

To: [redacted] 5.1.2e [redacted] 5.1.2e @rivm.nl [redacted] 5.1.2e [redacted] 5.1.2e @rivm.nl]
 Cc: [redacted] 5.1.2e [redacted] 5.1.2e @rivm.nl]
 From: [redacted] 5.1.2e
 Sent: Thur 1/18/2024 2:34:29 PM
 Subject: RE: COFFI data sharing
 Received: Thur 1/18/2024 2:34:29 PM
[Aanvraag Inzet research managers EPI1 twee aanvragen](#) [redacted] 5.1.2e [docx](#)

Beste [redacted] 5.1.2e

De financiering van twee projecten is inmiddels rond! Dat is natuurlijk heel mooi, maar ook een flinke klus *

Zie in attach van beide projecten de beschrijving.

Vriendelijke groeten,

[redacted] 5.1.2e

[redacted] 5.1.2e

Center for Infectious Disease Control | Epidemiology and surveillance unit | Department Enteric, Vectorborne and Zoonotic infections (EVZ)
Dutch National Institute for Public Health and the Environment
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[redacted] 5.1.2e

RIVM Committed to health and sustainability

From: [redacted] 5.1.2e <[redacted] 5.1.2e @rivm.nl>
 Sent: vrijdag 6 oktober 2023 08:53
 To: [redacted] 5.1.2e <[redacted] 5.1.2e @rivm.nl>
 Cc: [redacted] 5.1.2e <[redacted] 5.1.2e @rivm.nl>; [redacted] 5.1.2e <[redacted] 5.1.2e @rivm.nl>
 Subject: RE: COFFI data sharing

Hoi [redacted] 5.1.2e

Oké, helemaal goed. Succes met het rondkrijgen van de financiering!

Met vriendelijke groet / Kind regards,

[redacted] 5.1.2e

.....
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Rijksinstituut voor Volksgezondheid en Milieu | RIVM
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[redacted] 5.1.2e

.....
RIVM De zorg voor morgen begint vandaag

Van: 5.1.2e <5.1.2e@rivm.nl>
Verzonden: woensdag 4 oktober 2023 08:58
Aan: 5.1.2e 5.1.2e @rivm.nl>
CC: 5.1.2e <5.1.2e@rivm.nl>
Onderwerp: FW: COFFI data sharing

Hoi 5.1.2e

Dank! Ik heb even pas op de plaats gemaakt na overleg met 5.1.2e deze werkzaamheden gaan we bij nader inzien pas oppakken als er ook echt financiering rond is.

Dus wie weet komen we er later nog op terug!

Vriendelijke groeten,
5.1.2e

5.1.2e

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From: 5.1.2e <5.1.2e@rivm.nl>
Sent: maandag 2 oktober 2023 12:06
To: 5.1.2e <5.1.2e@rivm.nl>
Subject: FW: COFFI data sharing

Beste 5.1.2e

Onderstaande mail kreeg ik doorgestuurd van 5.1.2e Voor nieuwe projectaanvragen hebben we een document aangemaakt met een aantal vragen om een goed beeld te krijgen van de werkzaamheden en de tijd die het kost. Zou je bijgaand document kunnen invullen? Dan kijken 5.1.2e wie van ons het kan oppakken. Alvast bedankt!

Met vriendelijke groet / Kind regards,

5.1.2e

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5.1.2e

RIVM De zorg voor morgen begint vandaag

From: 5.1.2e <5.1.2e@rivm.nl>
Sent: vrijdag 29 september 2023 08:42
To: 5.1.2e <5.1.2e@rivm.nl>
Subject: FW: COFFI data sharing

Ha 5.1.2e

Zie vraag hieronder voor het internationaal COFFI consortium waar ik deel vanuit maak. Plan is om voor LymeProspect en RIVM longCOVID datasharing mogelijk te maken.

Daarvoor moet eerst weer met onze eigen privacy afgestemd en goedgekeurd worden. Is er enige kans dat 5.1.2e of een andere 5.1.2e me daarbij kan helpen, of zitten die helemaal vol....?

Momenteel is er geen speciaal budget voor gereserveerd, idee is wel dat we meer kans op funding maken als we dit geregeld hebben.

Vriendelijke groeten,
 5.1.2e

5.1.2e

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RIVM Committed to health and sustainability

From: 5.1.2e 5.1.2e@kirby.unsw.edu.au>
Sent: donderdag 28 september 2023 21:40
To: 5.1.2e <5.1.2e@rivm.nl>
Cc: 5.1.2e 5.1.2e@unsw.edu.au>; 5.1.2e <5.1.2e@medisin.uio.no>; 5.1.2e <5.1.2e@unsw.edu.au>
Subject: Re: COFFI data sharing

Dear 5.1.2e

I hope you are doing well. As we discussed during the last steering committee and following our previous communication, we hope to include all cohorts in the data-sharing effort. Obtaining privacy approval from your cohorts will be a significant achievement.

Please let us know if this is feasible. Achievements so far were due to the willingness of COFFI PIs to deal with the bureaucratic and tedious paperwork. We hope you can also contribute to this initiative. Let us know if 5.1.2e, or other COFFI members can support you in any way.

Kind regards,
 5.1.2e

From: [redacted] <[redacted]@rivm.nl>
Sent: Thursday, 20 July 2023 4:24 PM
To: [redacted] <[redacted]@kirby.unsw.edu.au>
Cc: [redacted] <[redacted]@unsw.edu.au> [redacted] <[redacted]@unsw.edu.au>
Subject: RE: COFFI data sharing

Hi [redacted]

We need privacy approval for both studies (no ethical approval, that is differently organized here), if we do the paper work, approval can be expected.

Best,
 [redacted]

[redacted]

.....
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[redacted]

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From: [redacted] <[redacted]@kirby.unsw.edu.au>
Sent: donderdag 20 juli 2023 06:36
To: [redacted] <[redacted]@rivm.nl>
Cc: [redacted] <[redacted]@unsw.edu.au>; [redacted] <[redacted]@unsw.edu.au>
Subject: Re: COFFI data sharing

Thanks for replying, [redacted]

My comments/questions highlighted:

Regarding point 1: it appears that for the Lyme cohort we have to inform them about our intention to share data, so that participants can opt out. For the longcovid cohort that has been taken care of in the informed consent upon inclusion.

If the LongCOVID informed consent includes data sharing, I assume no ethics approval will be required. Is that correct?

Regarding point 2: for both studies we have quite a list of documents to fill in before we can share any data.

Are these documents for ethical application or governance/legal purposes? From your previous answer, I understood ethics are required only for the Lyme study

Regarding point 3: I assume that data is needed at record level, so not aggregated is that correct?

Yes, at a record level.

Enjoy your summer and let us know once you're back on duty.

Kind regards,

5.1.2e

From: 5.1.2e <5.1.2e@rivm.nl>
Sent: Tuesday, 18 July 2023 5:25 PM
To: 5.1.2e <5.1.2e@kirby.unsw.edu.au>
Cc: 5.1.2e <5.1.2e@unsw.edu.au>; 5.1.2e <5.1.2e@unsw.edu.au>
Subject: RE: COFFI data sharing

Dear 5.1.2e,

Regarding point 1: it appears that for the Lyme cohort we have to inform them about our intention to share data, so that participants can opt out. For the longcovid cohort that has been taken care of in the informed consent upon inclusion.

Regarding point 2: for both studies we have quite a list of documents to fill in before we can share any data.

Regarding point 3: I assume that data is needed at record level, so not aggregated is that correct?

That's it for now, have a good summer (or winter, at your side I realize now)!

Best,

5.1.2e

5.1.2e

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From: 5.1.2e <5.1.2e@kirby.unsw.edu.au>
Sent: woensdag 28 juni 2023 09:31
To: 5.1.2e <5.1.2e@rivm.nl>
Cc: 5.1.2e <5.1.2e@unsw.edu.au>; 5.1.2e <5.1.2e@unsw.edu.au>
Subject: Re: COFFI data sharing

Dear 5.1.2e

Thanks for the time and information provided during our last meeting.

These are the action points:

1. 5.1.2e will check if informed consent includes approval from participants to share data with Privacy Coordinators.
2. 5.1.2e will check if any additional ethics approval processes and Governance approval are required. Privacy coordinators to join this process, and 5.1.2e will assist if needed.
3. 5.1.2e will email 5.1.2e the data transfer agreement, TSD documentation, and description of the data anonymization process.

4. Further actions for data sharing progress will be paused until the Horizon grant is announced and when primary outcomes are published for both LymeProspect and Covid cohort (can do smaller checks)
5. 5.1.2e will check if other parties involved in cohorts would be willing to share data after outcomes are published.

Kind regards,

5.1.2e

From: 5.1.2e <5.1.2e@unsw.edu.au>
Sent: Wednesday, 14 June 2023 8:52 PM
To: 5.1.2e <5.1.2e@rivm.nl>
Cc: 5.1.2e <5.1.2e@kirby.unsw.edu.au>; 5.1.2e <5.1.2e@unsw.edu.au>
Subject: RE: COFFI data sharing

Dear 5.1.2e

Below are a few points we would like to discuss with you in the upcoming Zoom meeting regarding COFFI Database sharing (9.30 am CEST, 5.30pm AEST on Thursday 15th of June 2023).

- Ethics
- Governance
- Dataset
- Action plan

Do you mind if I record the meeting? I would like to make sure all notes are captured accurately in the attached template. Thank you.

Regards,

5.1.2e

UNSW Fatigue Clinic, 32 Botany St Randwick 2031

5.1.2e

T: 5.1.2e F: 5.1.2e
 E: 5.1.2e@unsw.edu.au
<http://www.fatigueclinic.unsw.edu.au/>

5.1.2e

Kirby Institute UNSW

5.1.2e

From: 5.1.2e
Sent: Tuesday, June 6, 2023 7:49 AM
To: 5.1.2e <5.1.2e@rivm.nl>
Cc: 5.1.2e <5.1.2e@kirby.unsw.edu.au>
Subject: RE: COFFI data sharing

Dear 5.1.2e thank you for getting back to me.

I have sent a calendar Zoom invitation for 9.30 am CEST on Thursday 15th of June 2023, hope that's okay. We have a meeting beforehand which usually runs overtime so 9.30 CEST just to make sure!

Regards,

5.1.2e

UNSW Fatigue Clinic, 32 Botany St Randwick 2031

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 E: 5.1.2e@unsw.edu.au

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5.1.2e

Kirby Institute UNSW

5.1.2e

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

Sent: Monday, June 5, 2023 5:04 PM

To: 5.1.2e <5.1.2e@unsw.edu.au>

Subject: RE: COFFI data sharing

Hi 5.1.2e

I am available at:

Thursday 15th of June 2023 – 9am or 10am CEST

Tuesday 20th of June- 2023 - 9am, 10am or 11am CEST

Best,

5.1.2e

5.1.2e

Center for Infectious Disease Control | Epidemiology and surveillance unit | Gastro enteritis and Zoonoses department

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5.1.2e

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From: 5.1.2e <5.1.2e@unsw.edu.au>

Sent: maandag 5 juni 2023 02:44

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

Cc: 5.1.2e <5.1.2e@westernsydney.edu.au>; 5.1.2e <5.1.2e@unsw.edu.au>; 5.1.2e

<5.1.2e@kirby.unsw.edu.au>

Subject: RE: COFFI data sharing

Importance: High

Dear @ 5.1.2e

Would you be able to join us for a Zoom meeting to discuss the next steps? Time and dates available:

Thursday 15th of June 2023 – 9am or 10am CEST

Monday 19th of June 2023 - 9am, 10am or 11am CEST

Tuesday 20th of June- 2023 - 9am, 10am or 11am CEST

Wednesday 21st of June 2023 - 9am or 10am CEST

If these dates don't work please let me know and I will provide more options.

Regards,

5.1.2e

UNSW Fatigue Clinic, 32 Botany St Randwick 2031

T: 5.1.2e
E: 5.1.2e [@unsw.edu.au](mailto:5.1.2e@unsw.edu.au)
<http://www.fatigueclinic.unsw.edu.au/>

5.1.2e
Kirby Institute UNSW

From: 5.1.2e <5.1.2e@kirby.unsw.edu.au>
Sent: Saturday, May 27, 2023 12:14 PM
To: 5.1.2e <5.1.2e@unsw.edu.au>
Cc: 5.1.2e <5.1.2e@westernsydney.edu.au>; 5.1.2e <5.1.2e@unsw.edu.au>
Subject: Re: COFFI data sharing

Hi 5.1.2e

Could you please set up a Zoom/teams meeting with 5.1.2e to discuss what the next steps are?

If 5.1.2e availability is limited, You 5.1.2e and I can have the meeting earlier.

Kind regards,

5.1.2e

From: 5.1.2e <5.1.2e@rivm.nl>
Sent: Monday, 15 May 2023 7:23 PM
To: 5.1.2e <5.1.2e@unsw.edu.au>
Cc: 5.1.2e <5.1.2e@unsw.edu.au>; 5.1.2e <5.1.2e@kirby.unsw.edu.au>; 5.1.2e <5.1.2e@westernsydney.edu.au>; 5.1.2e <5.1.2e@rivm.nl>
Subject: RE: COFFI data sharing

Hi 5.1.2e

Thanks for the invitation below. From the side of the RIVM I think we are willing to share data on:

- the LymeProspect cohort through the consortium that we have with Amsterdam UMC and Radboud Nijmegen UMC
- the RIVM longCOVID cohort (earlier coordinated by 5.1.2e for this one we are still analyzing 6-months data ourselves, which we would like to publish first, but that will probably be finished before the joint analyses get published.

We already received a first positive response of our 5.1.2e regarding feasibility to join this effort, so that is at least a good start! *

Best,
5.1.2e

5.1.2e

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From: 5.1.2e <5.1.2e@unsw.edu.au>

Sent: woensdag 10 mei 2023 07:43

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

Cc: 5.1.2e <5.1.2e@unsw.edu.au> 5.1.2e 5.1.2e @kirby.unsw.edu.au>; 5.1.2e <5.1.2e@westernsydney.edu.au>

Subject: COFFI data sharing

Dear 5.1.2e

You may recall that we have a longstanding goal for COFFI to establish data sharing and to populate a shared database from the COFFI cohorts with a view to combined analyses. It has been a long and arduous process to get the key regulatory and logistical elements in place, but we have now done so. This note is to open discussion with you about data sharing from your cohort. The key elements which have been resolved are:

1. The COFFI governance document (see https://www.coffi-collaborative.com/files/ugd/1738f4_4626ff2be51b4bac8cbcd34dc29fffb.pdf) indicates the arrangements we have agreed to upon joining the COFFI consortium.
2. The database which is being hosted by Vegard at the Akershus University Hospital, Norway using the Sensitive Data Services (TSD) (<https://www.uio.no/english/services/it/research/sensitive-data/index.html>) is in place with appropriate regulatory approvals for data handling.
3. The COFFI Steering Committee provided approval over a year ago for a concept sheet entitled "Investigating predictors of chronic fatigue following infection" which has now been expanded into a study protocol (attached). This project is being led by 5.1.2e
4. The process of gaining individual human research ethics and governance (institutional review board) approval for an individual cohort has been 'piloted' in Australia in relation to the Dubbo Infection Outcomes Study (DIOS).
5. I have been fortunate to be able to continue support for two key staff to support COFFI processes, including facilitating this data sharing activity - 5.1.2e
5.1.2e who championed the ethics and governance approvals here in Australia and can provide advice and support in similar processes for the other COFFI cohorts, and then assist with data sharing.

In the first instance, we are keen to resolve whether you have cohort data (as described in the Predictors protocol) and you are willing to embark on the data sharing endeavour. If so 5.1.2e will be in touch to set up a zoom call with 5.1.2e and I to talk through the next steps with you.

Yours sincerely

5.1.2e

and Kirby Institute University of NSW, Australia

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e: 5.1.2e@unsw.edu.au

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