Platform for Long term retention in MH setting – Researcher Front End

## Background:

Evidence suggests that participation in mental health services is not heterogenous with different groups experiencing different participation rates[[1]](#footnote-2). Retention in mental health research can be compounded by seeking access to services and adherence to treatments and therapies for mental illness more generally, which is further exacerbated by demographic factors such as age, gender, and ethnicity[[2]](#footnote-3).

Participation in research is burdensome. Naidoo et al[[3]](#footnote-4) found some factors for burdensome related to trial administration exacerbated by high volume, inadequate format, and high variety of complex information. Interventions to improve retention in mental health services focus on engagement and have demonstrated some positive impact[[4]](#footnote-5). The systematic review by Woodall et al found that some `research had reported outreach and engagement activities as beneficial to retention in studies[[5]](#footnote-6).

Using social communication tools, such as text messaging and WhatsApp, to engage with participants of mental health research could:

* Increase engagement by utilising communication tools that participants use routinely, reducing the burden to communication in a more unfamiliar forum (e.g., a new app),
* Increase engagement by providing opportunities for two-way discourse outside of traditional phone and email communication, which isn’t always convenient to research participants,
* Provide opportunities to personalise ways in which research participants engage by allowing them to select their communication method preference.

## Prototype:

What if we take the model of the CRM (Customer Relationship Management) system and make it a PRM (Participant Relationship Management) system? A traditional CRM manages contact details, and logs interactions to allow for easy follow up and prioritization – tasks which are equally key to the delivery of a research project. However, the core technology can be expanded on. In a world where interactions between human beings are increasingly digital, why can’t we leverage the growing world of communication technology to allow for interactions to be customized to the preferences of our participants without placing any extra pressure on the researcher?

In our prototype we have developed such a PRM - a unified web portal by which researchers can:

1. Register their participants and add appropriate meta data
2. Schedule and automate messaging to participants or groups
3. Receive, review and apply ML methods to triage and escalate responses
4. Audit and review their communication strategy to learn what does and doesn’t work.
5. Allow participants to define the method of communication that works for them.

The deep power of such a system comes from maturity. Once interactions have been recorded, the option presents itself to understand them. New participants can be compared to historical data to present suggestion methods of communication and models of care, giving a step towards person centred, tailored care. Similarly, with participant generated contacts captured, e.g. responding to sms, a level of automated triage can be applied. Such a system is not necessarily novel. CRM’s exist to manage relationships, and bulk mailing tools exist – but by building a single unified platform informed by the lived experiences of researchers and participants we can deliver an affordable tool with a low barrier to entry and endless possibilities.

## Plans for Future Work:

Centred around an experienced based co-design approach[[6]](#footnote-7) incorporating a human factors and systems thinking lens, we will work in partnership with people with lived experience of mental ill health and mental health researchers to design and develop a multi-modal communication platform to manage participant relationship (participant relationship manager – PRM).

To develop the prototype into a reliable, cost-effective and resilient tool there are two key streams of activity:

### Stream 1 – technical

The prototype only implements a handful of communication methodologies, and lacks key aspects of standard cyber security. To ensure a mature delivery, we would employ an experienced full-stack developer to expand on the existing codebase, ensuring interoperability with key communication services (e.g. whatsapp, messenger, VOIP providers) and interface with scheduling/calendar systems where appropriate. This stream would also ensure the best practices of data governance and confidentiality are enshrined in the platform, carrying out due diligence on the third party APIs required, and establishing routes for safeguarding and data restoration.

### Stream 2 – advisory and user experience testing

To ensure the tool remains fit for purpose, the aim is to partner with upto three mental health interventions that require strong communication and interaction with their participants and hold multiple advisory groups with both intervention delivery teams and participant. These steps will ensure the platform is created with the community, bringing together the lived experiences and struggles faced to solve real problems, not our perceptions.

These two streams of work would initially run in parallel (~2 month), solidifying the prototype while building a community of small mental health interventions interested in engaging with the platform. With the underpinning aspects of the platform secure, the two steams would converge with an Agile approach – aiming to present rapid iterations of the platform to MH stakeholders (service delivery and participant) for feedback, guidance, and feature requests.

Assuming the platform can be qualified as reliable and secure, it is envisioned at the mid point of the project (6 months) the first iteration of the platform would be delivered to the MH interventions for closed beta testing. The MH intervention partners will each be furnished with a small budget to aid adoption of the system, limiting risk of failure due to non-compliance. Over the final 6 months of the project, the aim will be to complete development of the platform while managing bug reports from the intervention teams.

The ‘success’ of the platform will be judged for increased retention as a short term consideration of ease of engagement. The platform will have the opportunity to succeed in the long term if it can prove capable of reactive development, able to identify and implement the workflows and features teams require to better communicate and identify those individuals most at risk of attrition.

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| Research Team | Personal attributes | Skills and expertise |
| Dr Robert Cook (PI) | Technical gremlin and data gubbins | Framework development, programming, implementation, analysis |
| Dr Md Asaduzzaman (Co-I) | Disruptor and critical thinker | Statistician/machine learning modeller, validation, verification and quality assurance |
| Dr Sarahjane Jones (Co-I) | Big picture thinker, jigsaw maker and cat herder | Research/data ethics, research governance, data and medical device legislation, partnerships and engagement |

## Budget – Year 1:

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| **Named project team** | | | | | |
| Name/Role | Personal attributes | Skills and expertise | Justification | FTE | Cost |
| Robert Cook | Technical gremlin and data gubbins | Framework development, programming, implementation, analysis | Principal investigator responsible for overall project delivery and oversight of technical development of tool | 0.15 |  |
| Dr Md Asaduzzaman | Disruptor and critical thinker | Statistician/machine learning modeller, validation, verification and quality assurance | Responsible for implementing and undertaking quality assurance methods to ensure code is fit for purpose | 0.1 |  |
| Sarahjane Jones | Big picture thinker, jigsaw maker and cat herder | Research/data ethics, research governance, data and medical device legislation, partnerships and engagement | Responsible for ensuring study is completed t highest ethical standard and compliant with all legislative conditions. | 0.05 |  |
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| Role | Justification | Decription of time | Cost |
| Full stack developer |  | 0.5fte |  |
| Graphic design consultant |  | 0.1 |  |
| Sarahjane Jones |  | 0.05 |  |
| Project management |  |  |  |

Salary:

Name Justification Period on project (months) % time Tota

* Full stack developer – 50% fte for 1 year (~£30,000)
* Graphic design consultant – 40 hours (~£1,000)
* Project management – 10% fte for 1 year (~£4,000)
* Project oversight – 30% fte for 1 year (~£20,000)

Materials/ Consumables and assistance cost

* Accounts and costing of messaging services for 1 year (£5,000)
* Assistance for ongoing MH interventions to implement the platform (3 X £6,000)

Travel, subsistence, and impact generation:

* £10,000 to hold technical advisory groups
* £5,000 for open access publishing fees
* £5,000 for other travel

Total cost: £98,000

1. Woodall, A., Morgan, C., Sloan, C., & Howard, L. (2010). Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers?. *BMC psychiatry*, *10*, 1-10. [↑](#footnote-ref-2)
2. Twomey, C. D., Baldwin, D. S., Hopfe, M., & Cieza, A. (2015). A systematic review of the predictors of health service utilisation by adults with mental disorders in the UK. BMJ open, 5(7), e007575. [↑](#footnote-ref-3)
3. Naidoo, N., Nguyen, V. T., Ravaud, P., Young, B., Amiel, P., Schanté, D., ... & Boutron, I. (2020). The research burden of randomized controlled trial participation: a systematic thematic synthesis of qualitative evidence. BMC medicine, 18(1), 1-11. [↑](#footnote-ref-4)
4. Greene, J. A., Bina, R., & Gum, A. M. (2016). Interventions to increase retention in mental health services: a systematic review. Psychiatric Services, 67(5), 485-495. [↑](#footnote-ref-5)
5. Woodall, A., Morgan, C., Sloan, C., & Howard, L. (2010). Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers?. BMC psychiatry, 10, 1-10. [↑](#footnote-ref-6)
6. Green, T., Bonner, A., Teleni, L., Bradford, N., Purtell, L., Douglas, C., ... & Chan, R. J. (2020). Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review. *BMJ quality & safety*, *29*(1), 64-76. [↑](#footnote-ref-7)