Minutes features post-COVID patient portal

Date: 12-2-2024, 14:00-15:00

Present: 5.1.2e 5.1.2e (LUMC, WP2), 5.1.2e (all Amsterdam UMC, WP3), 5.1.2e (both UMCU, WP5), 5.1.2e 5.1.2e (Radboudumc, WP7), 5.1.2e , 5.1.2e (both RIVM, WP2)

Background and purpose portal

The main goal of the portal is to create one central entrance for postCOVID condition patients who are interested in joining research studies. A national well-known portal, where the communication campaign of the national expertise network is focused on. The portal will be used as a recruitment entrance for WP3 and WP5, and other studies within the expertise network.

WP2-B. Description Patient portal in the grant proposal

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.

Flow and list of features

The draft flow and features list were discussed.

- Add the option where not only GP or patient can register, but also relative. This is something to check with privacy officers.
- Questions about the opt-out procedure for a shorter survey. When a patient opts-out it means they chose for a shorter survey, because they have to much burden of their symptoms to complete the standard survey. Risk to not have enough data. Maybe an option to ask patients with heavy symptoms to ask their GP to report them instead. Also give them the opportunity to finish the entire survey themselves later (the latter was not discussed).
- When deleting an account, the research data remains available. Only account data will be deleted.
- Concerns about the patient portal and trial platforms/systems. The patient portal is supposed to be the starting point for all patients and to serve all the other WP's. It is important to focus on one entry point for patients. Within the portal baseline registration will be done, followed by update surveys every 3 months. From the portal patients/contact information from eligible patients can be referred to other studies, with their own research platforms (e.g. biobank or trials platform of WP3/5). The portal could also be used for follow-up of a specific other study in the network, but only if requested.

- If patients are first included in another platform, e.g. the biobank or trial platform, they are preferably also registered on the patientportal, either by sharing their data, or by referring them to register there as well. We will discuss this in in the next meeting.
- Digital research environment (DRE): all participant consent for datalinkage within digital research environment and metadata dictionary. We will include a description of the portal into the dictionary and clinical trial data. Overarching topic.
- Questions about access to data for researchers. Direct access to the backend of the portal for the researcher or via data requests to RIVM.
- List of eligble patients with a linking code is a lot of responsibility in the hand of patient. They can forward mail to researcher of read out on the phone. Preferred option however is to do this at the back-end with access for the researcher so that patient does not heve to handle his own code.
- Inclusion of patients from C-support and longcovid.rivm.nl. Invite them by email.

Action RIVM: RIVM checks option to register/fill in survey as relative (not patient or GP) for other adults with privacy department. Now only approval to fill in for child. Explanation that some people cannot do it themselves.

Action RIVM: RIVM update the flow and list of features and send around

Action RIVM: contact web developer and start the developing of the portal

PROMs

WP7 will not collect data. They are not sure if they have to use the PROMs for the portal. And they will not be ready before the portal. Jos Bosch will take charge in the PROM selection together with 5.1.2e

Action 5.1.2e send out proposal for PROMs this week and send out Datumprikker to discuss.

Next meeting

Discuss in next meeting:

1) Linkage WP2, 3, 5 platforms

2) Development progress

Action RIVM: send out Datumprikker for next meeting