



I Know Me is a digital health start-up founded by Dr Michael Twomey PhD, a patient with Cystic Fibrosis (CF) and Senior Clinical Research Manager in Health Innovation Hub Ireland. His research and innovation journey is a rather personal one, motivated by the death of his sister Jane who died from CF in 1997.

Inspired by her, Michael decided to address a problem that he and other CF patients and carers have regarding the challenges of recalling medical history within the medical appointment setting.

The **I Know Me** platform allows CF patients and carers to capture their medical history as they go about their busy lives. Co-designed with other CF patients and carers. It allows a CF patient or carer to track medications, symptoms, and other key facets of their medical history including the generation of visual reports for same. Now the quality of the data recalled and provided to clinicians is far superior!

About Health Innovation Hub Ireland

Health Innovation Hub Ireland (HIHI) was established by the Department of Business, Enterprise and Innovation and the Department of Health and is supported by Enterprise Ireland (EI) and the Health Service Executive (HSE) to drive collaboration between the health service and enterprise. We offer companies the opportunity for pilot and clinical evaluation studies and we provide the health service access to innovative products, services and devices that they may not otherwise be exposed to.

HIHI is built on the recognition that collaboration with enterprise can benefit patient care, patient pathways

and outcomes. We assess all concepts for healthcare innovation from those on the frontline – from clinician to porter. We encourage healthcare professionals to get in touch with HIHI if they have an idea or solution to how something in your job might work better.



The Healthcare Challenge

Cystic fibrosis (CF) is a genetic disorder that primarily affects the lungs and digestive system. It's caused by mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene, which leads to the production of thick, sticky mucus in the lungs and other organs.

While there's no current cure for Cystic Fibrosis, treatments aim to manage symptoms and improve quality of life. This can include medications to thin mucus, antibiotics to treat lung infections, pancreatic enzyme supplements to aid digestion, therapies to help clear mucus from the lungs and new advanced drugs called CFTR modulators.

The primary aim of the medical appointment is to arrive at a correct decision or diagnosis via accurate information, some of which is elicited from the patient or carer by the doctor

during the medical history gathering phase of the medical appointment. This requires the retrieval of data from long-term declarative memory.

Unfortunately the recall of a medical history, like other modes of autobiographical memory, tends to be defective, incomplete, and erroneous. Additionally, the ability to remember what has occurred within the medical appointment (later) is also quite problematic. Such memory recall issues give rise to numerous pernicious effects, more especially, for the patient.



The Health Solution



Taking an Action Design Research/Design Thinking approach, the solution designed, built, and evaluated to address the problem of poor CF patient/carer memory recall is an app. The **I Know Me** design is based on current CF medical appointment workflows, CF patient / carer experiences, and helps the patient/carer record, track and report on key aspects of their medical history. These reports can then be shared with a patients clinical team.

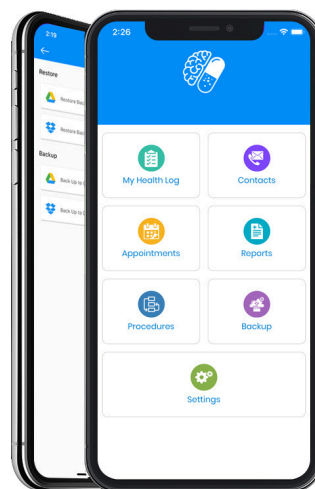
Additionally, the app allows for the capture of multiple health profiles on the one device, where switching between profiles is easy. This component of the app is vital for families with more than one CF patient.

Further details can be found on www.iknowme.info

HIHI Role

HIHI conducted a pilot of **I Know Me** with 15 CF patients/carers within Ireland, including the facilitation of a number of design workshops which helped offer a dynamic and inclusive approach to problem solving, enabling participants to create a solution that is not only functional, but also deeply resonant with CF patients/carers.

Finally, HIHI analysed the pilot results (end-user feedback) and prepared a final project report to disseminate outcome of the pilot. This pilot was granted ethical approval by SREC in UCC .



Outcome Report

- **67% of participants** use the app on a **weekly or monthly** basis.

- **93%** would describe the app as **useful for memory recall**, with **67%** stating that it was **Very or Extremely useful for memory recall of medical history**.

- **60% Agreed or Strongly Agreed** that using the app helped **reduce their stress levels** within the medical apt.

- **67% Agreed or Strongly Agreed** that using the app gave them a **real sense of empowerment**.

- **87% Agreed or Strongly Agreed** that using the app requires a **change in behaviour**.

- **93% Agreed or Strongly Agreed** that the app was **easy to navigate**.

- **86% Agreed or Strongly Agreed** that the app was **easy to use**.

Testimonials

"I Know Me is an app for us (CF patients / carers) designed by us, that's why it works! It allows us to track our medications, our symptoms etc effectively, our own unique health journeys, with the data captured available to us as required. We are empowered in the management of our own health and need to be. After-all, we need to be the CEOs of our own bodies!"

I'm delighted that we are making such progress, the insights gained from the pilot have been invaluable and will really aid our advancement of the I Know me app. Still more work to be done, I hope my sister (who passed away with CF in 1997) would be proud of what we have done so far." – Dr Michael Twomey, I Know Me, Founder.

"I really like the way the app gives you visuals on key metrics and allows one to generate reports that can be sent / given to the clinical team. It's wonderful to be able to refer to the app with confidence re my medical history" – CF patient.