

# MacHSR Future Leaders Fellowship program Final reporting (Cohort 1)

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**Project title:** Remote Symptom Monitoring and automated treatment plans in children with Cystic Fibrosis

## Project summary

In people with Cystic Fibrosis (CF) pulmonary exacerbations result in loss of lung function and in turn decreased life expectancy. It is proposed that delayed identification and treatment of pulmonary exacerbations may contribute to worse outcomes for people with CF. Several studies have found that those CF centres who review their patients more frequently and treat exacerbations more aggressively have better outcomes.

Like many CF centres we did not have capacity to increase the frequency of patient reviews; therefore came up with an alternative model of care. Through a co-design process (parents of people with CF, CF multidisciplinary team, Royal Children's Hospital Virtual Care team) created a new digital model of care involving a multimodal program of remote monitoring and automated treatment plans housed in the electronic medical record (EMR).

Each person with CF is prompted to complete a validated symptom monitoring questionnaire via the EMR portal twice a week. In built algorithms in EMR monitor the results of the symptom questionnaires to determine if there are any worsening in symptoms which may pertain to a pulmonary exacerbation. If the system detects an exacerbation it sends an individualised treatment plan to the patient, including required antibiotic use and airway clearance and inhalation therapy. A message is sent to the CF team alerting them of the exacerbation. A telehealth appointment will be made to perform lung function to provide further detail of the exacerbation and ongoing monitoring until the persons symptoms return back to their baseline.

## Project activities during the MacHSR Fellowship

Whilst much of the co-design process and EMR build occurred prior to the commencement of the fellowship, what was not fully formed was an evaluation plan for the project. Much of the first 6 months of the fellowship was spent designing a rigorous Pilot Randomised Control Trial (RCT), alongside gaining ethical approval.

The aims of the Pilot RCT are to:

- To assess the **uptake and feasibility** of the remote monitoring and automated treatment plans
- To assess the **impact and acceptability** of the remote system monitoring and automated treatment plans on **family experience**
- To assess the **impact and acceptability** of the remote system monitoring and automated treatment plans on **CF multidisciplinary team (MDT) experience**
- To understand **changes in outcome measures** over time between the two groups in children on highly effective modulators
- To assess the **cost-effectiveness** of the remote monitoring and automated treatment plans compared to usual care by undertaking a health economic evaluation from healthcare and societal (family) perspectives.

The study is mixed methods in nature utilising trial data from the EMR, surveys and semi structured interviews with both families and members of the CF multidisciplinary team.

Since gaining ethical approval we achieved the following:

- Recruited 32 participants
  - o 15 randomised to control group
  - o 16 randomised to intervention group



- Stepwise implementation of the new model of care involving:
  - o Engagement and upskilling of CF Team through:
    - Simulation sessions (low fidelity version of the Melbourne University Validatron) testing the workflows associated with the remote monitoring system
    - Creation of written and video educational documents
  - o Engagement and onboarding of participants through:
    - Creation of written and video educational documents
    - One on one set up assistance
    - Regular check ins with research team

The Pilot RCT officially commenced in May 2023. See below a summary of the results so far

- o 72% Response rate
- o 9 Exacerbations detected

Feedback from staff and participants relating to acceptability of the remote monitoring system in the first 3 months of the trial was collected through 22 semi structured interviews, see below some small extracts from the interviews (yet to be formally analysed):

- “It's easy to use, it's quick, it's not in the way at all” (participant 15 years of age)
- “You see the warnings signs before you get sick... So, you can adjust your plan before you really need it” (participant 16 years of age)
- “Been really good at increasing our ability to monitor patients at home and I'm pretty sure we've picked up exacerbations that we wouldn't have picked up otherwise...and that's kind of the whole aim” (CF consultant)
- “I think it's facilitating the patients being really engaged, it's facilitating engagement between the clinical team and those patients. And we know that having a really engaged patients is a characteristic of high performing CF centres in the US” (CF consultant)

## General Fellowship feedback

### Personal growth

The opportunity to be one of the MacHSR fellows has meant a lot to me. It has not only provided academic growth and opportunities, but it has also contributed to personal growth. It has challenged me to step out of my comfort zone, adapt to new environments, and overcome obstacles. These experiences have made me more resilient and adaptable.

### Building networks and collaborations

The fellowship fostered new networks and connections with experts and peers both internal and external to my organisation. These connections have been crucial to the success of the project and have opened up future collaborative opportunities both in developing my own research journey but also those of my hospital.

During the MacHSR fellowship I have liaised and worked with the following entities:

- Centre for Health Analytics (CHA)
  - o Murdoch Children's Research Institute (MCRI) (Respiratory Diseases Group & Health Services Research Group)
- RCH Virtual Care team
- EMR trials group
- US EPIC (EMR company) teams

### Increasing research capacity

Having access to experienced mentors both within MACH and my hospital has been invaluable. Their support has helped me to extend the breadth and quality of the research project in a way I could not have done

otherwise. The fellowship assisted in producing new knowledge and skills and has significantly increased my capacity to do further research. I believe that the fellowship and the new skills and experience I gained through it has led to me being more competitive in securing fellowships and grants. Since the completion of the fellowship I have been the successful recipient of the following:

- Research Fellowship grant through Cystic Fibrosis Australia
- Centre for Health Analytics Clinical Data Champion position

I have also been asked to present at the hospitals Grand Round on Digital Health Innovations on the project.

### Barriers & Enablers

After reflecting on how far into the research project I was able to progress during my MachSR fellowship, I did feel like with an extra 6 months I would have been able to achieve much more. I really spent the first 4-6 months learning about health service research, liaising with my mentors and making continuous iterative changes to the research protocol as my knowledge and experience increased. Allowing for another 6 months of the fellowship would then give participants that "learning time" alongside a further 12 months to enact their project.

One of the many highlights from the fellowship for me were the connections and networks I was able to build during my time. I have experienced great generosity from some extremely experienced researchers and clinicians and have learnt the power of learning from others. The other beneficial connections has been with my fellow fellows. We built a strong bond in a short period of time, shared successes and dead ends – connections I hope to hold onto for many years to come.

### Impacts on future career

I believe this fellowship will continue to shape and impact my future career in many ways. It has developed my research capabilities immensely and has enabled me to learn new skills which will be indispensable in the future. It has served as a strong foundation for pursuing a doctoral degree in the near future and I believe it will make me a competitive candidate for both academic and industry positions.

I am very grateful for the experiences and opportunities the MachSR fellowship has provided, from personal growth, to increasing research capacity, network and collaborative opportunities and future career opportunities, the benefits have been substantial. I look forward to continuing my health services research journey and linking in with future MachSR fellows and sharing in my own positive experience.