READmefirst: design patient-portal post-COVID expertise/research network, WP2B

Background

Main goal portal is to create one central entrance for postCOVID condition (PCC) 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.

Relevant documents sent to all stakeholders:

READmefirst_design_patientportal.doc (this document)

20240202_FlowOverview_patientportal.ppt for traffic flow on the portal.ppt

- Starts with a short differentiation survey after clicking on the report button
  - Are you patient or GP?
  - What do you want to report?
  - Age/sex?
- Reporters can be: PCC adult/PCC child/Control Adult/Control Child/(post-vaccine-syndrome?)
  - Each reporter type is guided through a specific flow on the portal, see ppt file
  - Separate reporter type for GPs yet to be discussed (AVG?)
  - Opt out for ultra short PROMs survey for patients with heavy burden, or have them reported by GP/a relative?
- After differentiation survey follows the baseline survey including PROMs
- Follow-up/update surveys every 3(?) months
- Screening and recruitment of patients for WP3/5 etc based upon most recent information from baseline en follow-up surveys
  -

20240202_postcovidpatientportal_features.xlsx for a detailed list of all planned features

- PROMs do be determined, led by WP7/PF1 in cooperation with WP2/3/5?
  - Possible to start with beta version of PROMs, and update later?
    - also through follow up surveys
- See especially features in red in .xlsx file
  - Features are divided over user roles:
    - Reporters (of PCC adult/PCC child etc see above)
    - (other) Citizens, interested in the portal
    - Principal investigator (+ deputies) responsible for the portal
    - Researchers working with the portal on the main study/substudies
      - both RIVM and consortiumpartners
      - main study is collecting PROMs etc, "sub"studies are recruitment for other studies/WPs

WP2-B. 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**.*

Further background

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. Na aanmelding volgt in elk geval een baseline vragenlijst met de gewenste PROMs, en een periodieke **update met een follow-up vragenlijst.** Indien mogelijk (AVG?) kan ook een **zorgverlener** een patiënt aanmelden.

Onderzoeken uit alle WPs kunnen de database screenen op gewenste patiënten (bijvoorbeeld op duur, ernst en type symptomen gemeten via de PROMs vragenlijst) en uitnodigen voor onderzoek. Zie voor details bijgevoegd .ppt en .xlsx file met flow op de portal en featureslijst.