

To: [redacted] 5.1.2e [redacted] 5.1.2e @rivm.nl]; [redacted] 5.1.2e [redacted] 5.1.2e @rivm.nl]
From: [redacted] 5.1.2e
Sent: Tue 3/5/2024 2:33:19 PM
Subject: FW: PROMS meeting in the week of the 11th
Received: Tue 3/5/2024 2:33:19 PM

FYI, ik heb die van woensdag afgewezen, donderdag geaccepteerd

Vriendelijke groeten,

[redacted] 5.1.2e
 [redacted] 5.1.2e LongCOVID and Vector-borne diseases

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From: [redacted] 5.1.2e <[redacted] 5.1.2e @mumc.nl>

Sent: dinsdag 5 maart 2024 15:30

To: [redacted] 5.1.2e <[redacted] 5.1.2e @rivm.nl>; [redacted] 5.1.2e @ggdzl.nl' <[redacted] 5.1.2e @ggdzl.nl> [redacted] 5.1.2e
 [redacted] 5.1.2e <[redacted] 5.1.2e @rivm.nl>; [redacted] 5.1.2e <[redacted] 5.1.2e @rivm.nl>; [redacted] 5.1.2e @lumc.nl';
 [redacted] 5.1.2e @radboudumc.nl'; [redacted] 5.1.2e @amsterdamumc.nl'; [redacted] 5.1.2e @uva.nl'; [redacted] 5.1.2e @amsterdamumc.nl';
 [redacted] 5.1.2e @hg-datasolutions.nl'; [redacted] 5.1.2e @amsterdamumc.nl'; [redacted] 5.1.2e @amsterdamumc.nl';
 [redacted] 5.1.2e @amsterdamumc.nl'; [redacted] 5.1.2e @umcutrecht.nl'; [redacted] 5.1.2e @umcutrecht.nl'; [redacted] 5.1.2e @umcutrecht.nl';
 [redacted] 5.1.2e @ggdzl.nl'; [redacted] 5.1.2e @c-support.nu'; [redacted] 5.1.2e @radboudumc.nl'; [redacted] 5.1.2e
 <[redacted] 5.1.2e @rivm.nl>; [redacted] 5.1.2e @lumc.nl'; [redacted] 5.1.2e <[redacted] 5.1.2e @maastrichtuniversity.nl>
Cc: [redacted] 5.1.2e @lumc.nl' <[redacted] 5.1.2e @lumc.nl>; [redacted] 5.1.2e @lumc.nl' <[redacted] 5.1.2e @lumc.nl>; [redacted] 5.1.2e
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 <[redacted] 5.1.2e @live.com>

Subject: PROMS meeting in the week of the 11th

Dear all,

I have had contact with [redacted] 5.1.2e of PF1 for a meeting next week on PROMS. I used *reply-to-all* on the last e-mail on this topic, so please decide whether you want to contribute to this meeting or not. I will submit two suggestions for next week using calendar invites coming ASAP:

Wednesday the 13th from 15 to 16

Thursday the 14th from 17 to 18

Please do accept or reject the meetings, so we can follow through with a meeting next week on which the most of you who are interested to contribute can attend. I realize not everyone will be able to attend due to the short notice, but this is just the start of a process of setting up uniform measures (when possible/ applicable).

Kind regards, on behalf of platform 1,

[redacted] 5.1.2e

[redacted] 5.1.2e



Klinisch Epidemioloog | 5.1.2e
 Klinische Epidemiologie en Medical Technology Assessment (KEMTA)
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 T: 043 5.1.2e
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Kijk voor informatie over de cursus Klinische Predictiemodellen op: www.klinishepredictiemodellen.nl

Van: 5.1.2e [5.1.2e @rivm.nl]

Verzonden: vrijdag 1 maart 2024 16:44

Aan: 5.1.2e @ggdzl.nl; 5.1.2e 5.1.2e; 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 @ggdzl.nl; 5.1.2e @c-support.nu;
CC: 5.1.2e @lumc.nl; 5.1.2e @lumc.nl; 5.1.2e @lumc.nl; 5.1.2e

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 on PF1 since today if I am not mistaken).

Have a nice weekend,

Best,

5.1.2e

5.1.2e

5.1.2e

LongCOVID and Vector-borne diseases

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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 >; Edine Bergsma-Spoelman < 5.1.2e @rivm.nl >; 5.1.2e
 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;
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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 and 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/judicial 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 AWPG-Mosa
 5.1.2e infectieziekten
 5.1.2e Gezondheidsbevordering en Preventie
 GGD afdeling SIM | AWPG-Mosa
 T 06 - 5.1.2e
 E 5.1.2e @ggdzl.nl

1 5.1.2e Living Lab-Mosa Public Health Service South Limburg (GGD)

2 5.1.2e Infectious Diseases (GGD; Maastricht University)
 3 5.1.2e Health Promotion and Prevention, Department of Health Promotion, Care and Public Health Research Institute (CAPHRI), Maastricht University

GGD Het Overloen 2, 6411 TE Heerlen | Postbus 33, 6400 AA Heerlen
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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 @umcutrecht.nl'; 5.1.2e @umcutrecht.nl'; 5.1.2e @umcutrecht.nl'; 5.1.2e @ggdzl.nl'; 5.1.2e @c-support.nu'; 5.1.2e @radboudumc.nl'; 5.1.2e <5.1.2e@rivm.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>

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

5.1.2e LongCOVID and Vector-borne diseases

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