Choosing language that recognises the contributions of people who take part in research

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Abstract

Medical communicators can choose words that influence how people perceive individuals and populations who take part in research. For many years, the term *subjects* was used ubiquitously and internationally in clinical research. However, this term can fuel disrespect, mistrust, and bias in clinical practice and research. As a result, *subjects* has been increasingly replaced with the more precise and respectful term *participants*. However, other terms may more accurately and precisely describe people who take part in clinical research while also recognising their contributions, autonomy, humanity, and individuality with respect, empathy, compassion, and kindness.

Introduction

Medical communicators have the power to choose words that influence how people perceive individuals and populations who take part in research. They can choose precise language that empowers, humanises, and builds trust with respect, empathy, compassion, and kindness. Or they can choose language that erodes trust, disregards the humanity and individuality of people, and contributes to explicit and implicit bias in health care.[1-4]

For many years, people who took part in clinical research were ubiquitously and internationally referred to as *subjects*. However, over the past three decades, *subjects* has been increasingly replaced with the term *participants*. This shift is due to differences in the denotations and connotations of these terms.

Denotation vs. connotation

Denotation refers to the direct and specific meaning of a word (i.e., the definition).[5] On the other hand, connotation refers to the suggested meaning of a word separate from the explicit name or definition (i.e., the ideas or feelings associated with that word).[6] In other words, denotation is the *explicit* or *objective* meaning of a word, and connotation is the *implicit* or *subjective* meaning of a word. For example, the denotation of "public speaking" is "the act or process of making speeches in public."[7] However, for many people, the connotation of "public speaking" includes feelings of anxiety, fear, and dread.

The denotations and connotations of the terms *subjects* and *participants* can give insight into the reasoning for shifting away from using *subjects* toward using *participants*. The word *subject* can be used as a noun, adjective, or verb and, therefore, has many definitions. As a result, use of *subjects* is imprecise and risks creating confusion and misunderstanding. As a noun (the appropriate use in the case of referring to study participants), the word "subject" can mean "an individual whose reactions or responses are studied."[8] This definition may seem appropriate in research and relatively harmless. However, other definitions include "one that is placed under authority or control" and "one that is acted on."[8] These definitions connote a power differential that can fuel a perception of people who participate in research as "less than". This connotation is disrespectful and contributes to bias.[9,10]

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On the other hand, the definition of *participant* is "one that participates."[11] With this singular and clear definition, there is no room for interpretation or misunderstanding. This term also does not connote a power differential and, thus, is more respectful to people who take part in research. Based on these definitions alone, one can deduce that the term *participants* is a better choice than *subjects*.

Alternatives to *participants*

Although *participants* is now the preferred term, some people argue that *participants* is not always the appropriate choice. For example, some believe that the term *subjects* more accurately and honestly represents a participant's vulnerability within research that requires formal protections.[12,13] Others acknowledge that they do not like the term *subject*, but they believe that the word is a clearer choice than *participants*. They argue that everyone who is involved in a study – patients, investigators, study coordinators, committee members, etc. – are all "participants" in a study.[14,15]

Given these perspectives, are there alternatives to the terms *subjects* and *participants*? One possibility is to use the term *volunteers*. However, this term may be most appropriate for non-therapeutic research[14] or in reference to a comparison group. For example, the National Institutes of Health (NIH) defines a *healthy volunteer* as "someone with no known significant health problems who participates in research to test a new drug, device, or intervention" and whose "health information can be used as a comparison."[16] Alternatively, the *AMA Manual of Style* defines such a person as a *control participant*, albeit with a more nuanced definition: "a person who does not have at least some of the characteristics under study or does not receive the intervention but provides a basis of comparison."[9] This definition infers that the control participant may not be "healthy," supporting that *healthy volunteers* may not be the most accurate choice for a comparison group.

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The term *volunteer* also may not be appropriate in other cases, such as studies involving people who could not consent or willingly participate (e.g., people who have died, people whose family provided consent on their behalf).

Another option is to use *patients*. However, this term may not be appropriate in all circumstances. For example, the *AMA Manual of Style* describes a *patient* as "a particular person under medical care."[9] Similarly, the *Publication Manual of the American Psychological Association* describes a *patient* as "an individual diagnosed with a mental health, behavioural health, and/or medical disease, disorder, or problem who is receiving services from a health care provider."[17] Given these definitions, *patients* may not be appropriate for studies in which people are not receiving medical care, such as survey research or community projects.

In some studies, *sample* might be the most appropriate term. This term would be most applicable to analyses of large, de-identified data sets. This term would also be appropriate when discussing established statistical terms and describing study designs (e.g., "between-samples estimate").[17]

Another consideration is to use the term *case*, but only with caution. Like *subject*, the term *case* can be dehumanising when referring to a specific person.[9] To distinguish *case* from *participant*, both the *AMA Manual of Style* and *Publication Manual of the American Psychological Association* specify that a *case* is an instance of a disease or disorder, and a *patient* or *person* is affected by a disease or disorder and is receiving care from a health care professional.[9,17] Thus, *case* is more appropriate for describing case-control studies (e.g., *cases, patients in the case group*, or *case patients* and *controls*).[9]

For example, use terms that clearly define the person or population, such as *children, adults, women, men, respondents,* or people with a certain condition (e.g., *patients with breast cancer*).

Other options include the terms *clients* and *consumers*. However, these terms are appropriate in limited settings. For example, *clients* might be appropriate in some academic, business, school, or other settings.[17] This term might also be appropriate for referring to people under the care of psychologists or enrolled in treatment programs for substance misuse or other disorders.[9] Occasionally, *consumer* might also be appropriate, such as describing people who "consume" information on the internet. However, this term should not be used to refer to patients.[9]

An ideal option is to choose the most specific language possible to describe people who take part in research.[17] For example, use terms that clearly define the person or population, such as *children, adults, women, men, respondents*, or people with a certain condition (e.g., *patients with breast cancer*). This approach ensures accuracy, precision, and clarity while respecting people who take part in research.

Recommendations

Many different terms can be used to refer to people who take part in clinical research. But is there one best term? Unfortunately, no. In many situations, *participants* is the most clear and respectful choice. In others, medical communicators must carefully consider the context and refer to people in a way that accurately acknowledges their contributions and autonomy. And in every case, medical communicators must use language that recognises people's humanity and individuality with respect, empathy, compassion, and kindness.

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Disclaimers

The opinions expressed in this article are the author's own and not necessarily shared by EMWA.

Disclosures and conflicts of interest

The author declares no conflicts of interest.

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