

To: 5.1.2e @ggdzl.nl 5.1.2e @ggdzl.nl; 5.1.2e @uva.nl 5.1.2e @uva.nl; 5.1.2e @radboudumc.nl 5.1.2e @radboudumc.nl
Cc: 5.1.2e @rivm.nl 5.1.2e @rivm.nl; 5.1.2e @lumc.nl 5.1.2e @lumc.nl; 5.1.2e @lumc.nl 5.1.2e @lumc.nl; 5.1.2e @lumc.nl
From: 5.1.2e
Sent: Mon 3/4/2024 10:50:44 AM
Subject: RE: Files and agenda for WP2B meeting postCOVID patientportal friday 1 march 15.00-16.00
Received: Mon 3/4/2024 10:50:44 AM

Dear 5.1.2e

I am not available this week, but next week should be possible.

Best,
5.1.2e

5.1.2e

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From: 5.1.2e <5.1.2e@ggdzl.nl>

Sent: maandag 4 maart 2024 09:56

To: 5.1.2e <5.1.2e@uva.nl>; 5.1.2e <5.1.2e@rivm.nl>; 5.1.2e <5.1.2e@radboudumc.nl>

Subject: Re: Files and agenda for WP2B meeting postCOVID patientportal friday 1 march 15.00-16.00

Dear 5.1.2e today is not possible unfortunately

Later today let me come back to you to plan a short meeting (ill check with pf1 rest)

Verzonden vanuit Outlook voor iOS

Van: 5.1.2e 5.1.2e @uva.nl>

Verzonden: Monday, March 4, 2024 9:46:19 AM

Aan: 5.1.2e < 5.1.2e @rivm.nl>; 5.1.2e < 5.1.2e @ggdzl.nl>; 5.1.2e 5.1.2e @radboudumc.nl>

Onderwerp: RE: Files and agenda for WP2B meeting postCOVID patientportal friday 1 march 15.00-16.00

Hi [REDACTED] 5.1.2e and I had already planned a meeting for this morning to discuss the workflow for the selection of PROMS and CRF, which aimed to divide in various workgroup each taking on a sub-topic. I think this can be done efficiently.

The meeting was planned for this morning; at 10:30; I apologize for the extremely short notice. Are you able to briefly attend? If not we find another way to communicate.

Let me know!

5.1.2e

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Van: 5.1.2e <5.1.2e@rivm.nl>
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Verzonden: Friday, 1 March 2024 16:44

Aan: 5.1.2e <@ggdzl.nl> <5.1.2e @ggdzl.nl> 5.1.2e <5.1.2e @rivm.nl>; 5.1.2e
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 5.1.2e @c-support.nu'; 5.1.2e @radboudumc.nl'; 5.1.2e <5.1.2e @rivm.nl>;
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 5.1.2e <5.1.2e @rivm.nl>

Onderwerp: RE: Files and agenda for WP2B meeting postCOVID patientportal friday 1 march 15.00-16.00

Hi 5.1.2e

Thanks for your input below, which is really helpful!

A meeting with PF1 would be very much appreciated. Would it be convenient to schedule that meeting in the week of March 11?

The time schedule for the patientportal is very tight, and we would like to finalize an initial launch version of the survey and PROMs before the end of March.

The team of 5.1.2e (WP3) would like to be involved in the meeting with PF1, and probably several others in CC as well (I also CC-ed 5.1.2e the LUMC post-doc on PF1 since today if I am not mistaken).

Have a nice weekend,

Best,

5.1.2e

5.1.2e

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From: 5.1.2e <5.1.2e @ggdzl.nl>

Sent: vrijdag 1 maart 2024 13:59

To: 5.1.2e <5.1.2e @rivm.nl>; 5.1.2e <5.1.2e @rivm.nl>; 5.1.2e
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 5.1.2e @umcutrecht.nl'; 5.1.2e @umcutrecht.nl'; 5.1.2e @umcutrecht.nl'; 5.1.2e @ggdzl.nl'; 5.1.2e
 5.1.2e @c-support.nu'; 5.1.2e @radboudumc.nl'; 5.1.2e <5.1.2e @rivm.nl>;
 5.1.2e @lumc.nl'
 Cc: 5.1.2e <5.1.2e @rivm.nl>; 5.1.2e @umcutrecht.nl' <5.1.2e @umcutrecht.nl>

Subject: RE: Files and agenda for WP2B meeting postCOVID patientportal friday 1 march 15.00-16.00

Hoi allemaal

Ik kan vanmiddag niet aansluiten, daarom bij deze mijn input per mail hieronder.

Comments Flow patients

- To make the registration optimally accessible for all patients:
 - Consider various alternatives for registration of reporters (PCC and controls): can be GP, but how do we motivate GPs to do this, make a plan? Consider also other people, mantelzorgers, close social network members, neighbor, a 'verzorger'.
 - Use alternative options for filling in Q; with our cohort study we also used call centres and option to be interviewed
 - Consider also option of shorter list.
- To make the list of essential PROMS (in the short list) and longer PROMS list, also align with PF1 Methodology (5.1.2e is in it; or check with 5.1.2e).
- What is the goal of the follow-ups? Is this to offer up-to-date data to the other WPs? Or also because we want to study progression? Then we need to set RQs on this (then also check with PF1).
- With filling in survey: provide opportunity to continue later (based on e.g. code and login or unique link in email/whatsapp)

Requirements

- The notules say: "The portal could also be used for follow-up of a specific other study in the network, but only if requested." Good to be clear on the requirements for the specific researchers; is all covered, are additional costs involved, does such study need extra ethical/juridical clearance? Etc.
- Regarding asking consent for data linkage to the patients: are we going to ask consent for each specific type of registry separate (or a general consent for linkage)?
- How are we going to 'use' the linkage data? For example providing the patient information data plus detailed CBS/UWV data to an individual researcher might pose challenges-- AVG wise; how do we approach this?

Survey

- Not assume that participants are Dutch residents (we should ask).
- Language?
- Do we have triage ? Which Qs?
- For the PROMS: please check with PF1; important to align; there is much discussion on severity assessment, I can set up a meeting let me know.

Hartelijke groet

5.1.2e



5.1.2e

5.1.2e

GGD afdeling SIM | AWPG-Mosa

T 06 - 5.1.2e

E 5.1.2e @ggdzl.nl

5.1.2e



Van: 5.1.2e <5.1.2e@rivm.nl>

Verzonden: donderdag 29 februari 2024 16:58

Aan: 5.1.2e <5.1.2e@rivm.nl>; 5.1.2e <5.1.2e@rivm.nl>; 5.1.2e @lumc.nl'; 5.1.2e @radboudumc.nl'; 5.1.2e @amsterdamumc.nl'; 5.1.2e @uva.nl'; 5.1.2e @amsterdamumc.nl'; 5.1.2e @hg-datasolutions.nl'; 5.1.2e @amsterdamumc.nl'; 5.1.2e @amsterdamumc.nl'; 5.1.2e @amsterdamumc.nl'; 5.1.2e @umcutrecht.nl'; 5.1.2e @umcutrecht.nl'; 5.1.2e @umcutrecht.nl'; 5.1.2e @ggdnl.nl'; 5.1.2e @c-support.nu'; 5.1.2e @radboudumc.nl'; 5.1.2e @lumc.nl' <5.1.2e@rivm.nl>; 5.1.2e @rivm.nl'; 5.1.2e @lumc.nl'

CC: 5.1.2e <5.1.2e@rivm.nl>; 5.1.2e @umcutrecht.nl' <5.1.2e@umcutrecht.nl>

Onderwerp: Files and agenda for WP2B meeting postCOVID patientportal friday 1 march 15.00-16.00

Dear all,

Please find attached the updated files about the design of the patient portal.

The "Concept Vragenlijsten... etc" file is new, and contains a first draft of what could be the initial version of the survey upon launch. Feedback is very welcome of course!

The agenda for tomorrow is to discuss:

- the present versions of the attached files
 - including the actions mentioned in the minutes of the last meeting
 - including the above mentioned draft version of the survey
- how and when to include feedback by patient representatives
- time schedule and next meeting

See you tomorrow!

Best,

5.1.2e

5.1.2e

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