

Data User Appeals Policy

Updated on 5/12/2020

Background

The *All of Us* Research Program (AoURP, the program) Data User Code of Conduct (DUCC) requires data users to establish a project workspace for each unique research project. Each project workspace, in turn, must bear a “meaningful and accurate description of [the] research purpose” that is created at the time of workspace initiation. These workspaces and descriptions are subject to review upon public or user request or during periodic audits of the Research Hub. The *All of Us* Resource Access Board (RAB) is charged with conducting any reviews necessary to determine compliance with the DUCC, and shall do so, according to the policies and guidelines set forth by the program. The RAB will determine whether the workspace project is compliant with the DUCC and recommend corrective or enforcement action. In some instances, data users may disagree with RAB determinations. In these situations, data users may lodge an appeal according to the policy below.

Policy Statement

Each original RAB determination may be appealed twice, as described below. Such appeals must be submitted within 30 days of the determination made by the RAB, as measured from the date upon which notice of the determination was sent to the user(s). An extension may be requested for extenuating circumstances.

To submit an initial appeal, the data user(s) must submit a request to the program consisting of the following information:

- 1) The record identifier for their case;
- 2) A statement outlining the reason(s) for the appeal; and
- 3) Any additional information the data user(s) believes supports their position.

The program will send the data user(s) confirmation immediately upon receipt of the user(s) appeal request. At any point in the appeal review, the program may leverage strategies to protect program resources and participants, such as preventing access to the Research Hub or monitoring user behavior, as appropriate. The decisions/enforcement actions will remain in effect during the appeal process.

All appeals will be assigned to a review team with appropriate expertise, which may include AoURP staff members and program leadership. The review team may consult with consortium subject matter experts as needed.

User(s) will receive a status update from the program within 14 days of the receipt of their initial appeal request and at least every 14 days thereafter until a decision is reached. The review team may solicit additional information or supporting materials from the user(s) to assist in the appeal review. The program will transmit the program’s appeal decisions to the user through the RAB, and the communication will document the decision and detail subsequent penalties, adjustments in remedial actions, and any additional steps the user may take, as appropriate.

If a user disagrees with the outcome of their initial appeal, the user may submit a final appeal within 30 days of the determination made by the program, as measured from the date upon which notice of the initial appeal determination was sent to the user(s).

To submit a final appeal, the data user(s) must submit a request to the program consisting of the following information:

- 1) The record identifier for their case;
- 2) A statement outlining the reason(s) the user considers the initial appeal to have been wrongly decided; and
- 3) Any additional information the data user(s) believes supports their position.

The program will send the data user(s) confirmation immediately upon receipt of the user(s) appeal request.

The *All of Us* Chief Executive Officer, or his or her delegate, will review and decide all final appeals. In his or her sole discretion, the *All of Us* Chief Executive Officer, or his or her delegate, may consult with AoURP staff members and program leadership and consortium subject matter experts. User(s) will receive a status update from the program within 14 days of the receipt of their initial appeal request and at least every 14 days thereafter until a decision is reached. There are no further appeals.