From: 5.1.2e
Location: Microsoft Teams Meeting
Importance: Normal
Subject: Voorbespreking WP2 patientportal longCovid
Start Date/Time: Thur 1/18/2024 1:00:00 PM
End Date/Time: Thur 1/18/2024 1:50:00 PM

Zoals besproken: uitleg over opzet van RIVM citizen science portals, en vertaling naar de longcovid patient portal, als voorbereiding op afstemming met WP3/5
Aandachtspunten:

-software/hosting, voorbeelden van RIVM portals en bemensing (oa data scientist)
-DPIA
-niet-WMO?
-consortiumagreement voor toegang partners?
-list of requirements

Beschrijving portal in de subsidie aanvraag onder WP2:
B. Patient portal
To create a portal where patients can enroll themselves and healthcare workers can enroll the patients for participation in research activities (e.g., WP3 (biobank) and WP5 (platform trial), with online informed consent enabling to be approached for new studies and/or biobanks. In addition, through this portal standardized data will be collected (e.g., on CRF, patient reported outcome measures (PROMs)), and patients' informed consent will also be requested for both data linkage with the national registries (e.g., Population Register (PR), National Cause of Death Registry (NCDR), CIMS (national COVID-19 vaccination registry), GGD COVID19 besmettingsmeldingen, INDICWLZ (Indications issued for long-term care), and linkage with GEBWLZ (long-term care used), Dutch Hospital Discharge Registry (DHDR), medicijntab, NIVEL, VEKTIS claims data, GP data registries, UWV, etc.). The portal will include both post-Covid patients as well as patients whose data can be used for appropriate control groups.

5.1.2i Digitale overleggen