IMMERSE minutes 16/11/23 & 17/11/23
Live Steering Committee Edinburgh

1. General Management

See slides.

Martine will leave IMMERSE by the end of March, so please all email both Martine and Silke in the coming months. Please all submit your quarterly report R2_4 by the deadline December 11th 2023. We still need the quarterly reports from WP3 for the last 9 months (that was when we received the last quarterly). Period 2 will end March 31st 2024, the deadline for the last quarterly reports of this Period is March 17th 2024. Please really keep to this deadline because Martine will then only have 2 weeks to compile the Technical Report. We will do another full day evaluation with the PO and the external evaluators sometime after April 1st 2024 (mandatory for all WP leads and local WP7 leads), so next year we all need to prepare for this. Also, we need to make sure that we have done something with their feedback from last time.
The deadline for the financial reports will be 60 days after April 1st. The last round went very well, so it shouldn't be a problem this time if everyone submits something similar.

Please all keep posting tweets, and contact Jeroen if you want to post directly through the Immerse account. Maybe we also need to think about another platform, like Mastodon? Blijke is not part of the team anymore, we now have a vacancy for a student who might have some other ideas (e.g. videos). Jeroen will address this in the WP8 session. In any case, we need to keep publishing content for dissemination purposes!

Inez was already planning to publish something about the issues with MDR, maybe we should do this as a group, so everyone does something similar in their country, like a joint statement? Inez will take the lead.

We will have a GA in Germany on April 11th and 12th, in Heidelberg. Please register asap, and communicate this to your team. Also register if you are not coming.

2. WP5

See slides.

D5.1 (Report on self-tracking context and technology practices) and Milestone 6 (feedback report) are complete, D5.2 (Report on user experience during deployment) is ongoing (deadline is end of the project). Maria will start working on how to finalize D5.2 mid 2024.

General constraints: Maria's group in Edinburgh is winding down, but she is setting up her group in Oldenburg. However, Oldenburg has not signed the data processing agreement, so it's more

difficult to get support from Edinburgh (Theresa is busy and no longer on the project). WP needs to find a new rhythm for WP5 meetings.

All survey data are in and diagnoses are annotated. The coding of remaining full text fields will be done by February 2024, and there will be an upload at Erlangen in March 2024. Until then, if informal provision of data to writers with accepted preregistrations is possible.

All interview data is transcribed, and the coding of the clinician interviews will be done by February 2024. There will be an informal upload at Erlangen this December, the qualitative data will be cleaned and merged in April 2024, and then there will be an upload of those data at Erlangen in May 2024. Here also informal provision of data is possible.

Maria has four suggested papers, abstracts of these will be done early next year, and four people are now working on secondary papers (2 of which have preregistrations done, 2 others are waiting for preregistration).

Everyone who publishes after the Data Set Papers are published and uses relevant phase 1 data has to cite the Data Set papers. Each paper can link to the repository, which has a detailed description of the codes and variables. In order to get these Data Set papers out, Maria will need 1 person per paper who has time to help write the abstract and get the preregistration out.
For the D5.1 abstract – please leave your feedback in the reviewing box. Matthias is willing to support the SEM in the D5.1, but is very busy, so Maria needs someone else for that.

WP5 now has a system to set priorities for the PABs. Belgium will test a first iteration of a workshop, UK uses an adapted version, Kosice and Germany will start soon.

Maria and Matthias will get together to see what is needed for the SEM, if that takes too long (until after next GA) then we will just keep what we did in the Deliverable and drop SEM.
The dataset papers can be written by a PhD student if they want, or we will have an OS page with the full description.

Lena's papers still need quite some work, the privacy paper has lower priority than the D5.1 paper. The preregs of Adam and Julia should also be done by the next GA. Lotte will also work on clinician data (and will try to get preregs out soon).

3. WP7

See slides.

Germany has just about reached the target, the other countries still have some way to go, but there have been increases there. The total number is 56% of the target. In order to finish recruitment by April 2024 the average rate of recruitment should be around 1-2 participants per week across 3-6 units.
The focus now should be to get that minimum of 10 participants per unit. We will keep recruiting until at least March 2024 (but we need to discuss whether we should extend further). The target is very important to reach in particular for the primary outcome at t1.
There is an attrition rate to the first follow up of about 41%, which is about what was expected. There are differences in retention rates across sites, and we need to figure out how to account for it (and do something about it possibly). For the process evaluation, some sites also need to pick up the pace, but we'll discuss in the sites what we can do.

We will discuss in the January SC whether we need to extend the recruitment period. With the current end date, we would finish the 12-month post baseline assessment by March 2025, do analyses on the main outcomes by April 2025, and have a drafts manuscript on main outcomes by July 2025. We should discuss these delays with the evaluators.

The deadline for data checking and cleaning of 50% of the sample (MS18) is now February 2024, will discuss with Wolfgang whether this is feasible (but April 2024 could also work). First, we need to establish all the steps that need to be taken systematically for data cleaning. Then, to actually run it should go quickly. Further discussion tomorrow during the WP3 session.

Maria will connect with Anita and Jessica to further discuss the process evaluation in March. The deliverable for this (WP5 deliverable) is due at the end of the project.

Edinburgh:
Strategies to increase recruitment: Maintain contact with clinical teams, make sure all clinicians have been contacted and informed, focus on recruitment strategies (flyers, research champion, mental health research network support, active feedback from live participants.
Minimize drop-out by: prioritization on assessment burden (bear in mind that this is an implementation study, not a clinical trial), better use of available data, stay in touch with participants, support/encourage clinicians to use IMMERSE in clinical activities.
The fact that clinicians need to be online to use the dashboard is a problem, as they don't always have WIFI connections. They have a spreadsheet where all issues like these are logged. PAB input will also be incorporated in this file.

It is an option to leave out some measures if burden is too big of an issue, as long as we have the brief self-report of the primary outcome. Also, when someone drops out try to get that measure. This will be discussed, so how to do this in a systematic way, in the next WP7 meeting.

Kosice:
Recruitment strategies: more frequent contact with clinicians, personal meetings, visually attractive materials for clinicians (i.e. leaflets, project achievements). General newsletters for site comparisons, show how we are progressing. Jeroen will be in touch with Anita about this.
Retention: Visually attractive materials for patients, patient experiences videos, sharing experience with other fellow patients (through PAB?), regular contacts, organization of seminars for patients.

Bratislava:
Recruitment: Replace clinicians with more motivated clinicians (others would be dropouts), recruit patients from a day hospital with 3-month program (but this will take too much time). Bratislava is still confident the will reach targets. Methodological problem because 'units' are artificially created (clinicians who also provide outpatient care) – clinicians should be randomly assigned to a 'unit' (2 or 3 units).

Belgium:
Recruitment: increase research team presence at sites, reduce clinician burden (contacting patients directly), focus on efforts to motivate clinicians/nurses
Retention: Same researcher follows up patients, informal check-ins with patients/clinicians, let patients decide where they can complete follow-ups.

Germany:
Recruitment: Keep contact with clinicians, reduce burden, remind clinicians how they can benefit from the study, make sure flyers etc are available and visible, newsletters for clinicians, be present at sites, see SOP on motivation, list benefits of the study to patients, point out how we reduce workload for patients (e.g. online assessments).

Retention:
If clinicians are able to charge for this treatment it would make a huge difference.

4. WP2

See slides.

Export API:
There is an integration with WP3 on staging system, and are exporting participant data and the intervention design there. Current problem is when a huge amount of data is exported it interferes with DMMH execution. They are looking into that. See slides for an example of what the data looks like. Their output is for WP3, WP3 provided data in format researchers can use more easily.

Maintenance:
Most problems are participant specific problems, and most have been solved. There was a problem with the server provider, so servers weren't available for a whole day, after that it worked again as usual. There have been 4 new releases since August, each release includes an intensive system test.

Inez will connect the interested student from Delft with Simon, she can possibly help (depending on skillset)

5. Dissemination

We now have some primary papers that are hopefully preprinted before the EC Evaluation. Inez is working on overall IMMERSE paper based on the grant application, she will do this during her sabbatical early next year, preprint also ready before Evaluation. Uli is nearly done with protocol paper (condensed version of CIP).

Effects of extended recruitment for PhD students: it is unclear what will be available of phase 2 data (and when) when it's not related to a primary outcome, we still need to develop a process of how these processed data can be delivered, and need to make sure this doesn't cause any deblinding. DMMH data will be available for all PhD students. We just need to make sure that the main papers will be submitted first, if outcome data are used in the secondary papers (and check whether this is relevant for each paper). Access to analyses is always open.
There needs to be a mechanism for students to have access to DMMH data via the established route (abstract submission etc), to make sure we work on a consistent dataset, and so they have access somewhere next year. So, in the example of Rafaels paper, he needs access to basic participant characteristics data, but not the outcome data, so WP3 needs to make sure students only get the variables they request and nothing else. Not only Wolfgang, but for example also Uli or a statistician would have to sign off on whether certain data can be released. Jeroen will talk with Wolfgang about how the variable requests will work.
No major problems are expected for any of the students.

Jeroen and Silke are interviewing students, this student will work on creating an IMMERSE video. We could also all make user videos? Another idea is to have a script, record de voice of participants in different languages, and then have an animation. Jeroen will coordinate this.

We can also organize symposia on phase 1 data and the set-up of phase 2 data, and present these at conferences, like psychiatry meetings, SAA, and maybe some tech conferences. We need a concrete plan for this for the Evaluation. We'll list these on Basecamp, anyone who has ideas can add it there.

Timing of opinion paper on MDR regulations: aim for February to release this. Inez and Elisa will meet with Uli and Matthias to discuss and get things started.

DAY 2

6. WP8

See slides.

We will hire someone to help out with graphical design, making videos, …

Inez will write a paper on IMMERSE in January – then this will be adjusted (laymen terms, shorten, more applicated version) and translated for all countries so it can be published in local, more clinically oriented magazines/journals

Inez contacted an advisor (LRD) on investment management – start with an overview of all the investments that were made already + overview of intellectual contribution of all the different groups

7. WP3

See slides.

Data storage on UKER cloud folders is available – Anita has a list of folders with corresponding links and passwords, if you want to access these contact her. This is a transfer/sharing location (not long term storage). → keep open science principles in mind!

Exporting DMMH data puts strain on the system: back-up system? Data export in segments?

- Database export in April/May? Updated export in June? Create versions in separate releases which can then be referred to (e.g. in PhD theses)?
- DMMH data needs to be prioritized
- Set up a follow up meeting with Wolfgang, Georgia, Manu, Anita and possibly Thomas

8. WP4

See slides.

How will we decide on priorities concerning wearables data and outcomes?

- From a machine learning perspective, we would put all data in to predict time series.
- This could help us determine which measures are good predictors and which can be dropped. What would be clinically relevant to predict? → these are very consuming analyses that are not yet incorporated in the proposal but Georgia will think about how we could go about this.
- Set up a follow up meeting (including Matthias & Uli)

9. **SAB**

See slides.

How can we continue to improve recruitment/reach our target?

- Overrecruiting in sites that are reaching the target might be biased and will have impact on external validity, but this seems to be the most feasible option. So keep recruiting in sites that are going well.
- Try to keep close contact with clinicians as much as possible
- Publish in local journals that clinicians read (but probably too late to boost recruitment in the current time scheme)
- Share testimonies of people using the dashboard
- Clinicians sometimes assume some service users aren't open to participating, but we could emphasize that it doesn't hurt to ask and that we can let the service user decide this themselves
- Target service users directly (leaflets, videos, posters, …) so patients can inform their clinician that they want to participate
- Additional barrier: not all clinicians/service user have easy access to computer/phone service/wifi in the sites
- Simplicity is key, instructions and explanation should be very short and straight forward.

How can we improve retention?

- Inform service-users about the follow-up appointments from the beginning. Give them the dates and location of all the appointments, hand this out, give them reminders, ..
- Highlight the last appointment (e.g. "you're almost there, last one!")
- Highlight the primary outcomes
- Increase reimbursement for last measuring point?

10. WP6

See slides

Ask sites if one delegate per site can join the ethics advisory board
Data collection White Paper has started (interviews with IMMERSE partners)

11. Final discussion

MedX monitoring: schedule this the day before general assembly in Germany?

Stream of contributing to papers: you can get involved at two stages.

- 1) After the abstract you can join in if you want to get closely involved (from pre-registration on (e.g. think about hypotheses, code, statistical plan, …)). This can only be a

limited amount of people. When the abstract is posted you will receive an email from Jeroen and you have three weeks to express your interest.

- 2) In a second phase, when the paper is already written you can join in as co-author, only if you actively contribute feedback. You can also decide to opt out if you don't have time or are not interested in contributing to the specific topic of the paper.
    - Jeroen will circulate all papers and keep track of who wants to be involved and who wants to opt out. So when you have the full draft of your paper, send it to Jeroen.
    - We have to keep in mind the culture of citations for specific topics (e.g. machine learning papers can have 8 authors max.). As author of a paper you can therefore ask for an exception to the 'everyone is author unless they don't contribute'-rule. If this is applicable to your paper, inform Jeroen about this when sending through your paper. This will then be discussed.
- Papers that are related to IMMERSE but not necessarily a product of IMMERSE: it would be helpful if IMMERSE could be mentioned in the funding section, because we need to create output. But these papers don't have to be circulated through the stream mentioned above.

Wolfgang will check with Thomas about the use of Dataquier and give an update about this