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## Introduction

How can co-creative research & design methodologies support the development of accessible musical instruments?

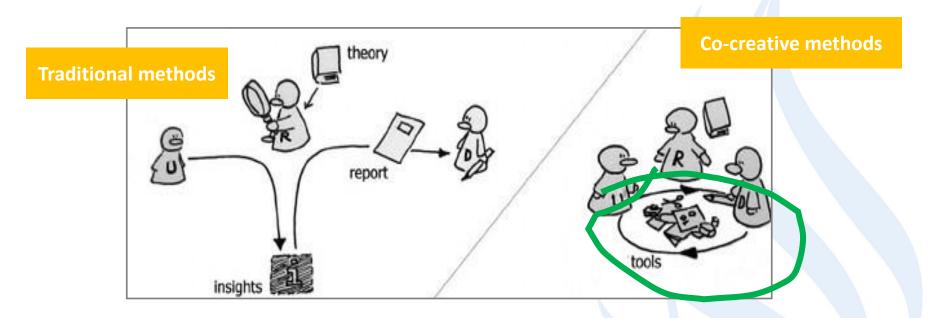




### What is co-creation

Sanders and Stappers (2008; 2014)

"Any act of collective creativity, i.e. creativity that is shared by two or more people"





## **Stages of co-creation**

Pearce and Magee (2024)





### Co-creation vs. 'usual' methods

(Holliday et al, 2015; Holliday et al 2017; Bul et al 2020)

- Traditional research methods can view participants as passive sources of data not active participants
- Focus groups can enforce traditional power structures and it is difficult to include a range of voices within one space
- Doesn't allow participants to fully immerse themselves in the project, or interact with the product/service/solution being designed



## Why co-creation

(Holliday et al, 2015; Holliday et al 2017; Bul et al 2020)

- Ability to meaningfully involve people at early stages of the design process and throughout
- Allows people the space to play and explore the possibilities of the solution being developed
- Inclusive to a range a communication preferences
- Inclusion of a range of perspectives
- Development of original, innovative ideas
- Can save time everyone in one space, creating together
- Improved match between citizen need and end-product
- Reduces risk when launching products/services



### What do co-creation methods look like?

Loisel, Agnello & Chastin (2022)















# How can we use co-creation to develop accessible products and research?



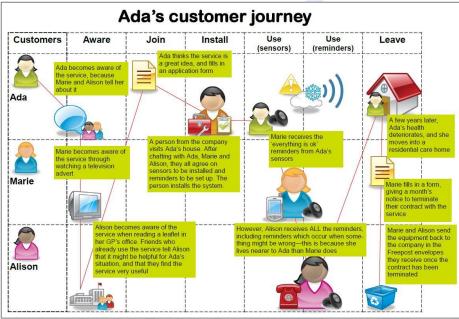
- Development of a new technology service for older/vulnerable people and their carers
- Development of a new intervention and trial



# Development of an accessible technology service for older and vulnerable people

Ward et al (2015)







# Development of an accessible technology service for older and vulnerable people

Ward et al (2015)





Your friend is active

Your friend is inactive

Your friend's house is cold



# Developing an accessible and acceptable feasibility trial for people living with POTS



- The aim was to co-create a feasibility trial protocol and a rehabilitation intervention for people living with POTS.
- 18 patients/carers attended the codefine session (tele-conference), and 16 co-creators with a mix of expertise attended the subsequent co-design and co-refine sessions (co-creation workshops & meetings).



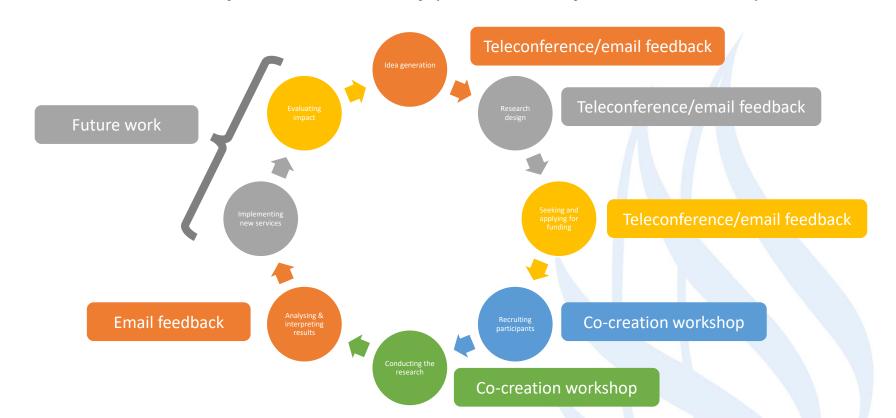
## **Case Study**

- An active living intervention designed by people with POTS, for people with POTS
- Postural Orthostatic Tachycardia Syndrome (POTS) can seriously affect well-being and quality of life, due to its many disabling symptoms. The condition mostly (but not only) affects women aged 13 to 50. People with POTS have an abnormal heart rate rise when they stand up, with symptoms including palpitations, dizziness, fainting, and long-lasting fatigue. Attending education, earning a living, and caring for dependants can be severely affected, and the impact on the healthcare system is significant.
- Medical treatment is not always effective for POTS, but active living interventions like exercise may help some people. We aim to find out if people with POTS will enrol on, and complete, a supervised exercise programme.



# Developing an accessible and acceptable feasibility trial for people living with POTS







## **Case Study: Co-Define Stage**

- Teleconferencing was used to include people with POTS across the UK, including those who
  would struggle to travel... People unable to attend were invited to provide feedback via email
- Explored: Research needs, appropriate exercises for this patient group, terminology recruitment methods, inclusion & exclusion criteria, important outcome measures
- Two members of the group provided feedback on the research grant funding application and become members of the trial management group after funding was secured from the British Heart Foundation



## **Case Study: Co-Define Stage**

- Key findings from the Co-Define stage:
  - Research topic important area of study exercise and increasing activity was important to the patient group
  - Concerns about language use avoid using the word 'exercise' as this could suggest vigorous levels of activity, which could be off-putting for this patient group. Focus should be on movement based activities with slow progression. Course should be tailored to people's needs
  - Pacing and other psychological techniques are important to ensure any increase in physical activity is manageable within daily routines
  - Practitioners should receive specialist training to enable them to appropriately support common comorbidities with POTS such as hEDS/HSD and CFS/ME, where inappropriate support can exacerbate symptoms
  - Preferred delivery model of the trial would be a mixture of group and one to one sessions supervised by healthcare professional who "listen to people living with POTS and understand the everyday challenges they face"



## **Case Study: Co-Design Stage**

- Wider stakeholder group took part in our co-design workshop: people living with POTS, clinical exercise physiologists, researchers, health psychologist, nurses, charity representatives, healthcare professionals delivering POTS services, physiotherapists, patient services coordinators, designers, project managers.
- Explored: concerns raised in the co-define session (worries about the intervention, use of language in the study), trial participant recruitment, intervention design, outcome measures





## **Case Study: Co-Refine Stage**

The PostUraL Orthostatic Tachycardia Exercise study (Pearce, Holliday, Sandhu et al, 2023)

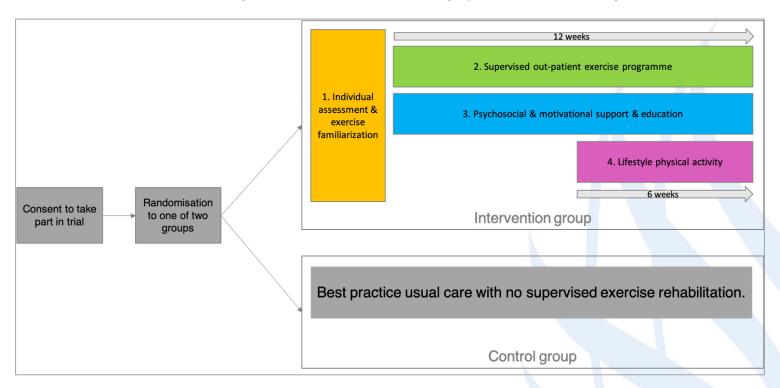
3 co-refine rounds: (1) online workshop to gather feedback on the draft co-designed intervention (2) online workshop to further refine the intervention in response to Covid-19 guidelines, and (3) further development of a Intervention Manual for staff, including staff

training.





## How did our co-creation impact on our project?





## A case study from a student

#### Golden Lane Housing, UK

"As a Regulated Social Housing Provider, Golden Lane Housing is constantly looking at ways to improve our consultation and involvement with tenants. As we work directly with autistic people and people with a learning disability, we are constantly looking at ways to make discussions about their housing accessible. After attending the CoCreating Wellbeing Course at Coventry University, I was able to put in practice new and creative ways to engage with both our current tenants and any prospective tenants to Golden Lane Housing"



## A case study from a student

#### Golden Lane Housing, UK

- Since July 2023, I have managed to develop consultation resources for Golden Lane Housing to use in working with current and prospective tenants. The aim of developing these new resources were to make conversations about housing more accessible, to engage with more tenants, and to help our tenants develop better ways of communicating to us about their homes.
- I created separate rooms and used prebuilt houses to help explain our role as Landlord. By doing this families and tenants could tell me what is important for them in their home for example showing they wanted a bath not a shower or that they didn't want a bedroom upstairs. One prospective tenant, who I was told always throws anything in front of him, sat with me the whole time while I showed the Lego rooms and people.
- I used the minifigures to explain who comes to the house, how Golden Lane Housing works and checking when people come to the door. This helped raise our tenant's awareness further about how to keep safe. I also used small tubs of loose Lego to get prospective tenants and their circles of support to talk about living with other people and shared housing, this meant having good open discussions and lots of laughter.



# A case study from a student

### **Golden Lane Housing**







## **Summary**

- Co-creation methods can support the development of accessible products and services
- Key stakeholders important to accessibility feedback should be included from the very start of the project to ensure that important voices are heard
- People should be involved in a meaningful, and not tokenistic way – again, just checking in every now and then to get user feedback leaves you at risk of developing a product that is not fully inclusive.





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