Minutes Patient-portal post-COVID expertise network

Date: 25-1-2024, 9:00-10:00

Present: 5.1.2e 5.1.2e (LUMC, WP2), 5.1.2e , 5.1.2e 5.1.2e (all Amsterdam UMC, WP3) 5.1.2e (UMCU, WP5), 5.1.2e (C-support, WP7) 5.1.2e 5.1.2e , 5.1.2e (all RIVM, WP2),

Apologies: 5.1.2e 5. 5.1.2e (both UMCU, WP5), 5.1.2e (both Amsterdam UMC, WP3), 5.1.2e (Radboudumc, WP2).

Agenda points

1. Background and purpose portal:

See attachment.

2. Afstemming en samenwerking met WP3/5/7 en overige WPs

Main goal portal is to create one central entrance for postCOVID patients who are interested in joining research studies. 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.

WP5:

Patient register centrally via the portal and fill in central PROMS if they are able to (if not an option can be selected for a minimal questionnaire). Patients registered and selected based upon their characteristics in PROMs/questionnaires can be contacted by the trial team to further screen for eligibility. Then consented and go to full screening, inclusion and baseline follow up study measurements and follow-up. Only invite patients that are most likely eligible for each study. What about people not interested in research? We cannot prevent those people from registering, but the focus should be on patients that are willing to participate in studies GPs and other health-care providers should also be able to register a patient.

Make sure to have a questionnaires as minimally complicated/short as possible, because of the fatigue and brain fog of some patients. Idea: Permission from patient to share information backwards to portal. What is the most simple way for patients?

The WP5 time schedule of starting the inclusion is around June 2024. So implementation of the patient portal should be around the same time or a little earlier to facilitate recruitment. An extra option could be to direct patients of the existing longcovid.rivm.nl

WP3

Similar process for this portal as NMCB infrastructure, with registration and pre-screening of patients through the national patient portal, to facilitate recruitment for WP3. Don't have a timeline yet to start inclusion. We would like to harmonize data collection (PROMs/eCRF) as much as possible. Our goal: how to use same infrastructure and utilize what we are already doing?

WP7

We did not yet do extensive planning regarding PROMs. Compare clinical pathways within package and use PROMS for that purpose. What PROMS are critical and less critical? Join meeting next week

WP3, next Wednesday 17-18.

We need to think and decide on how much we pack the portal full or leave some things to the individual research efforts. How big is common trunk?
Different pathways that exist next to each other. Make branches in platform. Common trunk: register as patient. Important to differentiate patients in questionnaire so you can focus on the right patients. We can work with or without a general consortium agreement and a data processing agreement. With is more complicated, but everyone has access to data. It is also possible to work without an CA, then you need to work with codes and inform consent, but still need a data processing agreement (see also under point 4/5).

New portal or adapt longcovid.rivm.nl?
Disadvantages adaption: more complicated, currently owned entirely RIVM, so the already given consent from patients is only for RIVM. So we prefer something new. Everyone in meeting agrees. We need a name for the new website, postcovid.nl may be lead to confusion because postcovidNL is an existing patient organization.
Action everyone: Think about a name (postcovid.patientportal.nl?).

Existing patients on other portals will be invited for this new portal. Patients on C-support portal will also be invited (28.000 patients) as well as longcovid.rivm.nl (>10.000 postcovid patients) .

Idea is that patients receive a follow-up questionnaire after 6 months after registering. So that situation is updated. Not discussed yet: think of using a 3 months interval instead, to keep contact with the patient, and if one follow-up moment is missed, the interval will not be that long.

Control patient groups that are needed
Control group of patients with a recent positive COVID test is difficult to register, self-testing is rare. We nevertheless need to be able to facilitate registration for controls.

Idea: randomly invite patients from general population using the basisregistratie personen (BRP) through the RIVM. Or let patients bring their own control contacts (spouse, neighbour, friend etc). Make arrangements in portal so that it is possible and implement it when needed.

3. List of requirements
Action RIVM: RIVM will work on draft list of requirements as soon as possible. With must haves and nice to haves. We will circulate it and finalize it together.

Action everyone: discuss about must haves and nice to haves within your WP's

4/5. DPIA & METC
If we sign a consortium agreement with all research partners, ownership of the portal can be shared. RIVM will be responsible for hosting and managing the portal. Other parties will be processors. DPIA can be processed by the RIVM.

A data processing agreement can be attached to a central CA or be a separate document signed by only the parties that need to access the portal data and database. We should not wait too long starting the legal process, because it takes much time to complete the contracts.

Idea start in time as well with not-WMO declaration, can be processed by the RIVM.

6. Needed data scientist researcher Leiden and RIVM
Data scientist researcher that works on implementing portal. Facilitating requirements. Contribute to research if needed.
Action everyone: If you know anyone please contact RIVM

7. Next meeting? Comments?
Two-weekly meeting, especially in the beginning of the project.
Action RIVM: Datumprikker will be send.

Attachment: Beschrijving portal in de subsidie aanvraag onder WP2, en aanvullende toelichting:

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**.*

Aanvullende toelichting:

Het RIVM heeft ervaring met verschillende patientportals (Tekenradar.nl, Infectieradar.nl en longcovid.rivm.nl). Voor de patientportal kan dezelfde software en infrastructuur worden gebruikt voor ontwikkeling van functionaliteiten en hosting van de portal. Patienten kunnen zich aanmelden met een eigen account gekoppeld aan hun email adres, 2FA beveiliging daarvan zal naar verwachting op korte termijn worden toegevoegd. Na aanmelding volgt in elk geval een baseline vragenlijst met de gewenste PROMs, **update daarvan met een periodieke follow-up is mogelijk**. Er is nog afstemming nodig over **aanmelden door de zorgverlener**: mag die volgens de AVG een email adres invullen van de patient, en ook andere relevante gegevens invullen?

Onderzoeken uit alle WPs kunnen de database screenen op gewenste patiënten (bijvoorbeeld op duur, ernst en type symptomen gemeten via de PROMs vragenlijst). Doorverwijzing naar andere onderzoeken is mogelijk via een simpele route, en via de portal zelf: 1)voor de simpele route krijgen geselecteerde patienten een email vanuit de portal, met contactgegevens van het andere onderzoek, en een datalink-code. Ze melden zichzelf bij het andere onderzoek, en geven daar informed consent voor eventuele koppeling van hun portal PROMs data. 2)Via de portal zelf kunnen consortiumpartners-onderzoekers in een beveiligde back-end inloggen, waar ze zelf direct bij de contactgegevens en PROMs kunnen van patienten die geschikt zijn voor hun onderzoek.

Als een korte termijn oplossing voor werving kan eventueel de huidige RIVM-portal longcovid.rivm.nl worden gebruikt, waarin o.a. meer dan 10k deelnemers met bestaande post-COVID klachten zijn aangemeld. Daarvoor kan waarschijnlijk de "simpele route" via e-mail en link-code zoals hierboven worden gebruikt.

Voor aanvullende vragen over bovenstaande: 5.1.2e @rivm.nl.