



UCL

A view of the health of people both inside and outside hospital

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The studies

How do people live their lives with technology?



- Home hemodialysis
 - Interviews and observations with 19 participants across 4 hospital trusts
- Diabetes management
 - Interviews and diary studies with over 40 participants in UK, US, Canada
- Medication management
 - Survey of strategies and app use, over 1000 respondents
- Use of Patient Controlled EHR
 - Interviews with 16 families
- Use of mindfulness app
 - Pre- and post-use interviews with 16 participants

Patients... or people?

- “Unit patients live to dialyse, home patients dialyse to live” (technician)
- “now I’ve come home, I’ve got my life back, and I fit the dialysis around my life” (person with CKD)



When health management is not optional...



- People are living their lives and finding ways to fit health management (and device use) into lives
- This can be an almost constant struggle
 - E.g. working out insulin dosing when timing and content of meal are unusual
- Poor design results in workarounds and non-adherence
 - E.g. speeding up start and finish of hemodialysis cycle; patching up tubing
 - E.g. not carrying blood glucometer / insulin

Safety and user experience

- Managing technology glitches
 - *“Never been so glad to be in the pharmacy!! Batteries in my meter died this morning right before I taught class WOW. Made it through yay!!”*
 - Improvising to deal with kink in line
- Avoiding unintentional non-adherence
 - Habits and external reminders
- Trying to live lives to the full
 - Insulin pumps interfere with sports and sex
- Living with the load of responsibility
 - *“Scared that the children would blame me if anything happened”*



People... or individuals?



- What conditions people are managing (if any)
 - CKD / diabetes / hypertension / weight / stress ...
- Their values and interests
 - Karl dialyses on his verandah
 - Emma doesn't test her blood sugar on a first date, whereas Diane tests blood sugar to test the new partner
 - Jemima runs for the sheer pleasure of running, Angeles want to improve her performance, Brian is concerned about his blood pressure, Colin wants to lose weight...

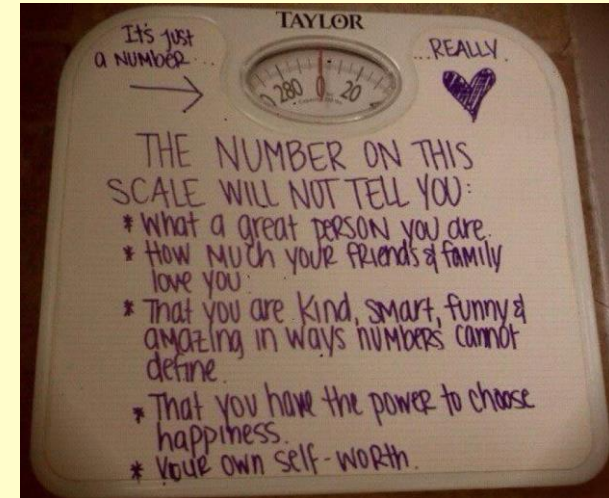


What technology works...

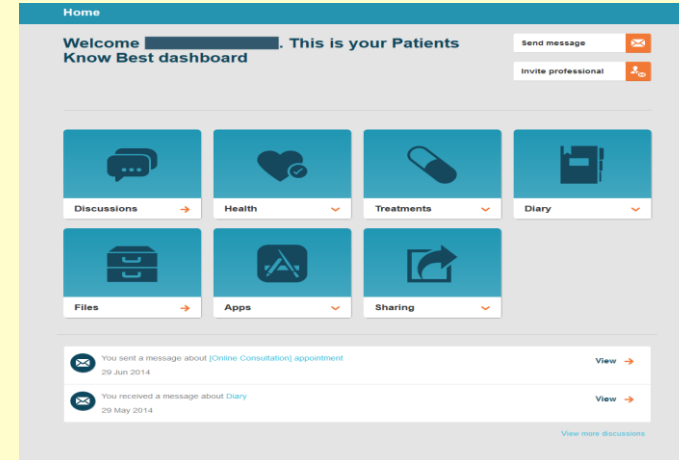
- Jemima doesn't need anything: the feedback from her body is enough.
- Agnes wants performance measures and a way to compare her performance over time
- Brian wants occasional feedback on his cardiovascular health and needs encouragement to persevere
- ...etc....

Individual attributes

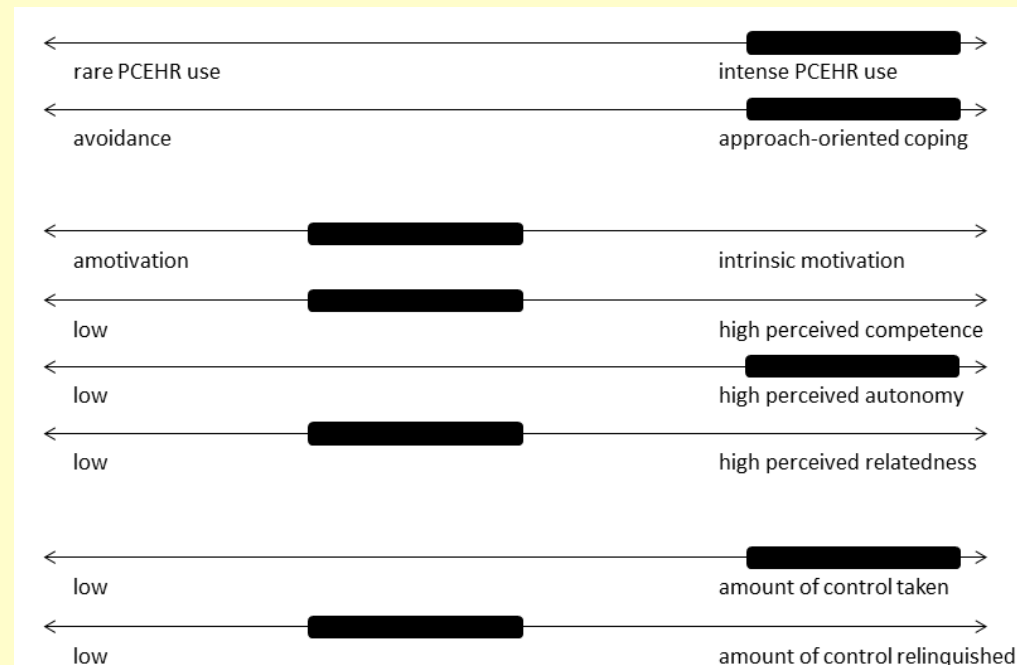
- Attitudes to quantification
- Engagement with digital technologies
- Interest in health
- Knowledge of health condition(s)
- Self-efficacy / sense of being empowered
- Coping style
- Lifestyle



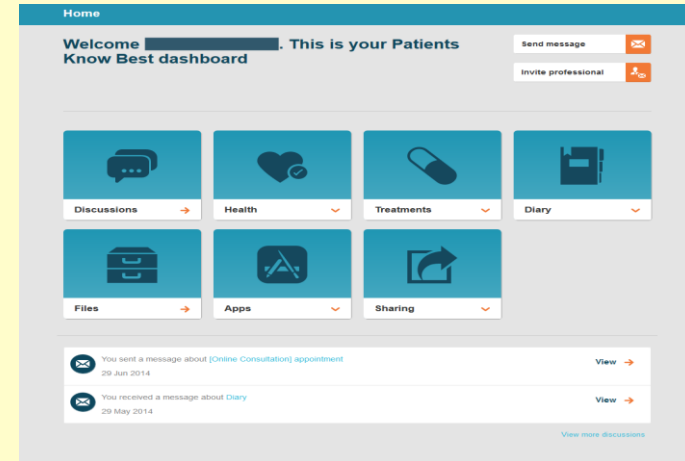
Engagement with a PCEHR



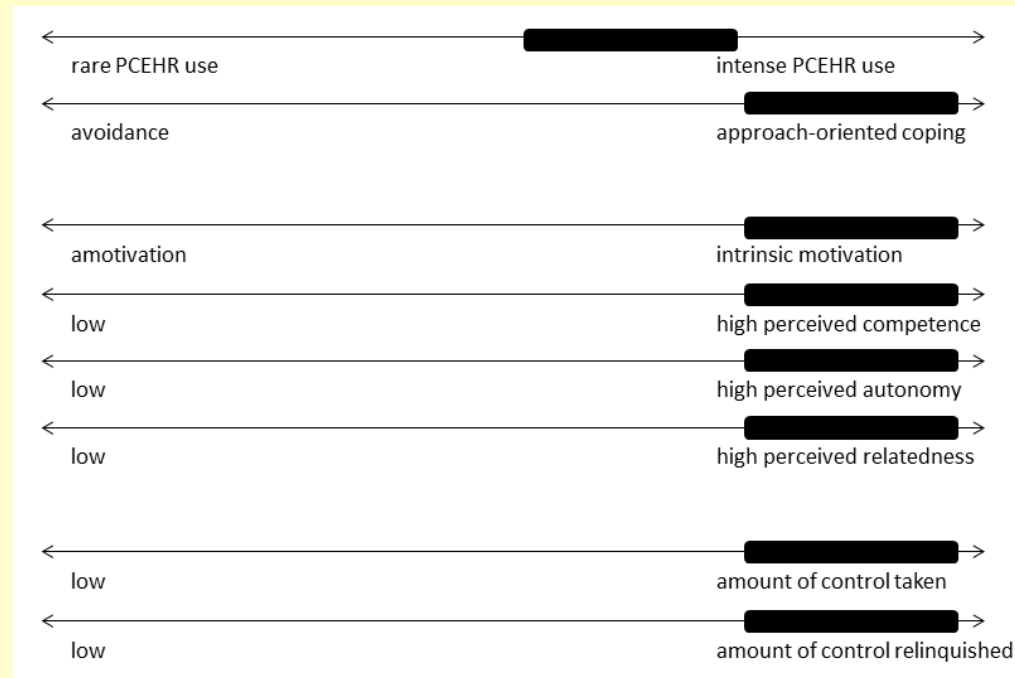
- Identified four groups of participants:
 - controllers,
 - collaborators,
 - cooperators,
 - avoiders



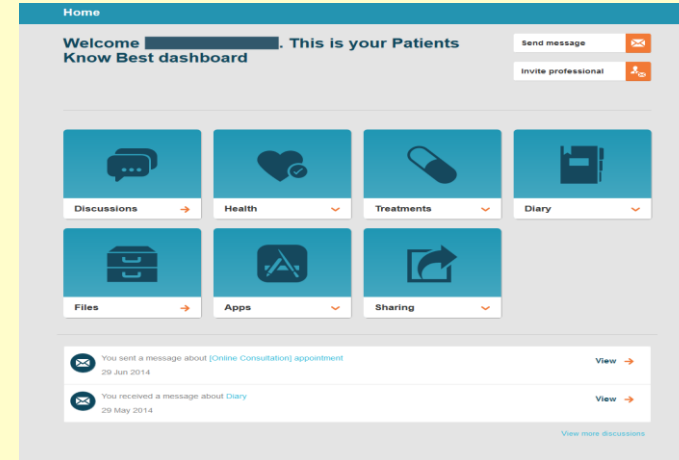
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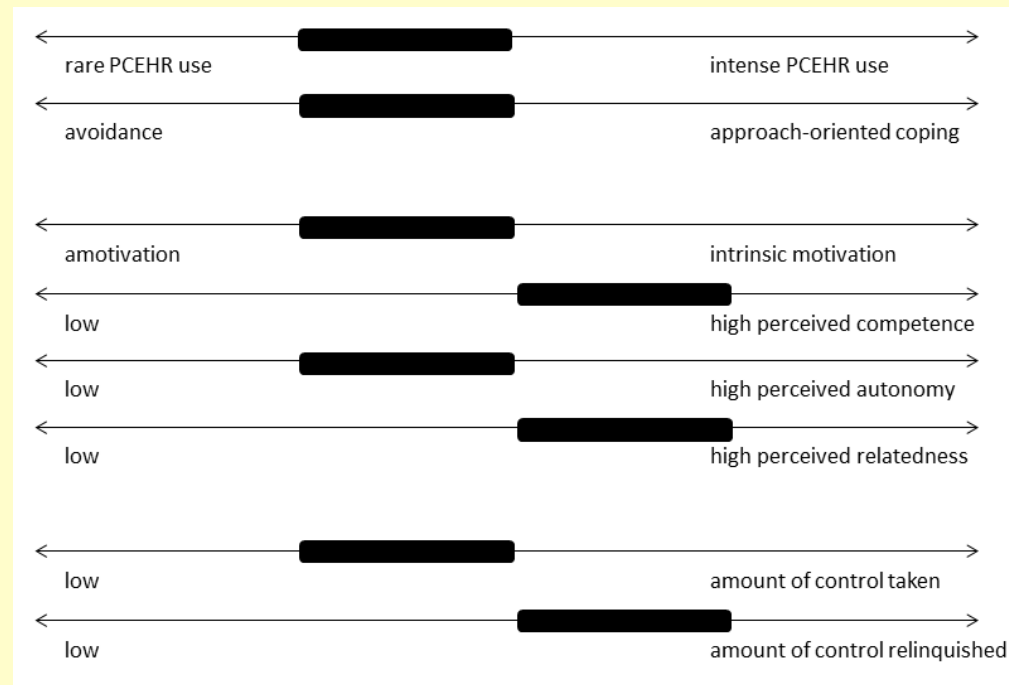
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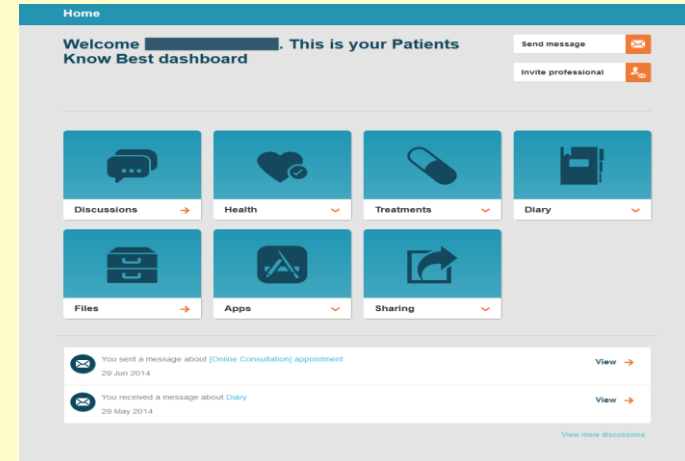
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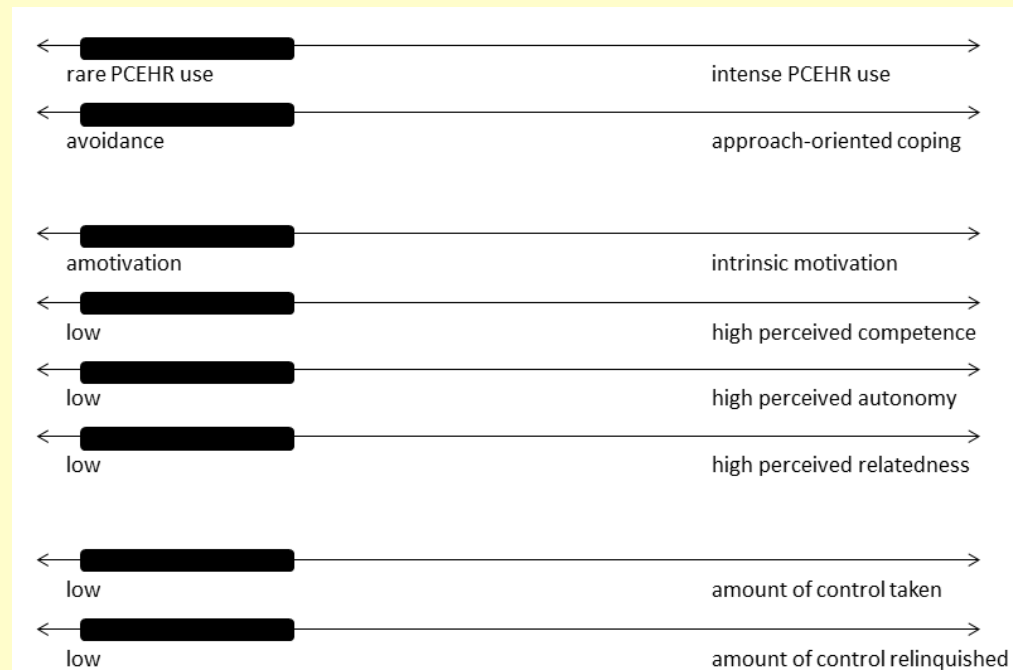
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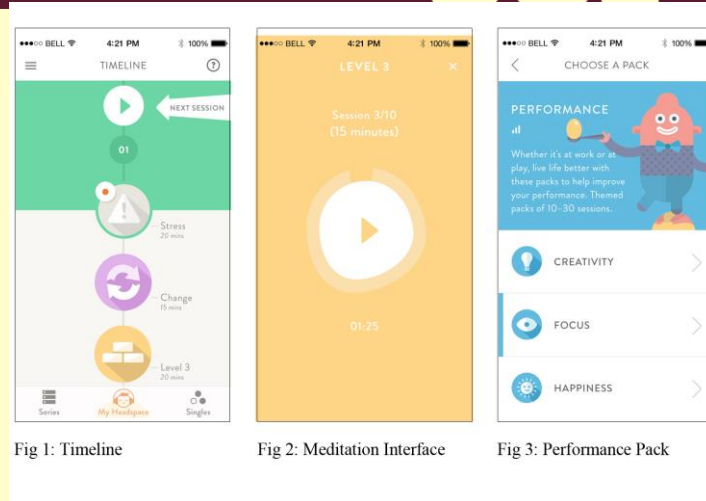


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Making time for mindfulness

- App on phone was portable, but not every place was suitable
- App interfered with other phone functions
- Making time was often difficult
 - “I would get into the routine of it for several nights a few nights and I would do it every day and then I would get out of it and there would be a whole week where I wouldn't have used it and I'd be like ‘dammit I want to use it more.’”



So what?

- Health technologies need to be fit for purpose
 - Clinically effective
 - Fit with people's lives, practices and values
- One size does not fit all
 - Need to design for different 'markets' / audiences
 - Need to support (appropriate) personalisation

Thank you!

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This is not a lecture on behaviour change 😊

