosconi et al., 2016)

English

1. Bandolier, an independent journal about evidence-based health care (www.bandolier.org.uk/glossary.html)
2. Centre for Evidence-Based Medicine, Oxford (www.cebm.net)
3. CenterWatch, overview of clinical trials (<http://centerwatch.com/health-resources/glossary>)
4. IFA, Italian Medicines Agency (www.agenziafarmaco.gov.it/sites/default/files/phis_glossary_updatedapril2011.pdf)
5. International Federation of Pharmaceutical Manufacturers and Associations (IFPMA) Clinical Trials Portal
6. MRC Clinical Trials Unit (www.ctu.mrc.ac.uk/about_clinical_trials/glossary)
7. National Cancer Institute (www.cancer.gov)
8. NIHR Clinical Research Network (<https://www.nihr.ac.uk/02-documents/policy-and-standards/Faster-easier-clinical-research/Research-Support-Service/RSS%20framework%20docs/Annex%201%20NIHR%20RSS%20Framework%20Glossary.pdf>)
9. Stanford School of Medicine, Stanford Cancer Institutes (<http://cancer.stanford.edu/information/Glossary.html>)
10. US National Institutes of Health (www.nih.gov/health/clinicaltrials/glossary.htm)

French

1. Euro Stem Cell (www.eurostemcell.org/fr/glossaire)
2. IFPMA Clinical Trials Portal

German

1. Deutsches Netzwerk Evidenzbasierte Medizin e.V. (www.ebm-netzwerk.de/was-ist-ebm/images/dnebm-glossar-2011.pdf)
2. Deutsches Register Klinischer Studien (https://drks-neu.uniklinik-freiburg.de/drks_web/navigate.do?navigationId=glossar&messageDE=Glossar&messageEN=Glossary)

3. GLOSSAR ZUR BIOSTATISTIK in klinischen Studien (<http://medistat.de/statistikberatung-glossar.php>)
4. Horten-Zentrum für praxisorientierte Forschung und Wissenstransfer (www.evimed.ch/glossar)
5. IFPMA Clinical Trials Portal
6. MSD Sharp & Dohme GmbH (www.msd.de/forschung/glos_8500.html)
7. Myeloma Euronet (<http://www.myelom.net/glossar>)
8. The Klinikum Nürnberg Glossary (www.klinikum-nuernberg.de/DE/ueber_uns/Fachabteilungen_KN/zentren/studienzentrum/docs_pics/Glossar_Klinische_Studien.pdf)

Italian

1. Agenzia Italiana del Farmaco: Come nasce un farmaco (www.agenziafarmaco.gov.it/it/glossary/20/lettera)
2. Associazione Italiana Malati di Cancro, parenti e amici. Gli studi clinici sul cancro (www.aimac.it/glossario-tumore/glossario-cancro_k6SY_kqib_1p.html)
3. Euro Stem Cell. Che cos'è un trial clinico? (www.eurostemcell.org/it/glossario)
4. La ricerca contro la SMA. Capire i trial clinici (http://ricercasma.famigliesma.org/index.php?option=com_content&view=article&id=48&Itemid=58&lang=it)
5. Partecipasalute: Glossario della ricerca clinica (www.partecipasalute.it/cms_2/node/44)
6. Saperidoc: Valutare le prove di efficacia (www.saperidoc.it/flex/cm/pages/ServeBLOB.php/L/IT/IDPagina/397)

Polish

1. Euro Stem Cell (www.eurostemcell.org/pl/stem-cell-glossary)

Spanish

1. Euro Stem Cell (www.eurostemcell.org/es/glosario)
2. IFPMA Clinical Trials Portal
3. National Cancer Institute (www.cancer.gov/espanol)

Other relevant glossaries

1. American Family Physician EBM Glossary (www.aafp.org/journals/afp/authors/ebm-toolkit/glossary.html)
2. Boston University Medical Center (<http://medlib.bu.edu/bugms/content.php?faq=ebmglossary>)
3. CDISC Clinical Research Glossary (www.cdisc.org/standards/foundational/glossary/cdisc-clinical-research-glossary-v9)
4. Centre for Evidence-Based Medicine, Toronto (<http://ktclearinghouse.ca/cebm/glossary>; site currently being reconstructed)
5. Clinical Epidemiology Glossary (www.ebm.med.ualberta.ca/Glossary.html)
6. Clinical Evidence glossary of EBM terms (<http://clinicalevidence.bmj.com/x/set/static/ebm/toolbox/678178.html>; login required)
7. Clinical Evidence Glossary of Economic Terms (<http://clinicalevidence.bmj.com/x/set/static/ebm/toolbox/678253.html>; login required)

8. Clinical Practice Guideline for the Assessment and Prevention of Falls in Older People (www.ncbi.nlm.nih.gov/books/NBK55850/)
9. US National Library of Medicine ClinicalTrials.gov (<http://clinicaltrials.gov/ct2/about-studies/glossary>)
10. Cochrane Collaboration (<http://community.cochrane.org/glossary>)
11. US National Library of Medicine Health Economics Information Resources (www.nlm.nih.gov/nichsr/edu/healthecon/glossary.html)
12. HTAi consumer and patient glossary (<http://htaglossary.net/HomePage>)
13. National Guideline Clearing House (www.guideline.gov/about/glossary.aspx)
14. NICE National Institute for Health and Care Excellence (www.nice.org.uk/website/glossary/)
15. SUPPORT Tools for evidence-informed health policymaking (STP; <https://health-policy-systems.biomedcentral.com/articles/10.1186/1478-4505-7-S1-S1>)
16. Wikipedia Glossary of clinical research (http://en.wikipedia.org/wiki/Glossary_of_clinical_research)

Incorporation of terms and definitions in a spreadsheet

We collated all the terms identified from the sources listed above, and all the definitions assembled from the glossaries listed above, into a single Google Docs spreadsheet comprising the following columns:

- Term
- Synonyms
- Suggested plain language term
- See also (links to related terms)
- Short definition (with a limit of approximately 130 characters)
- Alternative definition(s) (with a limit of approximately 130 characters) (for use when more than one definition was proposed, and consideration by the editorial team was necessary)
- Technical definition (from *A Dictionary of Epidemiology* (Porta, 2008))
- Full explanation
- Links to Testing Treatments (www.testingtreatments.org/book) (Evans *et al.*, 2011)
- Links to the James Lind Library (www.jameslindlibrary.org) (Chalmers *et al.*, 2008)
- Links to other resources
- Offline resources
- Suggestions for resources.

We filled in the spreadsheet iteratively, drawing on other glossaries and resources, commenting on content suggested by each other, and then discussed and revised the content. Five of the authors met for a one-day meeting to go through the glossary line-by-line, with remaining authors commenting electronically on changes. To check completeness, we also compared our list of terms with terms listed in other English-language glossaries, selected because their aims overlapped with those of GET-IT (that is, to help people make informed choices about treatments).

We checked the glossaries listed in Box 1 and selected the following for our completeness check:

1. AHRQ Effective Health Care Program Glossary (no longer publicly available)
2. American Family Physician EBM Glossary (www.aafp.org/journals/afp/authors/ebm-toolkit/glossary.html)

3. Bandolier (an independent journal about evidence-based health care) Glossary (<http://www.bandolier.org.uk/glossary.html>)
4. Centre for Evidence-Based Medicine, Oxford Glossary (<http://www.cebm.net/glossary/>)
5. Centre for Evidence-Based Medicine, Toronto Glossary (<http://ktclearinghouse.ca/cebm/glossary>; site currently being reconstructed)
6. Clinical Epidemiology Glossary (www.ebm.med.ualberta.ca/Glossary.html)
7. Clinical Evidence Glossary of Economic Terms (<http://clinicalevidence.bmj.com/x/set/static/ebm/toolbox/678253.html>; login required)
8. Cochrane Collaboration Glossary (<http://community.cochrane.org/glossary>)
9. NICE National Institute for Health and Care Excellence Glossary (www.nice.org.uk/website/glossary/)
10. US National Institutes of Health Glossary (www.nih.gov/health/clinicaltrials/glossary.htm).

The glossary content was then transferred to a Word document and refined iteratively by all authors, but especially JM, IC, AA-D and AO. To inform the iterative refinement, we randomly selected ten terms from the glossary and tested our short definitions and full explanations in a workshop attended by members of the public and writers of patient information. For the same ten terms, we presented two versions, with different readability levels, of the short definitions and long explanations in six face-to-face user tests with people with no research background. We used the feedback from the workshop and user tests to develop a set of rules for all the terms, definitions and explanations, and to simplify the language throughout the glossary. These rules are set out in Appendix 1.

We used readability software available online (<https://readable.io/>). To try to ensure that the language used in the definitions and explanations was as simple as possible, and that it could be easily read and understood by people who have completed high-school education, we tried to get the average grade level across five formulae to be under 16, and the Flesch-Kincaid Reading Ease score above 30.

All authors reviewed all the content and agreed on the version sent to a professional copy editor. The copy editor's version was checked by IC and JM.

Putting terms on to a website

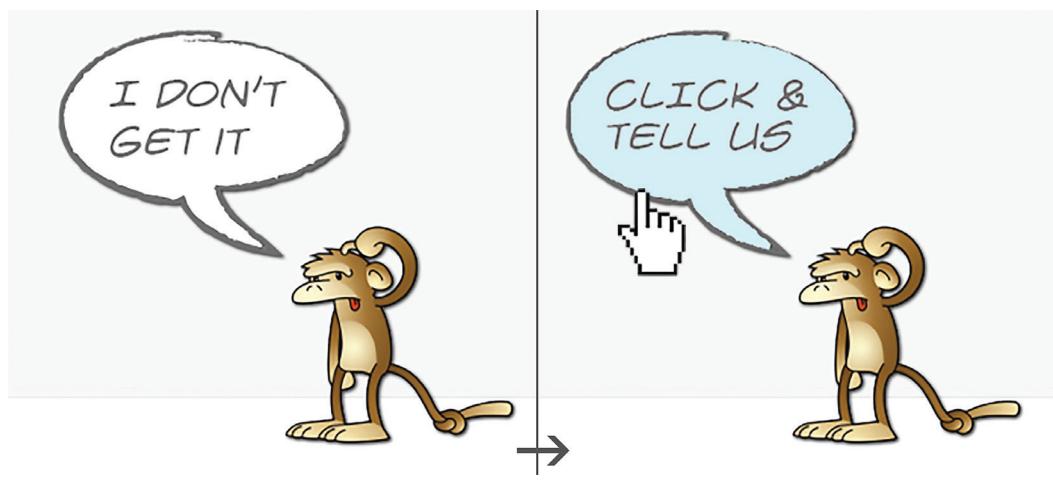
The terms included in the Word document were then put into a website version of the glossary. After discussion by the GET-IT project group, the following columns from the Word document were implemented on the website:

- Suggested preferred term (plain language term)
- Short definition (with a limit of approximately 130 characters)
- Synonyms
- Full explanation
- See also (links to related terms).

We created a simple content management system (CMS) that allows editors to manage the content of the glossary, including reviewer comments and version control. Additionally, we added a system for end users to send feedback when they find definitions or explanations unhelpful. By clicking an 'I don't get it!' button in the form of the 'IDGI Monkey', the terms are flagged (see Figure 1). These data are tracked and

presented to the editors through the CMS, so that they can see which terms might need improvement.

Figure 1: The 'I don't get it' button for user feedback



Developing and user testing the online glossary

Prior to developing the application, we carried out scoping interviews with three potential users of GET-IT. The findings of these interviews helped us to establish the design and functionality required to enhance appeal to end users and potential third-party users of GET-IT.

Once a pilot interface had been developed, we conducted hands-on testing with six people, and obtained feedback on design, functionality and content. We also commissioned an interaction designer to carry out a heuristic evaluation to identify any usability issues. This work informed a simplification of the interface and some changes to functionality.

Please see Appendix 2 for more information about user involvement in the development of definitions, explanations and the online interface of the glossary.

Results

The resulting GET-IT Glossary is freely available online at <http://getitglossary.org>. The GET-IT CMS supports translation to other languages and the creation of bespoke glossaries. A master glossary is used to populate new versions of the glossary, which can then be translated or edited using the CMS. Spanish and Finnish versions of the GET-IT glossary are currently being prepared.

The glossary can be embedded on third-party websites in two ways: (1) a WordPress plugin; and (2) an Application Programming Interface (API). These tools allow other websites to install GET-IT as a drop-down menu in a sidebar widget, and as pop-up boxes that appear over jargon terms when the user clicks on them (see Figure 2).

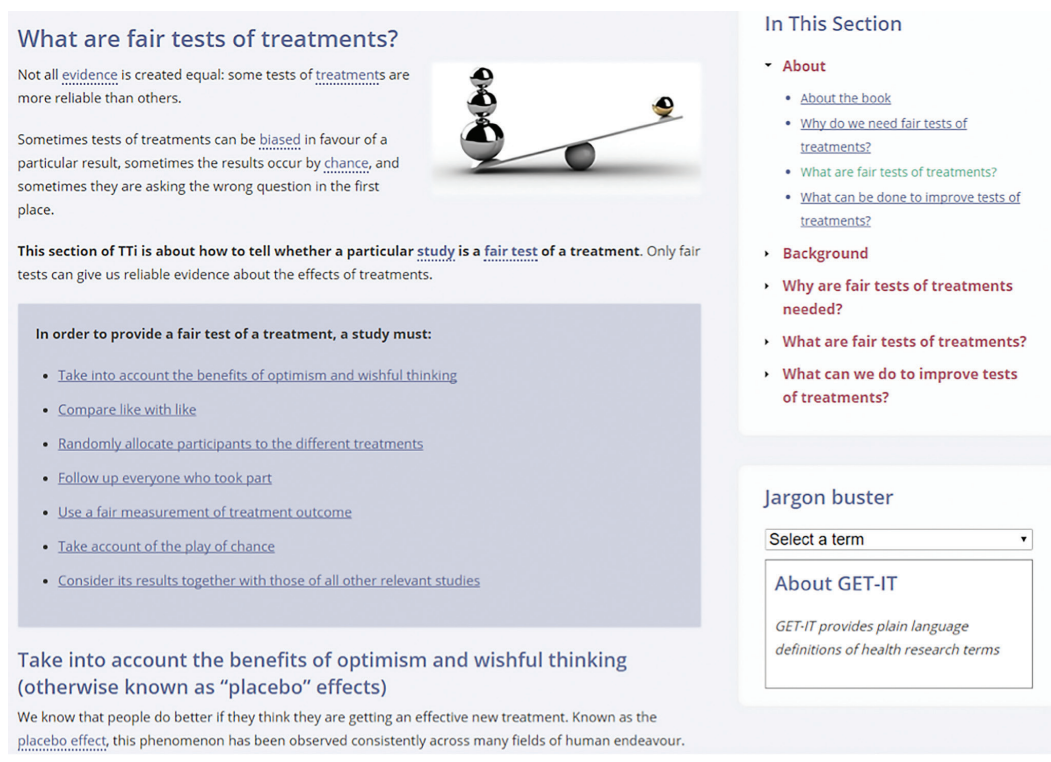
Figure 2: A pop-up box to clarify a term



An example of the GET-IT glossary embedded in a website can be viewed here: www.testingtreatments.org/book/about/fair-tests-treatments/ (see Figure 3).

After multiple iterations and revisions, the glossary currently contains 242 terms with definitions and explanations, with a readability level appropriate for a person who has completed high school. Although the primary focus of the glossary is on the effects of treatments, we also included terms that are relevant to going from evidence to decisions (Alonso-Coello et al., 2016a). This includes terms that are relevant to diagnostic tests (for example, sensitivity and specificity) and economic analyses (for example, cost-effectiveness and quality-adjusted life years).

Figure 3: The GET-IT glossary embedded in a website



Terms we recommend not using

In identifying terms for inclusion in GET-IT, we came across some that were frequently ambiguous or misinterpreted. The word 'significant' is an example of such a term. We have included, and have provided explanations of, these terms, and have explained why we advise against using them. We have used a warning symbol on terms in the glossary that we advise against using. These are summarized in Box 2.

Box 2: Terms we recommend not using

Single blinding (www.getitglossary.org/term/single+blinding) (single masking), **double blinding** (www.getitglossary.org/term/double+blinding) (double masking) and **triple blinding** (www.getitglossary.org/term/triple+blinding) (triple masking) – Because the meaning of 'single blind', 'double blind' and 'triple blind' are ambiguous in terms of who was blinded, we recommend not using the terms (Devereaux *et al.*, 2001; Schulz *et al.*, 2002). It is better to consider explicitly who was blinded, and who was not blinded, and how that might have protected against, or led to a risk of, bias, including placebo effects, differences in the care provided to the participants in a study other than the treatments being compared (performance bias), or differences in how outcomes are measured in treatment comparison groups (measurement bias).

Efficacy – The term 'efficacy' is sometimes used to indicate the desirable effects of treatments under ideal conditions, as measured in explanatory trials. However, 'efficacy' is also commonly used as a synonym for effectiveness. Because of this, the meaning of 'efficacy' is often unclear, and we recommend against using the term. In addition, pragmatic and explanatory trials can differ in a variety of ways and to different extents (Thorpe *et al.*, 2009).

Level of evidence (www.getitglossary.org/term/level+of+evidence) (hierarchy of evidence) – 'Level of evidence' is an ambiguous term, which sometimes refers to where a type of study (study design) lies in a hierarchy of evidence. Some types of study have less risk of bias for a particular type of question. For example, randomized studies have less risk of bias than non-randomized studies for questions about treatment effects. However, there are other factors that can increase or decrease the risk of bias in both randomized and non-randomized studies. Hierarchies of evidence (based on study design) can be useful, for example, in deciding which study designs to include in a systematic review. However, they should not be confused with assessments of the risk of bias, or the certainty of the evidence, which should be assessed using explicit criteria. Because 'level of evidence' can also refer to (or be confused with) the risk of bias, or the certainty of the evidence, we recommend against using this term.

Modified intention-to-treat analysis (www.getitglossary.org/term/modified+intention-to-treat+analysis) – There is no clear definition of what a 'modified intention-to-treat analysis' is, and descriptions of these analyses vary greatly from study to study. Studies that report modified intention-to-treat analyses often have industry funding and authors' conflicts of interest, and might have a higher risk of bias than studies that report an intention-to-treat analysis, due to disruption of the baseline equivalence established by random allocation and reporting bias. Because 'modified intention-to-treat analysis' is an ambiguous term, we recommend against using it.

Natural history (<http://getitglossary.org/term/natural+course+of+health+problems>) – ‘Natural course’ of health problems is a preferable term to ‘natural history’ and ‘natural progression’, because ‘course’ avoids inappropriate reference to ‘history’ (and associations with natural history museums), and because ‘course’ is more neutral than ‘progression’. ‘Course’ covers amelioration and deterioration, whereas ‘progression’ often implies deterioration.

Random selection (<http://getitglossary.org/term/random+allocation>) – ‘Random selection’ is most clearly appropriate when it refers to drawing a representative sample from a defined population. It is sometimes used inappropriately to refer to random allocation to treatment comparison groups (Forsetlund et al., 2007). Because of this, its meaning is ambiguous and it is best avoided.

Significant (www.getitglossary.org/term/important) – Because clinical significance is often confused with statistical significance (www.getitglossary.org/term/significant,%20statistically), we recommend against using the term ‘significant’ to describe treatment effects, especially without specifying what is meant. When scientific papers call results significant, they usually mean statistically significant. Using ‘important’ when referring to such effects deals with this ambiguity, because it prompts consideration of to whom the treatment effect is important.

Statistically significant (www.getitglossary.org/term/statistically+significant) – “‘Statistical significance’ is so commonly misreported and misinterpreted that we recommend that terms such as “not significant”, “not statistically significant”, “significant”, “statistically significant”, “trend towards [an effect]”, and “borderline significant” should not be used’ (EPOC, 2017a: n.p.). These terms are based on an arbitrary cut-off for statistical significance (typically 0.05). ‘Statistical significance’ (a ‘positive’ study) is often confused with ‘clinical significance’ (importance), especially when ‘significant’ is used rather than ‘statistically significant’. It also is often misinterpreted as meaning that the certainty of the evidence is high, when it might not be for other reasons, such as a high risk of bias. Conversely, ‘statistically non-significant’ is ambiguous. It is often misinterpreted as evidence of ‘no effect’ (a ‘negative’ study). However, results that are ‘not statistically significant’ can either be informative (if the confidence interval (and the certainty of the evidence) suggests that there is unlikely to be an important effect) or uninformative (inconclusive, if the confidence interval does not rule out an important effect). It is better to consider explicitly estimates of effect and confidence intervals, and to use plain language to describe effects based on the size of the effect and the certainty of the evidence (EPOC, 2017b).

Subjects (www.getitglossary.org/term/study+participants) – Participants in a study are sometimes referred to as ‘subjects’. We recommend against using this term, because it is demeaning (Chalmers, 1999).

Discussion

There are other glossaries that cover many of the terms used in connection with comparisons of treatments (see Box 1) and going from evidence to decisions, but GET-IT combines four features that we believe make it distinctive:

- **Use of plain language:** GET-IT definitions and explanations have been written in plain language to facilitate understanding by a wide range of people.

- **Provision of short definitions, explanations and examples:** GET-IT provides 130-character definitions that can be accessed as pop-ups within text, as well as longer explanations and illustrative examples, when needed.
- **Designed for sharing and adaptation:** GET-IT has been designed so that definitions and explanations can be adapted for specific user groups, translated into other languages and embedded in other resources.
- **Development through international collaboration:** GET-IT has resulted from collaboration among three international projects, to reduce redundancy and promote consistent use of language.

The main limitation of the glossary in its current iteration is that the readability level is targeted at people who have completed a high-school education. A lower readability level is recommended for patient materials, but this was difficult to achieve for many of the terms in the glossary. We found it challenging to establish an effective compromise between accuracy and lay-friendliness. For example, we received a suggestion that the definition for 'randomized study' should be something like 'how scientists work out which treatment is best'. We felt that this was too vague, and decided that our aim was to provide explanations to people who wanted to understand what a term means. To address this limitation, we built GET-IT with the facility to customize definitions for a particular audience. This was particularly important for website content editors, who wanted to add or edit definitions to fit their users' needs.

To assess claims about treatments, people need to be able to understand the terms used in those claims. Without this understanding, it is not possible for them to make informed decisions about treatments. The GET-IT glossary aims to support informed choices about treatments by people who do not have a research background; in other words, most people. It does this by promoting consistent use of plain language and providing plain language definitions and explanations of terms used in claims about treatment effects. GET-IT will be useful to people making choices about treatments for themselves, family members or friends, or decisions about health policies. In addition, it will be useful to people whose job it is to communicate research evidence to the general public, and to those who teach others how to assess claims made about the effects of treatments.

We anticipate that GET-IT will be an ongoing endeavour, with improvements made in the light of comments and suggestions from users. We encourage anyone interested in learning more about GET-IT, using it on their own website, developing or evaluating it further, to contact us at info@getitglossary.org.

Appendix 1: GET-IT glossary rules

According to the protocol, the glossary is specifically intended to be useful to people without a research background, particularly those:

1. wanting to make an informed choice about a treatment
2. communicating research evidence to the general public
3. teaching others about how to assess claims made about treatments.

At this stage, we are aiming for our definitions and explanations to be understandable for the 'informed consumer', that is someone who does not have a research background, but does have a little experience of reading information about medical research. We are aiming for short sentences and one concept per sentence, as far as possible.

In the next revision of the glossary, we aim to target younger readers, or those with less-developed health literacy (and literacy) skills.

In considering the terms, plain language terms, short definitions and explanations, we have tried to be consistent throughout the glossary by following these rules:

1. The word 'treatment/s' is used for any kind of health intervention.
2. The plain language term for all terms is used whenever referred to in 'see also' references, short definitions and explanations, with links to the definition of that word (for example, 'bias').
3. Definitions for categories of words use similar text and structure (for example, study designs and statistical terms).
4. The use of the term (or forms of it) in the definition and explanation is avoided, but it is used in some instances when it is a word that people should understand but has a specific meaning in this context, and when no other word will do as well.
5. There is a comment in the comments column when a word has multiple meanings (in research and everyday usage), or there is ambiguity about its meaning. This is clarified in the explanation.
6. Certain terms are avoided:
 - a. 'intervention' – for this, we use 'treatment'
 - b. 'estimate' – for this, we have used 'measure' and 'statistical value', neither of which are ideal but we think they convey the meaning
 - c. 'disease' – for this, we have generally used 'health problem'; 'condition' has been used in some definitions where 'health problem' would not be correct (for example, definitions of screening and overtreatment)
 - d. 'alternative' – for this, we have used 'different', if it is necessary (it may just be possible to remove the word 'alternative' without changing meaning)
 - e. 'those' (as in 'those who provide treatment') – for this, we have used 'the people'
 - f. 'measures' (as in 'measures taken to ...') – for this, we have used 'actions', 'methods' or 'steps taken'
 - g. 'patients' – for this, we have used 'participants', unless 'patients' is the only word that will do
 - h. 'relationship' – for this, we use 'association'.
7. Certain terms are consistently used:
 - a. 'study' – for any kind of study design; the definition always says whether it is an experimental or an observational study; the word 'trial' is avoided, as is 'fair test'
 - b. 'health-care staff' – for any kind of person delivering a treatment.
8. The groups of participants in an experimental study are called 'treatment comparison groups', whether they are receiving one or more different treatments, usual care, placebo or no care. The type of treatment may need to be specified. The terms 'intervention group' and 'control group' are avoided. 'Comparison group', meaning 'control group', is avoided. 'Treatment group', meaning 'intervention group', is avoided.

Appendix 2: User involvement

Testing short definitions and full explanations

As part of the process of refining the definitions and explanations, we randomly selected ten terms from the glossary and sought feedback on the short definitions and long explanations in a workshop with members of the public and people with an interest in writing patient materials.

We user tested two versions, with different readability levels, of the definitions and explanations of the same ten randomly selected terms on a convenience sample of seven people without research backgrounds. These were:

1. a journalist
2. a 17-year-old high-school student
3. a secondary school English teacher
4. a university lecturer in design
5. a retired biology teacher
6. a carpenter with a high-school education
7. a retired classical musician.

Scoping

We conducted telephone interviews with:

1. the website information manager for a large UK charity providing information for the public and professionals
2. a content manager for an English NHS body providing patient information
3. a content manager for an international health technology assessment programme that uses a similar glossary.

User testing

We conducted hands-on, face-to-face testing with:

1. a health sciences undergraduate student
2. a science blogger
3. a health professional, writer and educator in evidence-based dentistry
4. an NHS communications specialist
5. a retired teacher with no health background
6. an editor working in government, with no health background.

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