THE UNIVERSITY OF STRATHCLYDE

Brain Health (and dementia) Technologies: do we really need codesign?

Technologies for Brain Health

Scottish Dementia Research Consortium Workshop

Dr Kieren Egan

Monday 13 June 2022

Overview

1. What is co-design: using a worked example
2. What are our collective objectives for technologies in brain health and dementia?
3. Do we really need codesign? Challenges and opportunities
4. What are the next key questions for codesign in Brain Health and dementia?

1. What is Co-design? (and a working example)

Co-design

- Co-design is a well-established approach to creative practice, particularly within the public sector. It has its roots in the participatory design techniques **developed in Scandinavia in the 1970s**.

- Co-design is often used as an umbrella term for participatory, co-creation and open design processes.

- The approach goes beyond consultation by building and deepening equal collaboration between citizens affected by, or attempting to, resolve a particular challenge. A key tenet of co-design is that users, as 'experts' of their own experience, become central to the design process.

Design for Europe (sunlight foundation)

Co-design

Key components of a co-design process should involve:

- Intentionally involving target users in designing solutions
- Postponing design decisions until after gathering feedback
- Synthesizing feedback from target users into insights.
- Developing solutions based on feedback

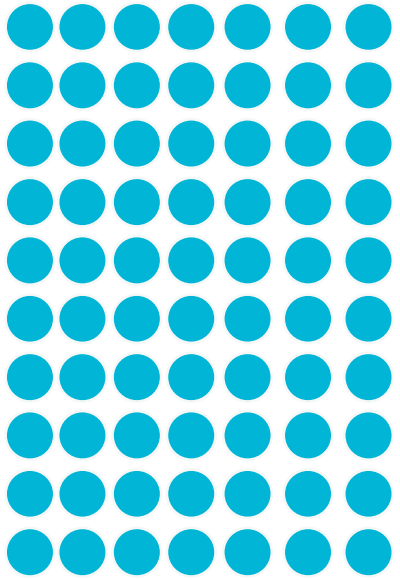
Design for Europe (sunlight foundation)

Codesign- an example from Carers and physical activity

Monday 13 June 2022

Context and Background: caring

NHS staff in Scotland
Approximately **140,000**



Informal Carers in Scotland
Approximately **700,000**

● 10, 000 people

Source: NHS Scotland Website (About NHS Scotland – Scotland's Health on the Web)

Context and Background: caring

4 in 5 unpaid carers (81%) were providing more care than before lockdown.

More than three quarters (78%) of carers reported that the needs of the person they care for have increased recently.

Isolation
Pressure on individuals and healthcare service
Becoming the “face” of rules and measures

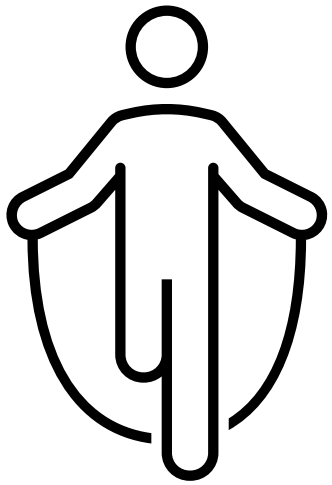
Empowering tools
support self-management
Increase carer health and wellbeing

Context and Background: caring

- The 2019 State of Caring survey (Carers UK) found that 81% of carers of all ages are not able to do as much physical activity as they would like.

- Systematic review work in this area identified only 14 studies to date with interventions mainly delivered face to face and/or by telephone-based approaches. Across these studies, improvements were observed in physical activity levels, distress, well-being, quality of life, and sleep quality. Such targeted solutions are yet to make the “leap” into the digital spectrum and mass impact potential of smartphone apps.

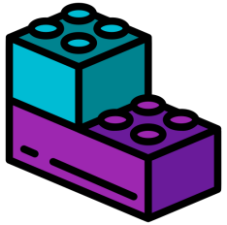
- U.K. National statistics report that four in five carers use digital technologies.



Codesigning an app for physical activity

1. Collate knowledge and identify needs

- Examine relevant behavioural change literature and activity guidelines
- Establish an expert group (including carers) to establish how to deliver current scientific knowledge around physical activity to carers (e.g. using U.K. physical activity guidelines). Key themes were identified through exploring follow up questionnaire feedback.



2. Build it

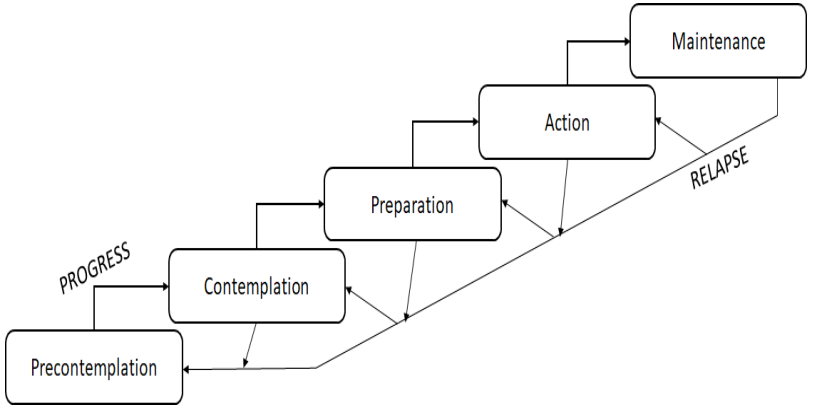
An “android” smartphone-based application, ‘CareFit’, instructed by the needs of carers and carer professionals, that could support caregiver physical wellbeing on a regular basis both during and beyond the COVID-19 pandemic.

3. Test it

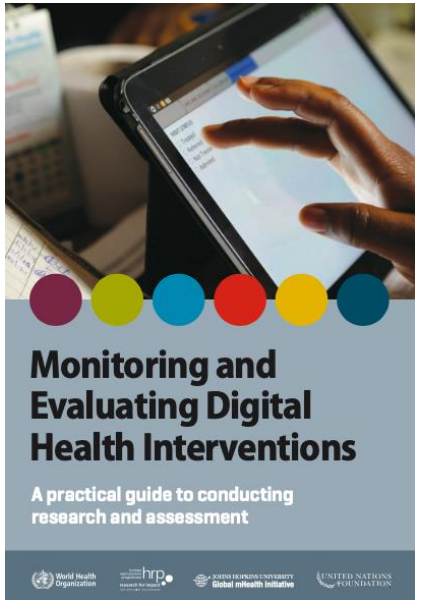
The codesigned developed smartphone app for a period of 3 weeks across Scotland to understand whether the concept could work in practice, and examine to whether caregivers could accept and see value in the overall approach.

Codesigning an app for physical activity

Physical activity guidelines

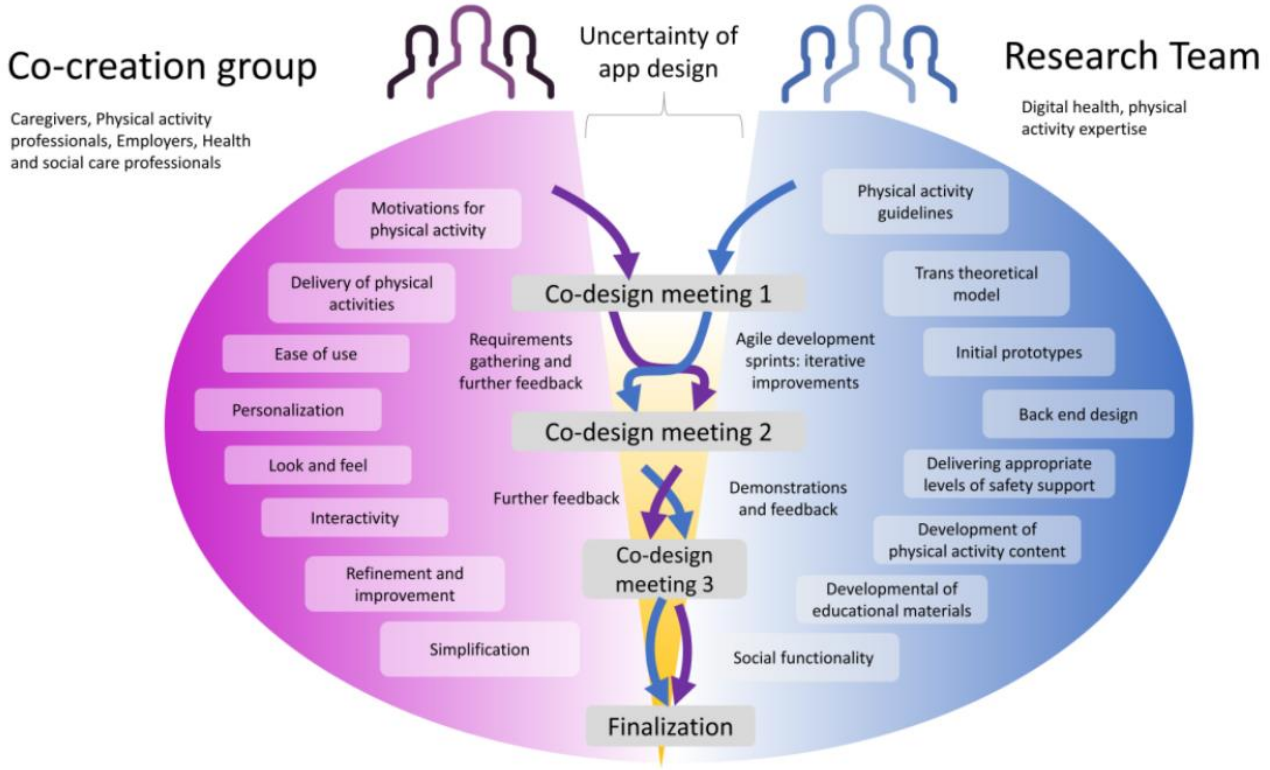


Transtheoretical Model



Frameworks for the development of Digital Health Interventions

Codesigning an app for physical activity



A strong emphasis on codesign

Codesigning an app for physical activity

Sprint (number of questionnaires completed)	Focus/aim	Detail of meeting used to guide sprint
1 (N=5)	To critique and present a simple initial app prototype; to collectively present the principles of the transtheoretical model (TTM) and the UK government national physical activity guidelines.	We explored the topics of motivation, goals, physical activity guidelines, delivery options, health, and safety. We also explored "keep, lose, change," and asked our participants to prioritize needs according to the MoSCoW[a] methodology.
2 (N=6)	To review the feedback from meeting 1 and progress during design sprint 1.	We explored how to deliver details within the educational, physical activity, and communication components, including the "keep, lose, change" format. We presented future options of the physical activities using videos and subsequent feedback.
3 (N=6)	To review and finalize the app design in preparation for a 3-week real-world study.	Final, detailed discussion on the presentation of the revised app developed, and further discussion of the education, physical activity, and communication sections.

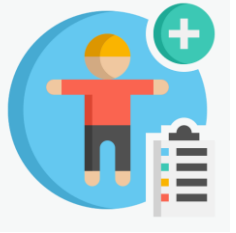
MoSCoW: "Must Have, Should Have, Could Have, Won't Have this time" prioritization.

Codesigning an app for physical activity

7 Carers & Care professionals involved in the design of the app

8 Carer focused Educational sections developed

9 Carer focused Physical activity sections



Our final prototype was therefore designed for use across 3 weeks including:

- A main menu screen with 4 different navigation options: planner, education, reminders, share progress and user guide.
- 8 educational “stages”: (1) Welcome and Introduction (2) Physical activity: Beginners Guide” (3) “Relationships and” Physical Activity”, (4) “Managing time”, (5)“Goals and Rewards”, (6) “Physical activity and consequences” , (7) “The Mind and body” and (8) “Knowledge Quiz”
  - Cardiovascular activities (Step workout, squat workout, march workout that have three levels of intensity of low medium and high) plus daily activities option where activity took place outside the app delivered elements.
  - Muscle and balance activities (Three different videos working a variety of muscle groups where the user could choose from low medium and high intensity levels)
  - Three sedentary breaker activities (Fast March, Supported sit to Stand, and hold movement) that users were free to choose from.

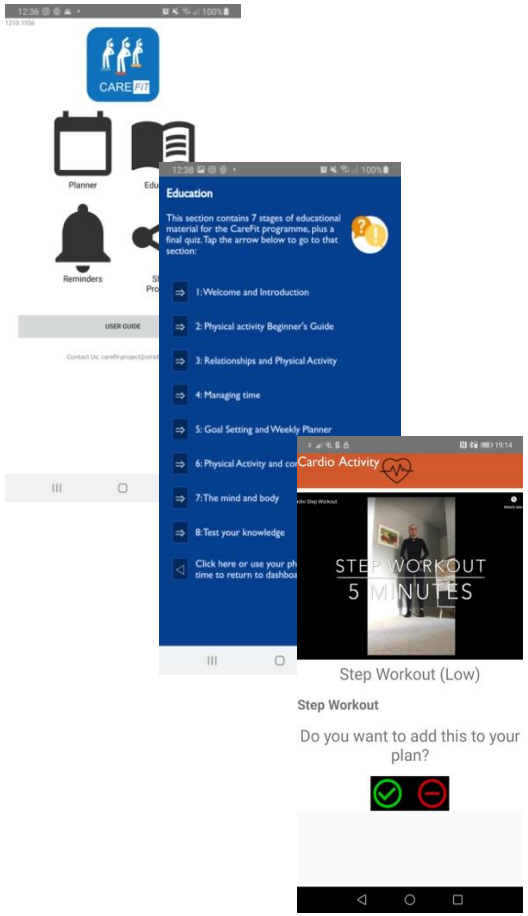
Evaluation: examples from participants

“The app was gently telling me to look after myself. I loved the instructor she just cared.”

“The education part lifted me to feeling I needed this and deserved this. Love the Schedule and the programming”

“I have been trying to lose weight and this app has got me thinking about not only exercise but my diet”

Example quotes from participants



2. What are our collective objectives for technologies in brain health and dementia?

Current landscape: Brain health and dementia

- The number of people in Scotland with dementia is approximately 90,000 where there is a need to support and improve the quality of life as much as possible.
- There are well established pathways for post diagnostic support across Scotland.
- Given that we know dementia begins years if not decades before the presence of behaviours, it is exciting to see recent initiatives such as Brain Health Scotland.
- Collectively, we are now in a position where there is scope for a lifelong path for support in terms of brain health. It is a story of both opportunities and challenges both for public health and research- including through technology innovation.

https://www.gov.scot/policies/mental-health/dementia/#

Current landscape: Brain health and dementia

PROMOTING EXCELLENCE 2021 in partnership with: A framework for all health and social services staff working with people with dementia, their families and carer.

Builds up further knowledge from the previous 3 Scottish Dementia plans

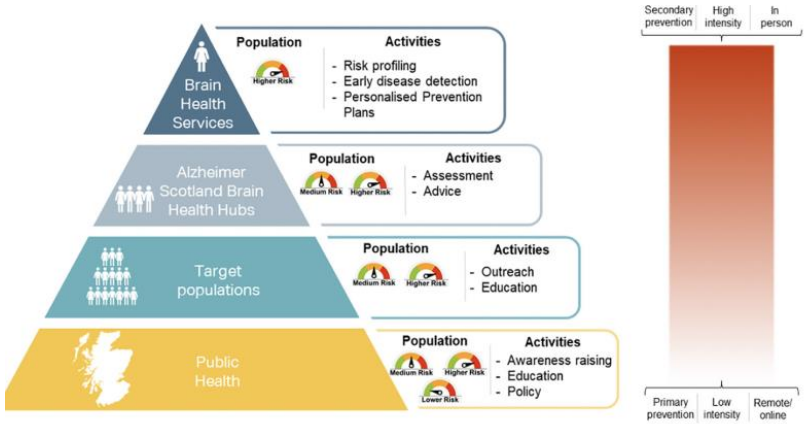
Promoting Excellence 2021: A framework for all health and social services staff working with people with dementia, their families and carers (www.gov.scot)

Current landscape: Brain health and dementia

- Scotland has clear potential for developing innovative and impactive services well before dementia takes place.
- There will also be scope to implement academic science into actionable insights for individuals to manage their own risk in an anticipatory manner.
- What is encouraging is that the public understanding is improving- for example 60% of people in 2018 thought that dementia is not a normal part of ageing vs. 68% in 2021.
- 75% of the public are willing to do something about brain health using their smartphone.
- Need for more personalisation at the individual citizen level

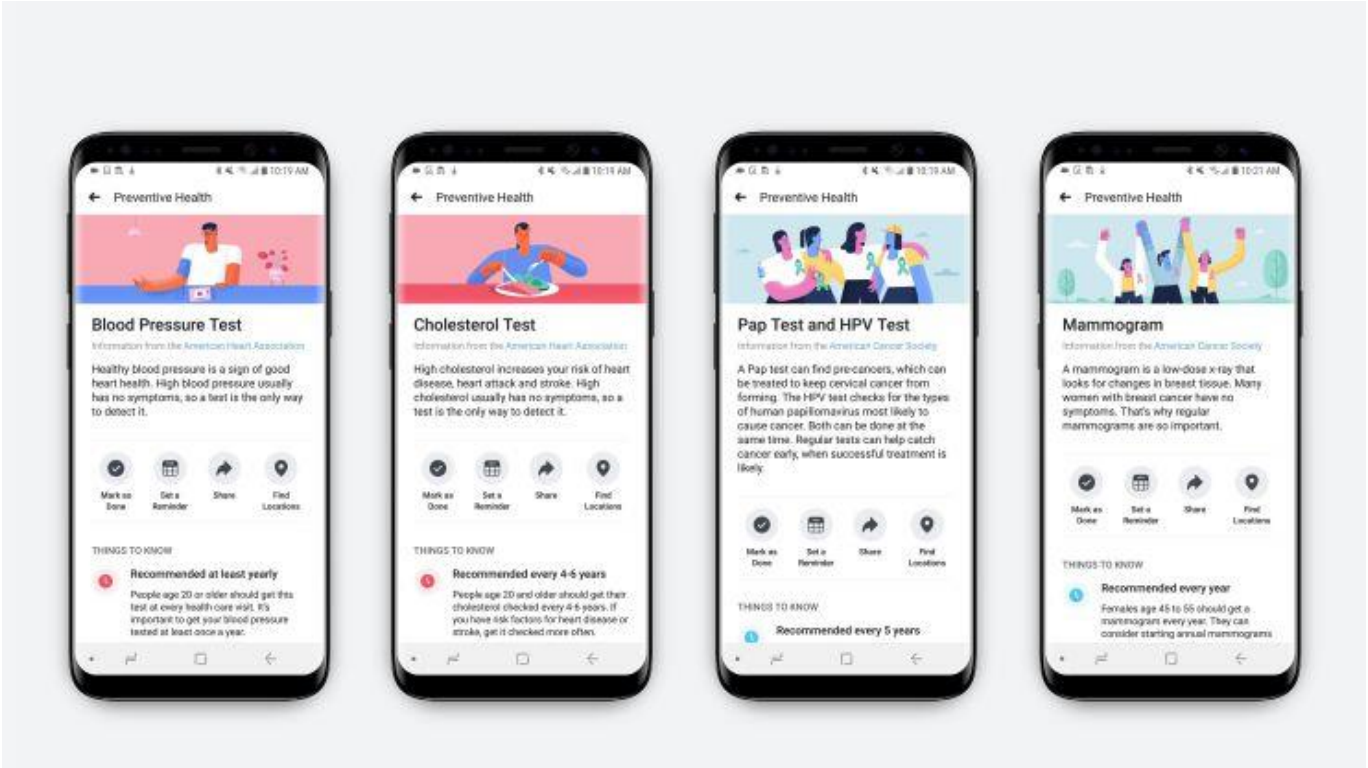
The Scottish Brain Health Service Model: Rationale and Scientific Basis for a National Care Pathway of Brain Health Services in Scotland

C.W. Ritchie[1,2,3], J.M.J. Waymont[2,4], C. Pennington[1,2,5], K. Draper[2], A. Borthwick[2], N. Fullerton[2], M. Chantler[6], M.E. Porteous[1,3], S.O. Danso[1], A. Green[1], L. McWhirter[1], G. Muniz Terrera[1], S. Simpson[7], G. Thompson[1], D. Trépel[8,9], T.J. Quinn[7], A. Kilgour[1,2]



ARUK website

Current landscape: Big Tech



2.7 billion

active users every month

>200 million individuals

in the USA at present

https://preventivehealth.facebook.com/

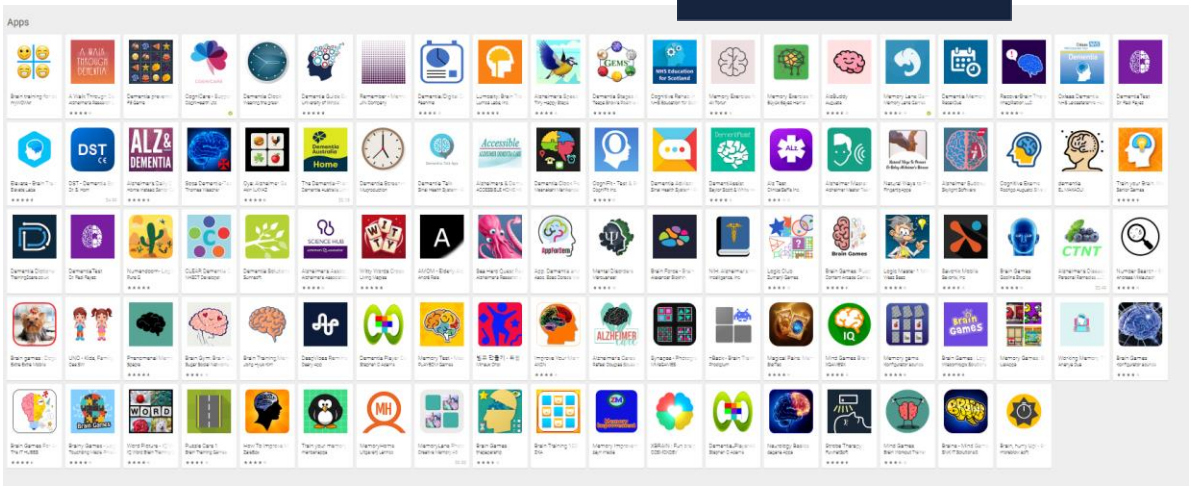
3. Do we really need codesign? Challenges and opportunities

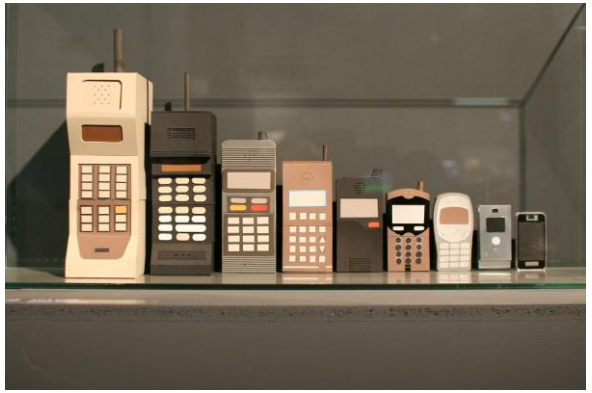
Co-design: reasons that researchers could be put off

- I don’t have enough time
- I don’t have enough resource
- I already know what I am going to do
- I’ve already done it an earlier stage of the research
- I’m worried about recruiting enough variation in the sample or having a big enough group
- I don’t know how I am going to combine different views
- I will be likely to speak to ‘Super users’

Citizens can't find what they need easily

- As a citizen interested in looking after my brain health or quality of life with dementia, I would likely need to:
  - Find what I need (difficult in a crowded marketplace).
  - Trust the information given to me is accurate+ ideally personalised.
  - Have/afford a technology that supports interventions- which often means having a mobile phone no more than 5 years old.
  - Be motivated to keep entering data and/or continuing positive behaviours regardless of my motivation type.
  - For brain health- we may be talking about many years if not decades. <u>It is important that we get the behavioural change science right.</u>

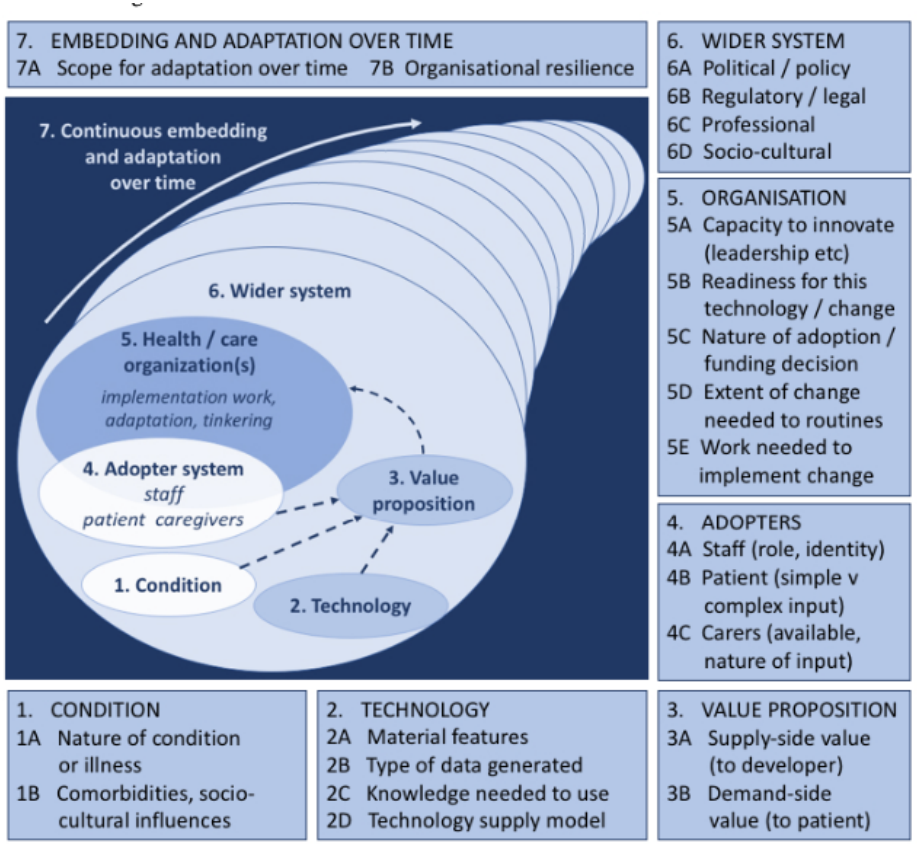




Good ideas can still be difficult to implement

- The NASSS framework was developed to analyse complexity in evolving health and care technology projects.
- NASSS has seven domains, each of which has several sub-domains.

- The NASSS-CAT tool is used to:
  - understand complexity and how it plays out across the system;
  - reduce complexity where possible (including systematically weeding out low-value technologies and high-risk ventures at an early stage); and
  - manage complexity by (e.g.) strengthening individuals' and organisations' capacity to innovate and adapt, building relationships, and harnessing conflict productively



Greenhalgh , JMIR, 2017

Citizens face many different barriers to successfully using technologies

University of Strathclyde Glasgow

Person based

Physical, cognitive and mental

Vision

Hearing

Cognition

Dexterity, fine motor control

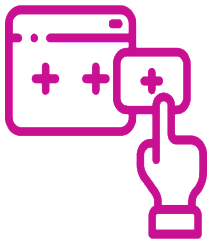
Technology based

Design and support

Lack of human touch

Confidence

Trust & transparency



Familiarity and intuition

+ Motivation

Codesign in practice- we're not there yet

- A research team in the Netherlands did a systematic review of the involvement of people with dementia in developing technologies.
- They found 49 studies involving people with dementia- often in the "generative" or "evaluative" stages of development.
- There is a lack of specific knowledge on appropriate methods for involvement of people with dementia in such studies.
- Impact on technology relatively low (often no changes or one aspect)

Journal of Alzheimer's Disease 69 (2019) 1041–1065
DOI 10.3233/JAD-190050
IOS Press

Active Involvement of People with Dementia: A Systematic Review of Studies Developing Supportive Technologies

Sandra Suijkerbuijk[a,b,*], Henk Herman Nap[a,b], Lotte Cornelisse[a], Wijnand A. IJsselsteijn[b], Yvonne A.W. de Kort[b] and Mirella M.N. Minkman[a,c]
[a]*Vilans, Centre of expertise Long-term care, Utrecht, The Netherlands*
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[c]*Tilburg University, TIAS School for Business and Society, Tilburg, The Netherlands*

4. What are the next key questions for codesign in Brain Health and dementia?

Designing for everyone?

- Vocabulary used around dementia?
- Empowerment? Trusting citizens to manage their own health?
- How do we sustain behavioural change (potentially for decades)?

Designing for selected groups?

- Catering to Physical, cognitive and mental needs?
- Targeting different age groups?
- Digital Divide?
- Socio-economic status?

Methodologies?

- How do we best integrate feedback and co-design input?
- It's unlikely that all stakeholders will agree on all approaches- how to best integrate?

How do we build an ecosystem of change?

- Sustainable? Financially stable innovations?
- Providing choice and personalisation?

Conclusions 1

- The landscape of brain health and dementia is clearly evolving.
- There is a growing interest in ensuring the rights of people with dementia across quality of life, care, level and type of support and the environment supported by policy. This is expanding to citizens/those at risk of dementia.
- There are new avenues to explore in brain health whereby the increasing recognition of brain health and some risk factors will allow unprecedented insights into an individuals risk.
- Such approaches can (and should) be supported with digital technologies wherever this would support individuals to stay well, or increase quality of life.

Conclusions 2

- Co-design can be used to reduce the likelihood of abandonment and help ensure citizens are motivated to use proposed digital health solutions.
- Adherence to behaviours (and/or technologies) for decades is challenging and methodologies are currently lacking.
- There are many varied + tricky problems we need to solve- including ownership, equity of delivery, and influence on overall designs.
- There is increasing evidence codesign examples across a range of digital health studies including work in the physical activity of carers.
- The dementia research landscape in Scotland (and beyond) opens new opportunities for learning in codesign.

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