

## Minutes features post-COVID patient portal

Date: 1-3-2024, 15:00-16:00

Present: 5.1.2e

5.1.2e

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(Radboudumc),

5.1.2e

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5.1.2e

Absent: 5.1.2e (GGD Zuid Limburg)

### Action points previous meeting

- Action RIVM: RIVM checks option to register/fill in survey as relative (not patient or GP) for other adults with privacy department → Follow GDPR, it allows that relative or friend can submit for a patient.
- Action RIVM: RIVM update the flow and list of features and send around → updated version send around
- Action RIVM: contact web developer and start the developing of the portal → development started
- Action 5.1.2e: send out proposal for PROMs this week and send out Datumprikker to discuss → no actions performed

### Routing and questionnaires

Routing and questionnaires were discussed. Name portal will be postcovidonderzoek.nl. The aim is to launch the portal June 1.

- GP routing: make burden for GP as minimal as possible. Option to contact GP for extra information if needed. Include in consent that GP's can be contacted for medical information from patient
- Can we ask general consent or need it to be more specific for type of research? Question for ethical group
- Connections with other apps is very difficult. Portal website will be responsive for access on mobile phone
- Preferred route: work with 'verwerkersovereenkomst' (data processing agreement). In that case researchers can enter the back-end of the system and have direct access to eligible patients and contact information.
- Now no function to download contact information, because of privacy. Maybe this option is nice to have if you want to send out bulk emails. Must be described in DPIA amendment
- Focus on determining PROMs. If not ready for launch, they can be updated later and within 3 months all participants have filled in the new PROMs. But for efficiency make it as final as possible before launch.
- Discussion about overlapping questionnaires. CRF long covid from WHO. Selection of validated questionnaires, also in English. Add questions about blood pressure and pulse from wearables might be relevant for the portal.
- Meeting needed with Platform 1 to further discuss the essential PROMs needed for screening in this portal.
- Keep in mind to adjust questionnaires/questions not relevant for specific groups (leave out pregnancy questions for kids reporting for example).

- Discussed language options for portal for diversity and inclusion purposes. Start with Dutch and maybe after that English version.
- Communication to all WP's about progress and decisions. Important for all to know and to have the opportunity to be involved.

**Next meeting**

Discuss in next meeting:

- 1) Questionnaires
- 2) Development progress

**Action points**

Action 5.1.2e reply to 5.1.2e to plan a meeting with Platform 1 in the week of March 11. Also invite 5.1.2e

Action RIVM: add possibility for email bulk/download contact information in DPIA amendment

Action 5.1.2e send the short WHO long covid CRF to WP2-B team

Action 5.1.2e: together with 5.1.2e, check in WP1 to get the ethical group on board

Action RIVM: Plan next WP2-B meeting in week of March 18

Action RIVM: Update version of questionnaires after meeting with Platform 1

Action WP2-B: communicate to all WP's about progress/decisions