

WP5: Stakeholder Experience

Dr Maria Wolters
University of Edinburgh

IMMERSE General Assembly Meeting Edinburgh
31 March-1 April 2022



This project has received funding from the European Union's Horizon 2020 research and innovation Programme under grant agreement 945263 (IMMERSE)

Overview



- Quick Reminder WP5
- Current state of T5.1
- Current state of T5.2
- Timelines, Deliverables, Milestones – Quo Vadis?
- Discussion items for General Assembly

Please save comments until end of talk



This project has received funding from the European Union's Horizon 2020 research and innovation Programme under grant agreement 945263 (IMMERSE)

WP5 – Key Staff



Dr Maria Wolters (WP Lead, Edinburgh)

Dr Theresa Ikegwuonu (RA, Edinburgh)

Phase I Study Protocol: Prof Ulrich Reininghaus & Site PIs for WP7 & WP5 / WP7 team

Data Collectors and Analysts:

Dr Anita Schick, Julia Schulte-Strathaus, Fiona Dörr, and Team DE

Rafael Bonnier, Lotte Uytendroek, Lena de Thurah, Dr Glenn Kiekens

Dr Simona Di Folco, Koraima Sotomayor Enriquez, Islay Barne

Adam Kurilla, Matej Hrabovsky, and Team Slovakia



This project has received funding from the European Union's Horizon 2020 research and innovation Programme under grant agreement 945263 (IMMERSE)

WP5 - Objectives



- How can we make sure that service users, clinicians, and service users' supporters have a **good user experience** with DMMH? (T5.1 Questionnaire / T5.2 Interviews)
- How do service users and clinicians **adapt and appropriate** DMMH for their own needs? (T5.3)



WP5 – The Plan



- Task 5.1: What is the general technology context?
April 2021-December 2021 (M1-M9)
- Task 5.2: What is the specific ESM / Self Tracking context?
June 2021-September 2022 (M3-M18)
- Task 5.3: Tracking Appropriation of DMMH
Mar 2022-Mar 2025 (M12-M48)



WP5 – Year 1



- Finalise study design for T5.1 / T5.2
- Ethical Approval for T5.1 / T5.2
- Data collection and analysis for T5.1
- Data collection and initial data analysis, including analysis framework, for T5.2
- Intermediate report for consortium



T5.1 + T5.2 + T7.1 = Phase 1



- Merging of data collection for T5.1, T5.2, and T7.1 as Phase I, lead Ulrich Reininghaus, joint design WP5, WP7, Site PIs, Postdocs, and PhD students
- Advantages:
 - Far more efficient use of available staff time
 - Decision to target Phase II implementation sites allowed for dry run of ethics and recruitment
 - Dry run of protocol development / collaboration management for Phase II
- Disadvantages:
 - Longer, more complex instruments
 - Detection of issues slowed down start of recruitment



WP5 – The Reality



- Task 5.1: What is the general technology context?
Data Collection ongoing, Analysis to be modified based on potential change in targets
- Task 5.2: What is the specific ESM / Self Tracking context?
Data Collection ongoing, Analysis protocol under iterative development
- Task 5.3: Tracking Appropriation of DMMH
Mar 2022-Mar 2025 (M12-M48)



WP5 – Task 5.1: What is the general technology context? - Plan



- Method:
 - Questionnaire, informed by theoretical framework
 - Structural equation modelling / content analysis
- Outcomes:
 - Use of, attitudes to, experience with technology in general and for self care / patient care



WP5 – T5.1 Reality



- Survey was implemented using RedCap, with several iterations of testing and feedback from all sites
 - Pro: allows coordination across sites and secure data management
 - Con: bad user experience for those completing surveys
- Paper versions at some sites to increase completion rates
- Target: 100 patients, 50 supporters, 25 clinicians/country + admin



WP5 – T5.1 Below Target



	Patients	Supporters	Clinicians	Admins
Target / Site	100	50	25	10
DE	57	25	39	9
SK	99	10	20	10
UK	0	0	5	0
BE	3	0	38	8
TOTAL	159	35	102	27



This project has received funding from the European Union's Horizon 2020 research and innovation Programme under grant agreement 945263 (IMMERSE)

WP5 – T5.1 Where do we lose them?



	Demographics	Technology	PSSI	Implementation
DE	172	164	134	130
SK	168	161	148	139
UK	6	5	5	5

Start: Context and Framing

Middle: Detail

End: Given framing,
what about DMMH?

- > 75% make it through to the end – good for long survey with no compensation!
- No detailed data for BE – but R Script available to run



WP5 – T5.1 Lessons Learned



- Drop off consistent with effect of survey length
- Large numbers require either a massive personal effort or targeted mail shots (paper / email)
 - > will be mitigated in Phase II as questionnaires administered as part of intake and follow up
- Sites using paper questionnaires (DE, SK?) did well
 - > paper versions important for ease of access, since MedX also uses RedCap



WP5 – Survey: Recruit ‘Til We Drop?



- On balance, high quality phase II more important than full phase I
- Due to heterogeneity, adjust statistical analysis
 - regression instead of SEM
 - well targeted Factor Analysis / Latent Class Analysis possible
- For D5.1
 - in-depth analysis of DE/SK data
 - descriptive analysis of BE/UK data
 - joint analysis if Data Sharing Agreement ratified by August 1, 2022

Wolf EJ, Harrington KM, Clark SL, Miller MW. Sample Size Requirements for Structural Equation Models: An Evaluation of Power, Bias, and Solution Propriety. *Educ Psychol Meas.* 2013 Dec;76(6):913-934. doi: 10.1177/0013164413495237. PMID: 25705052; PMCID: PMC4334479.



This project has received funding from the European Union's Horizon 2020 research and innovation Programme under grant agreement 945263 (IMMERSE)

WP5 – T5.1: What's Next?



- We need decision from General Assembly, and then each site, when to stop active recruitment for surveys
- Based on that, adjusted statistical analysis plan
 - R Markdown script co-produced with Belgium that transforms data, checks scales, does D5.1 analyses, and produces SPSS output
 - Script to be put on GitHub, analysis to be put on BaseCamp
- Coding plan for open answers (meeting tbc)
- Additional analysis from Mannheim Master Student



WP5 – Task 5.2: Specific ESM Context



- Method:
 - Interviews / workshops with technology probes based on DMMH prototypes
 - Framework Analysis / descriptive statistics
- Outcomes:
 - Barriers and facilitators
 - Inform development of implementation theory
 - Additional usability data



WP5 – Task 5.2: Reality

- Method:
 - Interviews with vignettes and videos based on DMMH prototypes
 - Top-down **qualitative content analysis** for initial reporting and ease of analysis
- Outcomes:
 - Barriers and facilitators
 - Additional implementation ideas through interviewer notes



WP5 – T5.2 Looking Much Better!



	Leuven	BE To Do	CIMH	PCN	DE To Do	UK	UK To Do	Bratis.	Kosice	SK To Do
Patients	6	4	12	0	-2	0	10	5	8	-3
Clinicians	4	1	6	1	-2	3	2	8	2	-5
Supporters	0	5	2	0	3	0	5	3	2	0
Admins	4	1	3	1	1	0	5	4	2	-1



This project has received funding from the European Union's Horizon 2020 research and innovation Programme under grant agreement 945263 (IMMERSE)

WP5 – Interviews: What's Next?



- We need decision from General Assembly, and then each site, when to stop active recruitment for interviews
- March 30:
Kick off workshop for analysis laying groundwork (common understanding)
- Simple, straightforward qualitative content analysis codebook that requires only fortnightly coordination meetings between analysts (EDI) while transcription ongoing in BE / SK / DE (in development)
- Coding in original language, with only qualitative codebooks exported for sharing



WP5 – Year 1 After Contact with Reality



- Finalise study design for T5.1 / T5.2 - DONE
- Ethical Approval for T5.1 / T5.2 - DONE
- **Data collection** ~~and analysis~~ for T5.1
- **Data collection** ~~and initial data analysis, including analysis framework,~~ for T5.2
- **Intermediate report for consortium**



WP5 – Deliverables & Milestones



- MS1: Framework for initial studies in place – M3 (Jun 2021)
DONE
- MS6: Internal report on findings – M12 (Mar 2022) 2-3 weeks late
- D5.1: Report on Tasks 5.1 and 5.2 on target somehow
DMMH Stakeholder Experience Context – M18 (Sept 2022)



M6: Intermediate Report

- From T5.2:
 - Interviewers are also on implementation strategy committee
 - Detailed written memos produced by interviewers
- From T5.1:
 - Co-analysis meeting in person with UK team on April 4 looking at SK / DE data – report to be provided, follow up meetings with other partners to be arranged
 - Intermediate presentation of plan and findings to date once T5.1 adjustment decisions made



Suggested Actions for Discussion (1/2)

- Emphasise Phase II now
- Detailed description of recruitment from each sites
- T5.2:
 - Sites that don't have supporter/admin data yet: stop
 - Sites that don't have patient interviews yet: do at least 5
 - Focus on initial qualitative content analysis with simplified procedures



Suggested Actions for Discussion (2/2)

- T5.1:
 - RedCAP remains open in case stragglers complete survey
 - UK stops and focuses on interviews
 - BE makes one final push for patients and then stops
 - DE / SK stop
 - SEM second-line analysis after completed data sharing agreement



WP5 – Task 5.3: Tracking Appropriation



- Examining qualitative and quantitative evidence for usage patterns, especially
 - those that deviate from original intention
 - those that show barriers to use



User Experience



- Preparation for deployment
- How can DMMH help service users, clinicians, and service users' supporters fulfil their goals?
- What's it like to use DMMH?
 - quick, pleasant, fun, insightful, worthwhile
 - cumbersome, annoying, painful, a burden



Appropriation



- Observation during deployment
- Clinicians, service users, and their support network will use IMMERSE
 - in unforeseen ways
 - to achieve unforeseen goals
- This leaves traces in the data generated

