- People are “participants” in research - http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1115535/
- What’s in a name? Subjects, volunteers, participants and activists in clinical research - http://lancaster.academia.edu/RTutton/Papers/274951/Whats_In_a_Name_Subjects_Volunteers_Participants_and_Activists_In_Clinical_Research
- From the *APA Style Publication Manual* 2010 http://www.apastyle.org/learn/faqs/subjects-and-participants.aspx

The first URL is a letter by Iain Chalmers, which contributed to the debate in the *BMJ*. The APA Style manual is particularly unhelpful. It states that you should write about people in your study in a way that acknowledges their participation but is also consistent with traditions in the field of study, adding that for more than 100 years the term “subject” has been used in experimental psychology. Corrigan and Tutton’s article starts by affirming that there has been a shift away from the use of “research subject” in favour of “research participant” in recent years. They list the bodies that have adopted “participant”: National Institutes of Health, Medical Research Council, to which to my knowledge the National Bioethics Advisory Commission, Association for the Accreditation of Human Research Protection Programs, and National Centre for the Dissemination of Disability Research can be added. Corrigan and Tutton, however, are concerned that although there have been initiatives to involve “subjects” more in research these might stem from researchers’ needs to recruit people to and retain them in the research cohort. They quote Cooke and Kothari, who have shown that participation practices can be manipulative or have harmed those they are intended to empower. Corrigan and Tutton propose using the terms “subject”, “participant”, or “patient activist” depending on which term reflects the actual involvement of people being studied. “Subject” would be appropriate when all that the people did was to give informed consent, “participant” where they have been involved in the design or use of the study, and “patient activist” where the study was instigated and managed by a patient group.

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This Site I Like

The HONcode: How to judge the medical information on the web?

(http://www.hon.ch/HONcode/)

Thousands of websites offer health information. Of course not all these sites are reliable and up to date, and assessing the credibility of the publisher as well as the relevance and accuracy of the information is not always simple. That’s why the Health On the Net Foundation (HON) – a non-profit, non-governmental organization, founded in 1995 under the auspices of the Geneva Ministry of Health – issued in 1996 the HONcode, the first code of practice for medical and health online publishing.

The purpose of certification is to improve the quality and transparency of Internet-based medical and health information. Its mission is not only to help health consumers identify quality sites, but also to bring about awareness among site publishers, underlying the importance of specific guidelines and mobilizing them around the certification process of their site.

According to its website, the HONcode has been translated into 35 languages, covering 72 countries, and is currently used by over 7300 certified websites.

A question of principles

To be considered reliable, a health-related website must make clear the sources used, and ensure that the information presented is appropriate, independent, and timely. It must identify who is most likely to visit the site and ensure that the information presented is as comprehensible and as easily accessible. Finally, relationships with possible sponsors should be clearly disclosed.

These aspects are summarized by the eight HONcode principles, which are the following: 1. Authoritative (the qualifications of authors of health information should be indicated); 2. Complementarity (the mission and target audience of the site have to be fully explained, and it should be clear that the websites aims at complementing and not replacing the doctor–patient relationship); 3. Privacy (privacy and confidentiality of personal data submitted to the site by the visitor should be respected); 4. Attribution (the sources of the health information and the dates of publication or last update on the pages should be provided); 5. Justifiability (the justifications for claims about the benefits and disadvantages of products, treatments, or services have to be disclosed); 6. Transparency (information should be accessible, with identification of the webmaster and the availability of at least one contact address); 7. Financial disclosure (ie sources of funding of the site); 8. Advertising policy (advertising should be clearly distinguished from editorial content).

Health websites often include collaborative and web 2.0 elements, such as discussion forums, social networking, wikis and blogs, and in general platforms or pages where the user can interact with other users or with the content. In medicine, these tools can be useful providing good information about specific diseases or disorders, but they can also lead to misinformation; therefore assessing their reliability is very important. The HONcode Web 2.0 is an adaptation of the eight principles, which focuses on the special features and functionalities of web 2.0 platforms, taking into account the dynamic interaction between internet users and developers.

The HON website also offers specialized medical search engines: MedHunt for patients, HONsearch and HONselect for medical professionals, and HONcodeHunt to search for HONcode certified websites. HON also provides two databases of trustworthy health information on eye diseases, Provisu.ch, accessible by those with poor or no vision through its variability of letter size and audio version, and Santeromande.ch (in French), a directory of registered health professionals, hospitals, and medical associations.

How to apply

The HONcode is voluntary, which means that webmasters can apply for HONcode certification. The complete procedure is fully explained on the website (http://www.hon.ch/HONcode/HONcode_membership.html). The application, free of charge, can be submitted by completing the HONcode questionnaire about the conformity of your website with the eight HONcode principles, then filling the application form with general information about the website. Then the evaluation process starts (it can take up to 18 months). Each application is checked by a review committee, including medical and legal professionals, for compliance with all eight principles. If the website is considered compliant, you can finally display the HONcode seal and associated text on your home page linked to your certificate. Sites displaying the foundation's symbol are generally considered credible sources of information. Since the HONcode certification is a dynamic state, a certified site receives a check-up visit periodically, beginning one year after the initial certification, and the certification is extended every year according to site compliance.

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