Policy on Stigmatizing Research

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Background

Central to the mission of the *All of Us* Research Program is the collection of information from diverse groups of people within the U.S. population. However, the program must recognize the potential for resources collected in good faith to be used towards social detriment. In order to take steps to minimize and/or prevent such actions, the program must establish a working definition upon which to base preventative measures.

Rule and Analysis

Stigma may be understood as convergence of the following components:[1]

1) **The identification and labeling of human differences.** Not all differences are deemed socially relevant. Certain differences—such as many of the differences which characterize groups that have historically been underrepresented in biomedical and health research—are considerably more prone to stigma than others. Salience of labels in such domains are dependent on a process during which gross oversimplification of an attribute or characteristic creates artificial categories, upon which contextually-specific social selection occurs.

2) **The linking of labeled persons by dominant cultural belief to undesirable characteristics and formation of negative stereotypes.** A key feature in this process is the provision of characteristics that may be linked to one or more social labels. Scientific research can provide just such fodder, and the result can be arbitrary stereotypes socially perpetuated under the banner of science.

3) **Separation of people into categories of "us" and "them" by applying said stereotypes.** The logical next step after the perpetration of a negative stereotype is the use of that stereotype to define in-groups and out-groups.

4) **The experience of loss of status and discrimination by labeled persons. This is the ultimate output of the stigma process.** Here, "out-group" members are downwardly placed, with regards to the "in-group," and subjected to detrimental treatment, consideration, or distinction based upon label(s), rather than merit.[2] Discrimination can be leveraged by an individual or group towards an individual or collection of individuals. However, discrimination is particularly dangerous in its structural form, when discriminatory behavior becomes culturally accepted and accumulates to shape institutional practices that work to the disadvantage of labeled group(s) even in the absence of individual prejudices or discrimination.[3]

5) **The exercise of social, economic, political, or other power that reinforces the above processes, translating them into significant consequences for labeled individuals.** Without the uneven distribution of power, in-group prejudices would not carry the same negative consequences for out-group members.

When these components converge, they produce widespread attitudes and beliefs that lead people to reject, avoid, or fear those they perceive as being different, resulting in detrimental inequities and unfair treatment at either the individual or group level.[4]

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[1] Link BG and Phelan JC. (2001). Conceptualizing Stigma. *Ann Rev Sociology*. 27:363-385.

[2] Discrimination. (n.d.) *West's Encyclopedia of American Law, edition 2*. (2008).

[3] Hatzenbuehler ML. (2017). Structural Stigma and Health. In B Major, JF Dovidio, and BJ Link (Editors), *The Oxford handbook of stigma, discrimination, and health.* New York: Oxford University Press.

[4] Goffman E. (1963). *Stigma: Notes on the Management of Spoiled Identity.* Englewood Cliffs, NJ: Prentice Hall.

Policy Statement

Stigmatizing research is any research proposal, project, or question that has the potential to instigate or promote marginalization, discrimination, or loss of status by a person or group of people. Stigma may be inherent in the research design (i.e., the formation of a research question based on prejudicial biases) or a byproduct of the research findings (i.e., the interpretation of findings in such a way as to promote negative stereotypes) and may be intentional or unintentional. While complete elimination of stigmatizing research based on use of the *All of Us* data resources is likely impossible, the program should take steps in earnest to prevent resource use with the potential to stigmatize and to punish bad actors, as appropriate.