

**Co-designing a  
sensor-assisted  
toolset to improve  
quality of life for  
people with early  
stages of dementia  
and Parkinson's**



<http://scampi.city.ac.uk/>

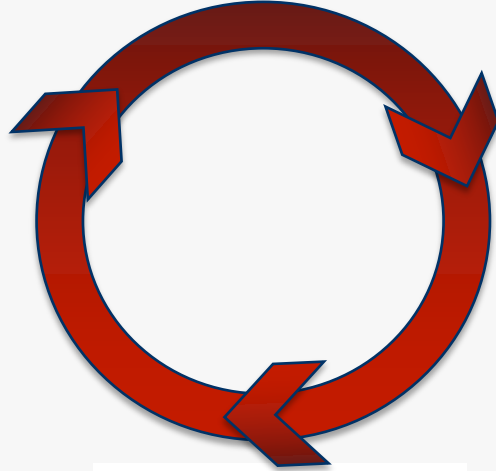
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<https://www.youtube.com/watch?v=SLIj6TmUCgQ>

SCAMPI

# The components

User  
Interface to  
manage  
and monitor  
quality of  
life

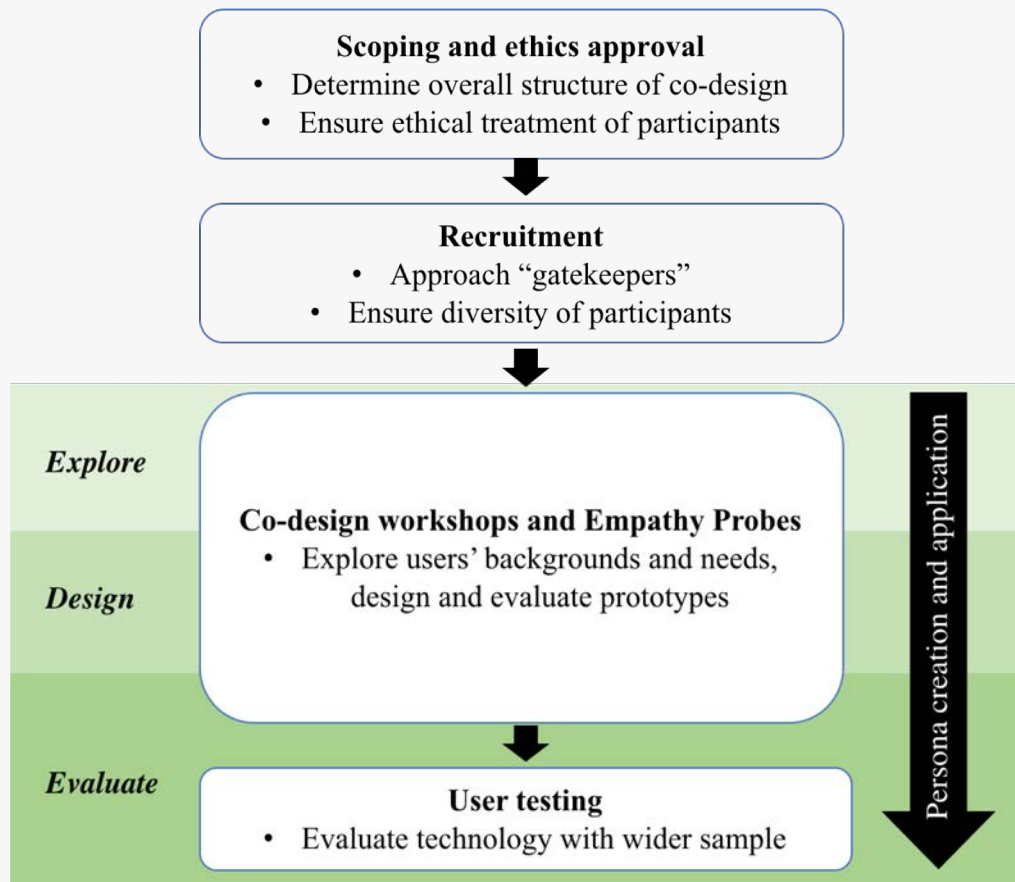


Sensor-based activity  
recognition to aid monitoring



Quality of Life  
model to  
support  
reasoning and  
suggestions

# Co-designing



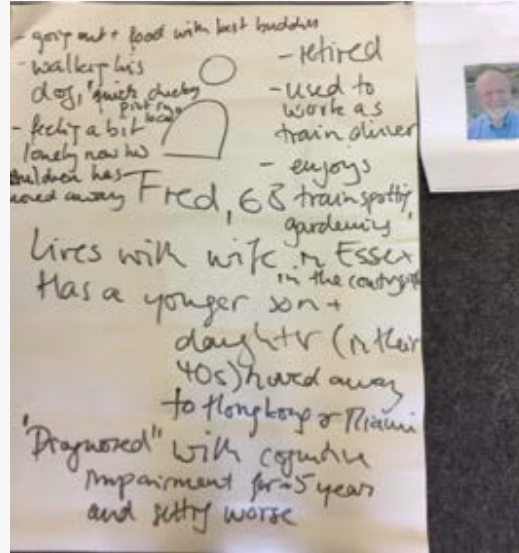
# Scoping and recruitment

- Ethics took up 25% of study timeline
  - Get staff trained
  - Get materials ready
  - Deal with informed consent and capacity to consent
- Recruitment through gatekeepers
  - Timing is crucial
  - Co-design study and materials
  - Need to spend time with volunteers

# Co-design workshops

- Series of 4 workshops with 2 people with dementia and their carers and 5 people with Parkinson's
  - Workshop 1: explore the background, technology use, activities and goals of users; *create initial personas*
  - Workshop 2: explore the use of sensors and gain input to the computational model; *review and extend personas*
  - Workshop 3: design the user interface using low-fidelity prototyping; *apply personas*
  - Workshop 4: evaluate the user interface design using an adapted cognitive walkthrough; *apply personas*

# Exploring (Workshop 1 and 2)



## What we learned:

- Personas are great for getting participants engaged and communicating their lived experience
- But some limitations: mirrored group composition, shorthand for condition



# The Co-Created Personas

**Enid**  
 "Be more social"  
 Age: 38  
 Work: Housewife  
 Family: Married, kids  
 Location: Miami, USA  
 Personality: Extrovert

**Bio**  
 Enid is Fred's daughter. She lives in Miami. She really enjoys riding. She organizes. She talks to...

**Goals**  
 • Be...  
 • R...

**Activities**  
 • Go to local swimming club and do aqua aerobics  
 • Girls days out...

**Technology at home**  
 • Doro phone  
 • Landline phone  
 • Electric buggy  
 • Desktop  
 • Sonic whistle for dog  
 • Panic button  
 • "Checking" alarm clock

**Sensor Use**  
 • I would like to use my dog's leash with beacons to track retrieving my dog's leash to achieve being...

**Vera**  
 "Aware people for dementia"  
 Age: 62  
 Work: Part-time at local shop  
 Family: Married, kids  
 Location: Essex, UK  
 Personality: Extrovert

**Bio**  
 Vera is Fred's wife. She is 62. She is the local shop. She really enjoys massages. She volunteers at awareness for dementia and she likes baking and watching show, and she has regular coffee volunteering at Oxfam.

**Goals**  
 • Raise awareness for dementia and cognitive impairments.  
 • Keep an eye on Fred.  
 • Keep a routine for Fred.

**Activities**  
 • Go to local swimming club and do aqua aerobics  
 • Girls days out...

**Technology at home**  
 • Smart Phone with Bluetooth for car  
 • Tablet  
 • Laptop  
 • Desktop  
 • Smart TV  
 • Video Entry System  
 • Remote Gates  
 • Car "Wife Positioning System"  
 • Sat/Nav  
 • Beer Fridge

**Fred**  
 "Keep being social"  
 Age: 68  
 Work: Retired, Train Driver  
 Family: Married, kids  
 Location: Essex, UK  
 Personality: Extrovert

**Bio**  
 Fred was working as a train driver. He has two kids, a son and a daughter in their 40s who live in Hong Kong and Miami respectively. 5 years ago, he was diagnosed with cognitive impairments and it is getting worse since then. Fred is very social, he likes to go out for dinner with his buddies and he enjoys train-spotting, walking his dog and gardening. He never says no to a quick cheeky pint at the local pub. Sometimes he feels quite lonely, now that his kids have moved quite far away.

**Goals**  
 • Keep being social.  
 • Maintain relationships with family.

**Activities**  
 • Gardening  
 • Walking dog  
 • Seeing best friends at pub  
 • Befriending at local voluntary center  
 • Go to train museums  
 • Go to local allotment clubs  
 • Take part in vegetable competitions

**Steven**  
 "Keep being social"  
 Age: 64  
 Work: Retired, Fashion Designer  
 Family: Married, kids, grandkids  
 Location: Goodwood, UK  
 Personality: Extrovert

**Bio**  
 Steven was working as a fashion designer. 7 years ago, he started having difficulties in buttoning up shirts at work and he was then diagnosed with Parkinson's. Steven is very social but he is having some difficulties to communicate with family and friends. Therefore, he needs to change mode of communication.

**Goals**  
 • Keep being social.  
 • Improve his putting.  
 • Maintain relationships with family.  
 • Feel less tired.

**Activities**  
 • Putting  
 • Use public transport  
 • BBCs  
 • Golf  
 • Go on holidays  
 • Bridge  
 • Attend GP appointments  
 • Shaving  
 • Dressing

**Technology at home**  
 • Smart Phone with Bluetooth for car  
 • Tablet  
 • Laptop  
 • Desktop  
 • Smart TV  
 • Video Entry System  
 • Remote Gates  
 • Car "Wife Positioning System"  
 • Sat/Nav  
 • Beer Fridge

**Pat**  
 "Continue with my career"  
 Age: 45  
 Work: Chief Executive at NHS  
 Family: Divorced  
 Location: Canary Wharf, UK  
 Personality: Introvert

**Bio**  
 Pat is working as a Chief Executive for NHS and she is very comfortable with technology. She was diagnosed with Parkinson's 2 years ago when she started having problems with the voice recognition system at work. She has a very busy lifestyle with no time for hobbies, just some private Pilates classes. She has a cleaner to do all her housekeeping and gets all her clothes dry-cleaned.

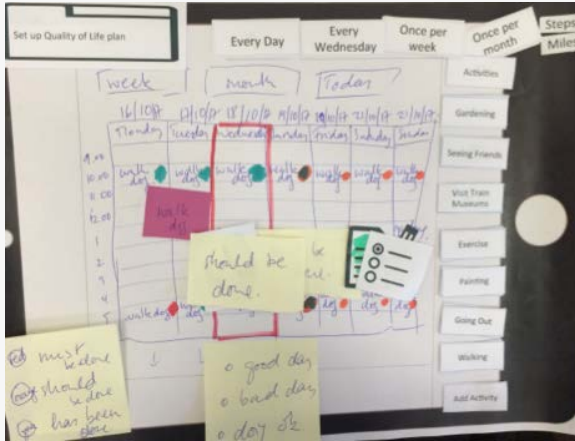
**Goals**  
 • Continue with her career.  
 • Manage her stress.  
 • Balance work and personal life.  
 • Feel less tired.

**Activities**  
 • Go on business trips  
 • Pilates  
 • Dating  
 • Sleeping  
 • Grooming for professional appearance

**Technology at home**  
 • Smart Phone  
 • Tablet  
 • Laptop  
 • Fitbit  
 • GPS  
 • (Personal) Alarm System  
 • Smart Metering  
 • Microwave  
 • Smart Fridge



# Designing and evaluating (Workshop 3 and 4)



## What we learned:

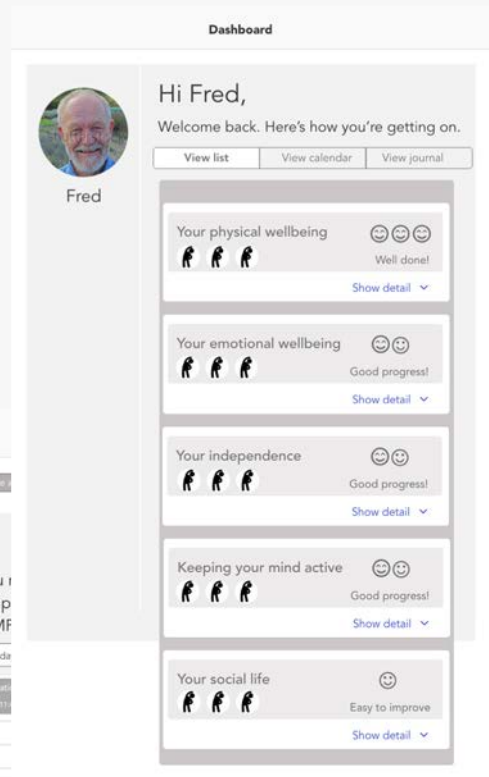
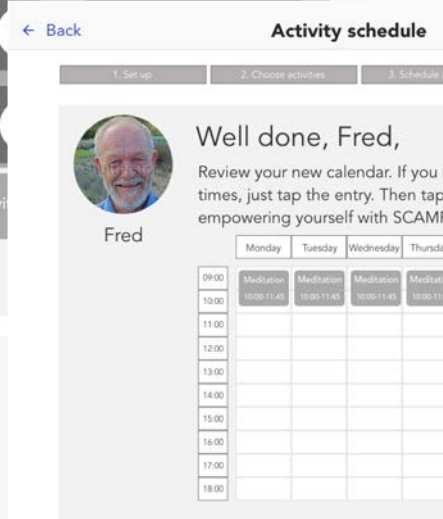
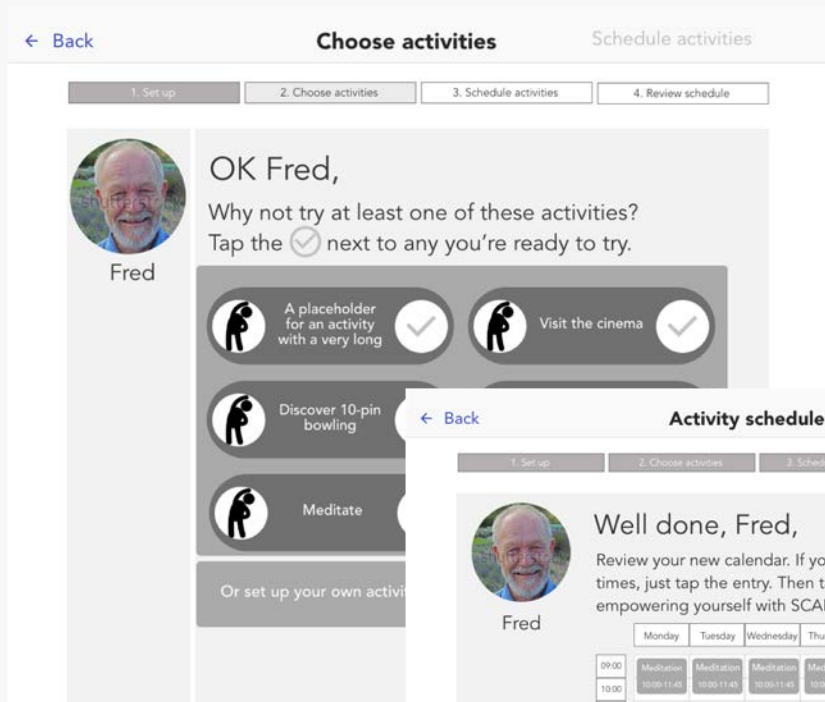
- Personas extensively used during paper-prototyping and evaluating
  - “What would Fred want?”
  - “I don’t see how this could help me but I think it would definitely help Steven”.
- Need to scaffold designing and evaluating



# The UI

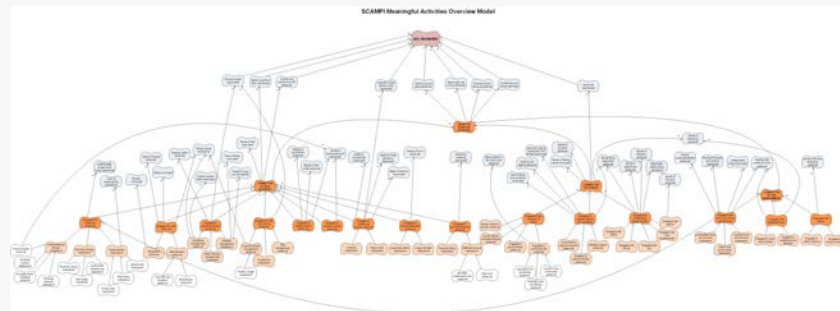


User Interface to  
manage and  
monitor quality  
of life



# Quality of Life model and reasoning

- Co-design with formal carers
  - Models for dementia and Parkinson's
  - ~800 known activities and their relationship to 8 high-level goals
- Reasoning engine to determine goal achievements
- Same engine used to suggest other activities to try



[Lockerbie and Maiden CAISE 2019]

# Sensor-based activity recognition

- Many challenges!
  - Hardware unreliable
  - Placement difficult
  - Multi-occupancy households
- Activity recognition is hard
  - RNN ~ 66% accuracy
  - SVM ~73% accuracy
  - But RNN's sensitivity is better



[Tewell et al. PUC 2019]

# Coming up...

- Field trials – Now for 8 weeks
- Commercialisation



# Conclusions

- Co-design is challenging but can lead to fantastic results
- Co-created personas are worth trying with your user group
- AI-assisted healthcare solutions need to be carefully designed and deployed into everyday practices