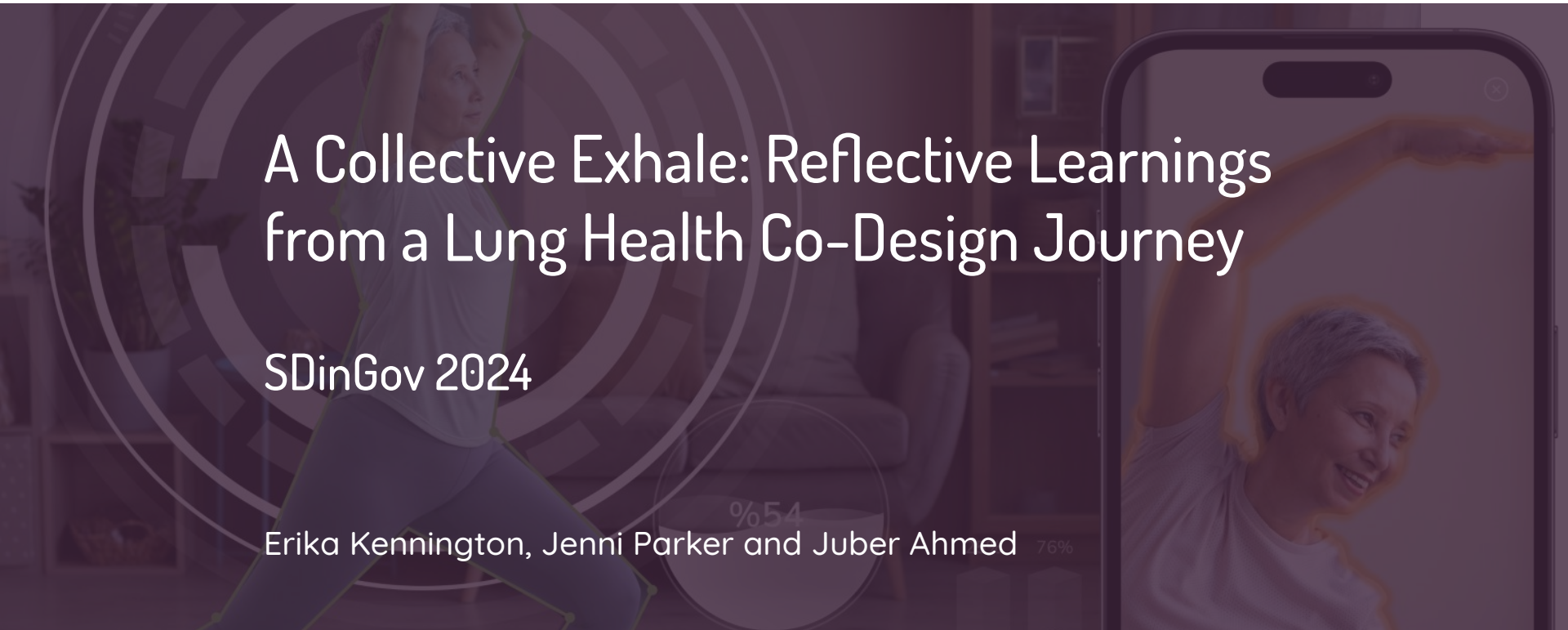


A Collective Exhale: Reflective Learnings from a Lung Health Co-Design Journey

SDinGov 2024

Erika Kennington, Jenni Parker and Juber Ahmed

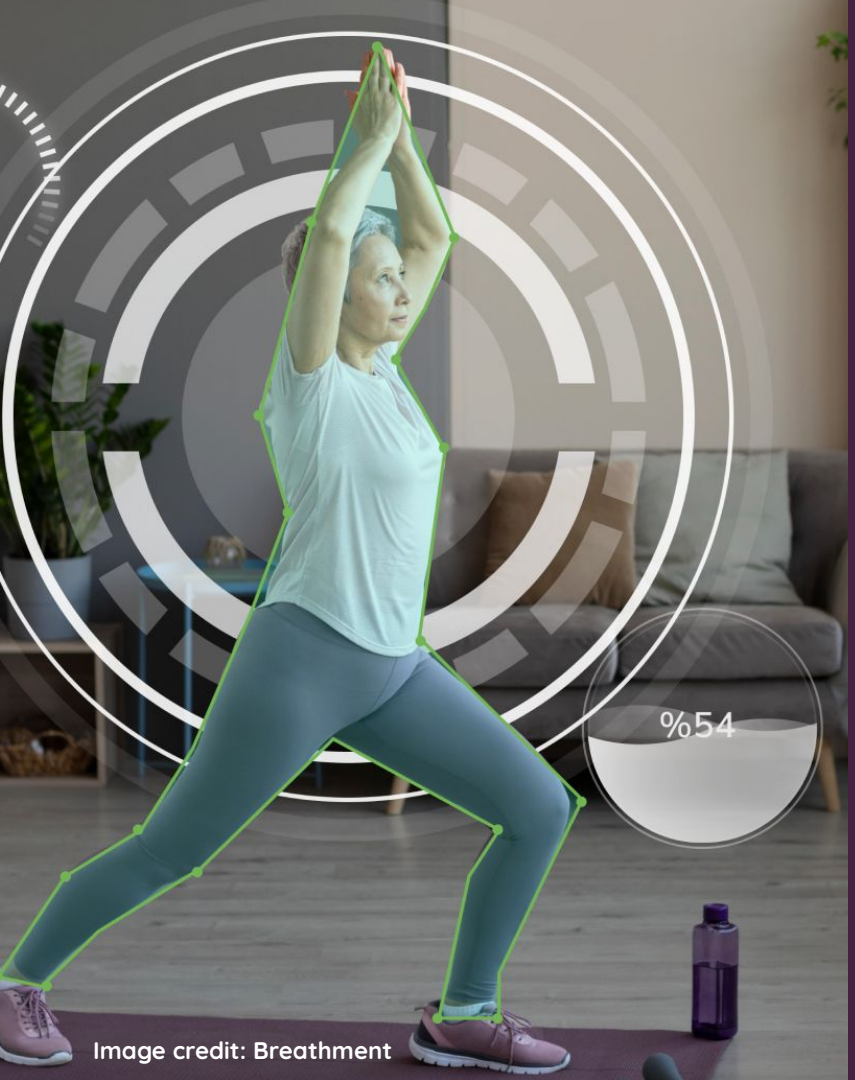


Image credit: Breathment

What we'll cover

1. Why a new approach is needed
2. The Innovation Accelerator process
3. How this will add value
4. Questions

About us



Juber Ahmed, he/him

Co-designer

Background in IT and a popular travel vlogger.

Passionate about the potential for innovation to improve the lives of people living with lung conditions, as he does himself.



Dr Erika Kennington, she/her

Head of Research at Asthma + Lung UK

Background as a published researcher across a number of biomedical and health disciplines.

Erika regularly comments on respiratory research in national and regional media.



Jenni Parker, she/her

Founder and Director of Humanly

Background in design.

13 years of working with a wide range of people in design for social impact projects

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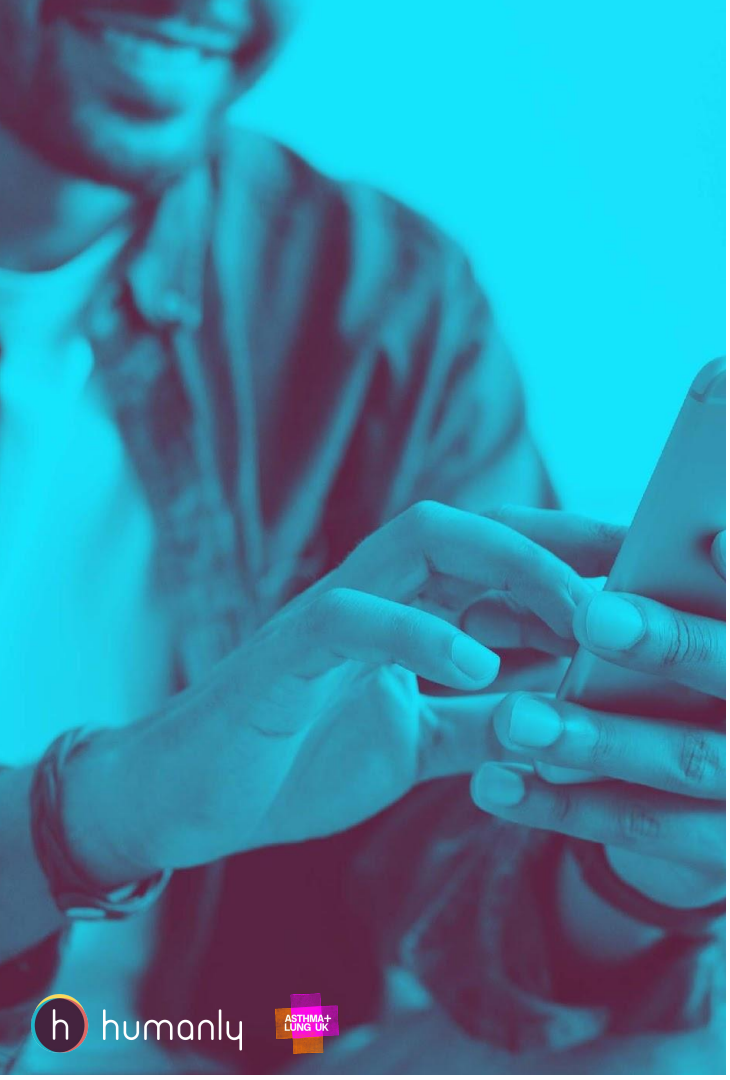
Why:

Why a new approach is needed

The Challenge - Self-management

- **12 million people in UK (1 in 5) will experience a lung condition.** For the vast majority, this persists for years or even decades.
- **Over half of asthma deaths are considered 'preventable'** because **effective self-management** should have prevented them.
- Good self-management keeps many people out of hospital, including winter admissions = **potential cost-saving for the health service**.





We want to see self-management tools in the hands of over 2 million people with lung conditions.

100s of apps, devices and products have been developed to encourage and support self-management for lung conditions.

Yet none of these are widely adopted or used at scale.

A+LUK Innovation Accelerator

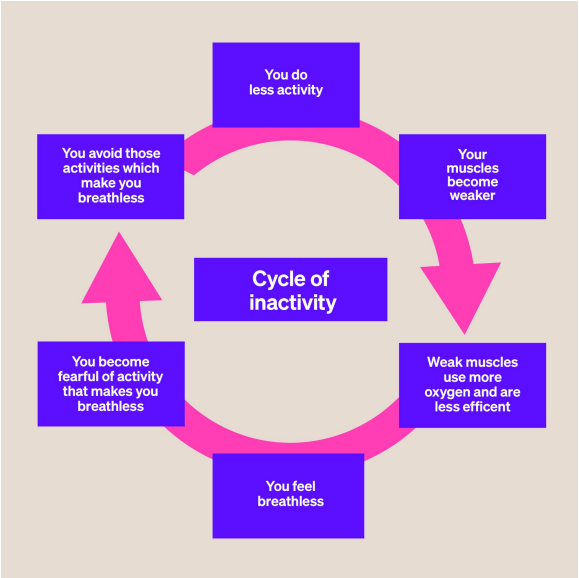
- The Innovation Accelerator aims to give respiratory innovations a **boost towards this goal**.
- We know that many **existing self-management tools are not developed or tested with target users** - hence are not fit for purpose.
- Aimed to identify **new, early-stage technologies that people want to use**, and to deliver a programme of **user experience testing and feedback** to improve the products - aiming to increase the potential for real-world impact of tech.



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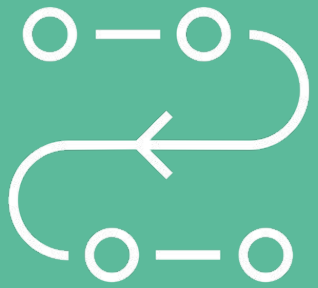
Selecting a theme and partner

- We chose a theme: **‘moving more’.**
- Selecting a theme allowed us to define parameters, focus efforts and maximise impact, ensuring the programme addressed a true unmet need.
- We chose a partner: through a tender process, we selected Humanly.



A+LUK: ‘Why keeping active is good for your lungs’

humanly



How:

The Innovation Accelerator process

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UX UK AWARDS WINNER

WE ARE MACMILLAN. CANCER SUPPORT

SCOPE Equality for disabled people

The Health Foundation

Public Health England

wellcome

Impact on Urban Health

mind

The Scottish Government Riaghaltas na h-Alba

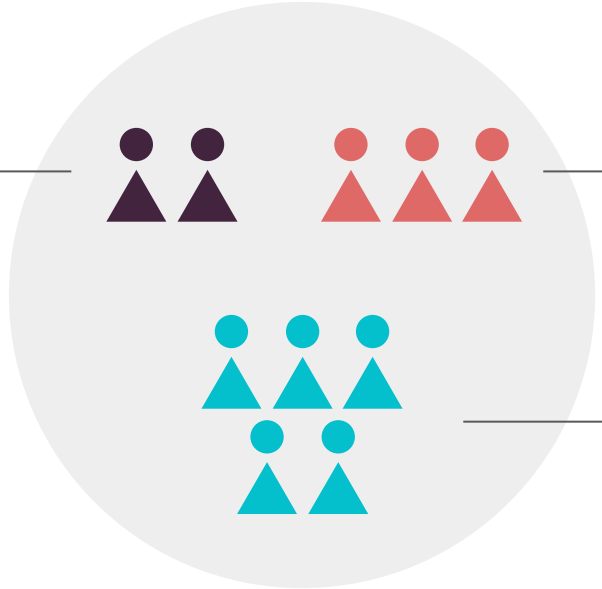
M&C SAATCHI WORLD SERVICES

Couch to 5K

Weight loss

Quit smoking

Core co-design team



Humanly

Bringing experience of co-designing high quality, user-centred products and services that aim to improve people's quality of life

Asthma + Lung UK

Bringing expert knowledge of lung conditions and respiratory innovations

People living with lung conditions

Bringing valuable, diverse lived experiences and perspectives on what matters most to people living with lung conditions

The co-design process over 12 months



Sept 23 - Jan 24	Jan - Feb 24	Feb - Mar 24	Mar - Apr 24	Apr - July 24	Aug - Oct 24
Open call for innovations under the ‘moving more’ theme.	Shortlisting 6 innovations from 10 expressions of interest. Co-designing the application + selection process.	Reviewing applications + selecting 2 innovations for the accelerator.	Co-designing evaluation criteria to assess the innovations. Design and set up of the user testing process.	8 weeks of user testing. Co-analysing the results. Shaping insights + recommendations for each innovation.	Report drafting, refining + presenting to product teams. Evaluating the programme to inform future work.

‘If you don’t have time to build relationships, you don’t have time for co-design’

KA McKercher

Beyond Sticky Notes. Doing Co-design for real: mindsets, methods and movements. (2020)

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Creating a team



1:1 introductory chats on Zoom



First gathering at a community venue



Informal lunch in the cafe







Interactive activities

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Moving online

How to maintain the elements of collaboration, care and fun?

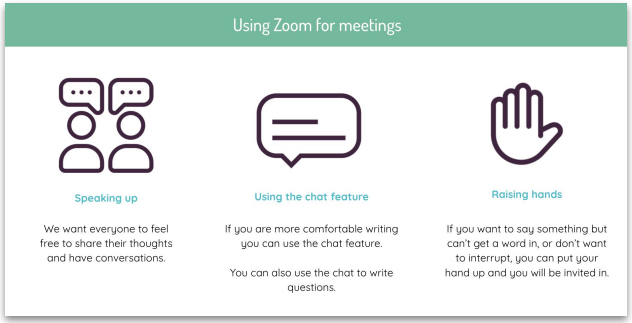


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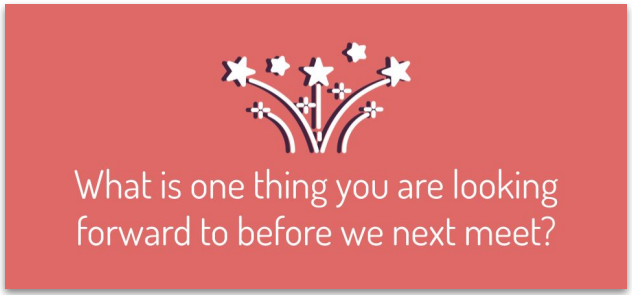
Moving online

What worked

- Staying together in one room
- Options on how to contribute, e.g. using the chat
- Keeping things simple, e.g. using Miro but scribing and screen sharing
- One cat check-ins!
- Continuing to build relationships, e.g. by inviting conversations outside of ‘the work’







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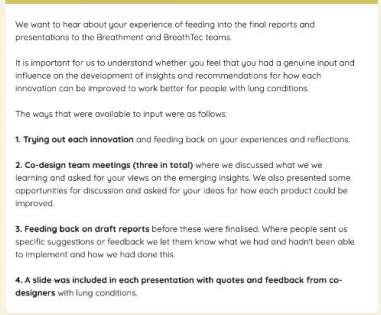
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Co-design

Feedback surveys

- Three word summaries of experience
- Feedback and suggestions on how meetings have gone
- Questions on psychological safety, adapted from those developed by Amy C. Edmondson*
- Information gathering, for example availability for dates

*The Fearless Organization: Creating Psychological Safety in the Workplace for Learning, Innovation and Growth


We want to hear about your experience of feeding into the final reports and presentations to the Breathment and BreathTec teams.

It is important for us to understand whether you feel that you had a genuine input and influence on the development of insights and recommendations for how each innovation can be improved to work better for people with lung conditions.

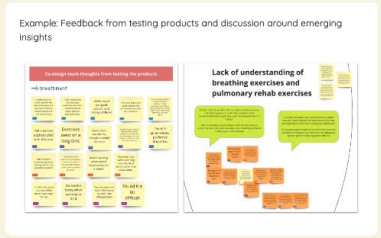
The ways that were available to input were as follows:

1. Trying out each innovation and feeding back on your experiences and reflections.

2. Co-design team meetings (three in total) where we discussed what we we learning and asked for your views on the emerging insights. We also presented some opportunities for discussion and asked for your ideas for how each product could be improved.

3. Feeding back on draft reports before these were finalised. Where people sent us specific suggestions or feedback we let them know what we had and hadn't been able to implement and how we had done this.

4. A slide was included in each presentation with quotes and feedback from co-designers with lung conditions.


Example: Feedback from testing products and discussion around emerging insights


Example: Idea generation session


Example: Slide from presentation to BreathTec with quotes and feedback from co-designers


What did you think about the range of ways to feed into the analysis process, reporting and presentations? *

'It is amazing how quickly the time went, and it shows how we needed more time to discuss what we needed to talk about.'

'Amazing, inspiring, collaborative'

'Exciting, purposeful, challenging'

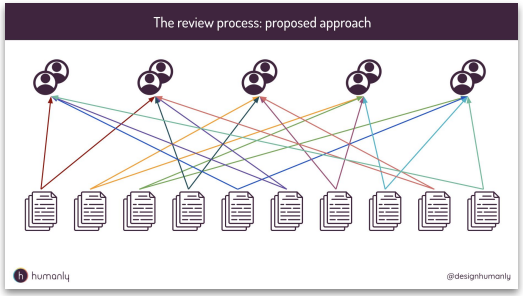
Quotes from co-designers living with a lung condition

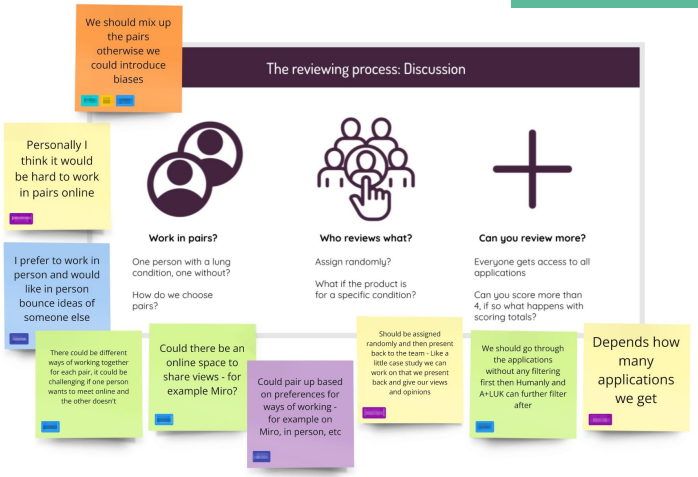
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Reviewing Expressions of Interest

> **‘I really enjoyed working in pairs and it was nice to be flexible.’**
>
> Co-designer living with a lung condition







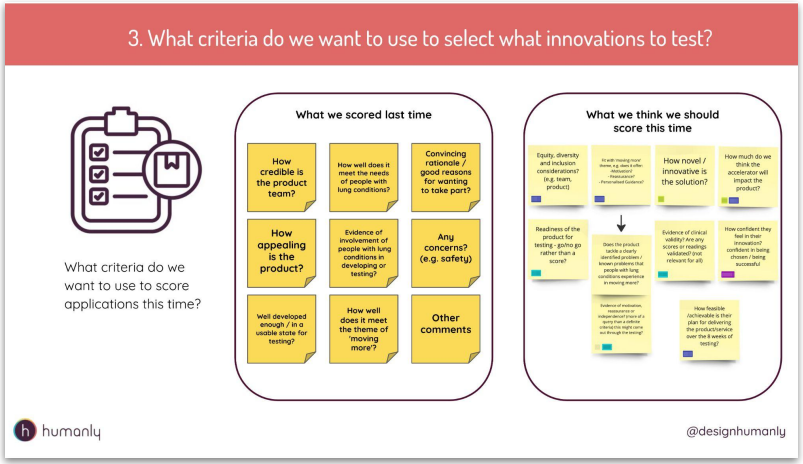
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Product selection

Sharing power

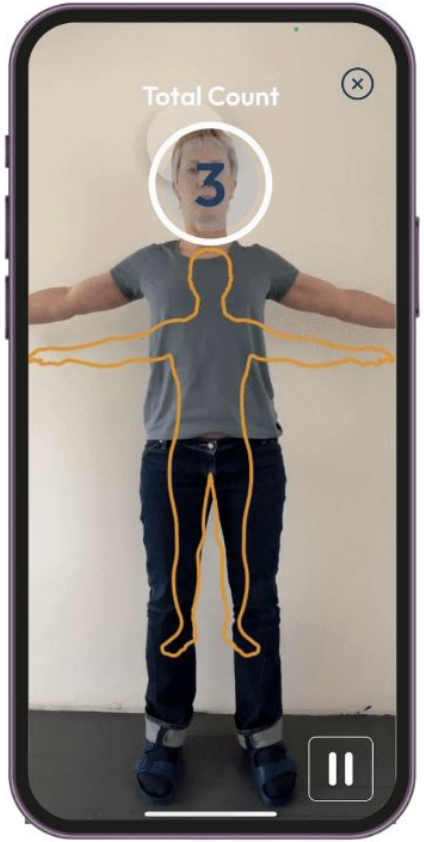
- Co-designing the **criteria we'd use to make decisions** about what products to take forward
- **Co-interviewing each applicant**, with equal representation from each perspective on the team
- **Shared decision making** through individual scoring of products and equal 'voting rights'





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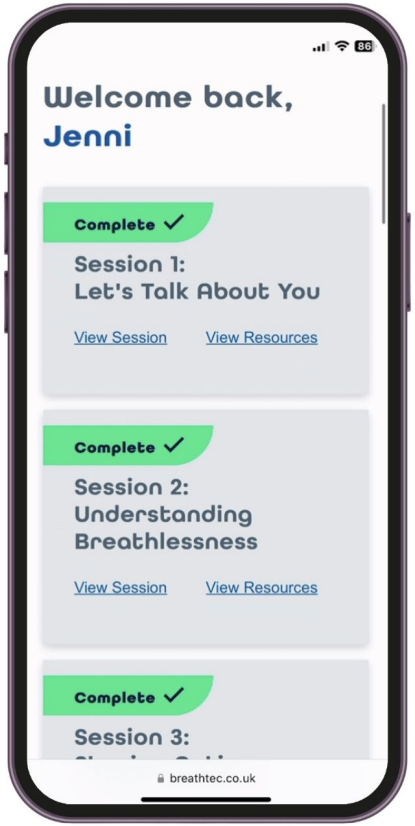


breathment

An app that supports people through a tailored programme of exercises, assigned by a physiotherapist and supported by AI analysis to monitor and improve their technique.

> ‘I really like that you get suggested tailor-made exercises based on your situation.’
>
> Co-designer living with a lung condition

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BreathTec

An online programme that supports people to manage breathlessness and encourages physical activity through CBT approaches.

‘As someone with asthma and trauma history, I’m really impressed with how they are linking mental health, anxiety and breathlessness and approaching them as one, to be tackled together.’

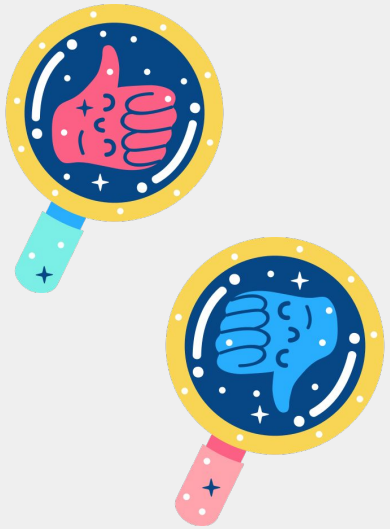
Co-designer living with a lung condition

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Defining what 'good' looks like

Co-designing product evaluation criteria



1. Do people want to use it?
2. How easy is it for people to use?
3. Do the benefits outweigh the effort required? (i.e. is it worth it?)
4. How well does it fit into people's lives?
5. How well does it meet the needs of different people?
6. Do people feel like it makes a difference?
7. How engaging is it?
8. Does it result in people moving more?

31 product testers from diverse backgrounds

Gender
14 men
17 women

Age range
25-70

Conditions
- 21 COPD
- 19 Asthma
- 1 Non-CF Bronchiectasis
- 16 living with multiple long-term health conditions

Socio-economic group
19 C2DE
12 BC1

Ethnic background
16 White British

15 Minority Ethnic Backgrounds, including:
- Black African
- Black Caribbean
- Indian
- Mixed White British & Arabic
- Pakistani
- Middle Eastern
- Mixed South African

Physical activity
A range of levels of physical activity from inactive to fairly active

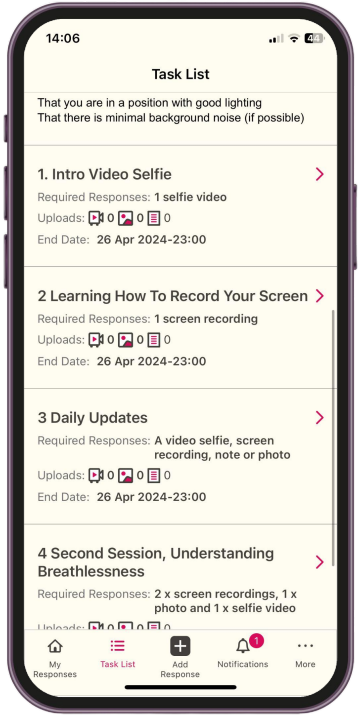
Digital literacy
A range of digital literacy and confidence

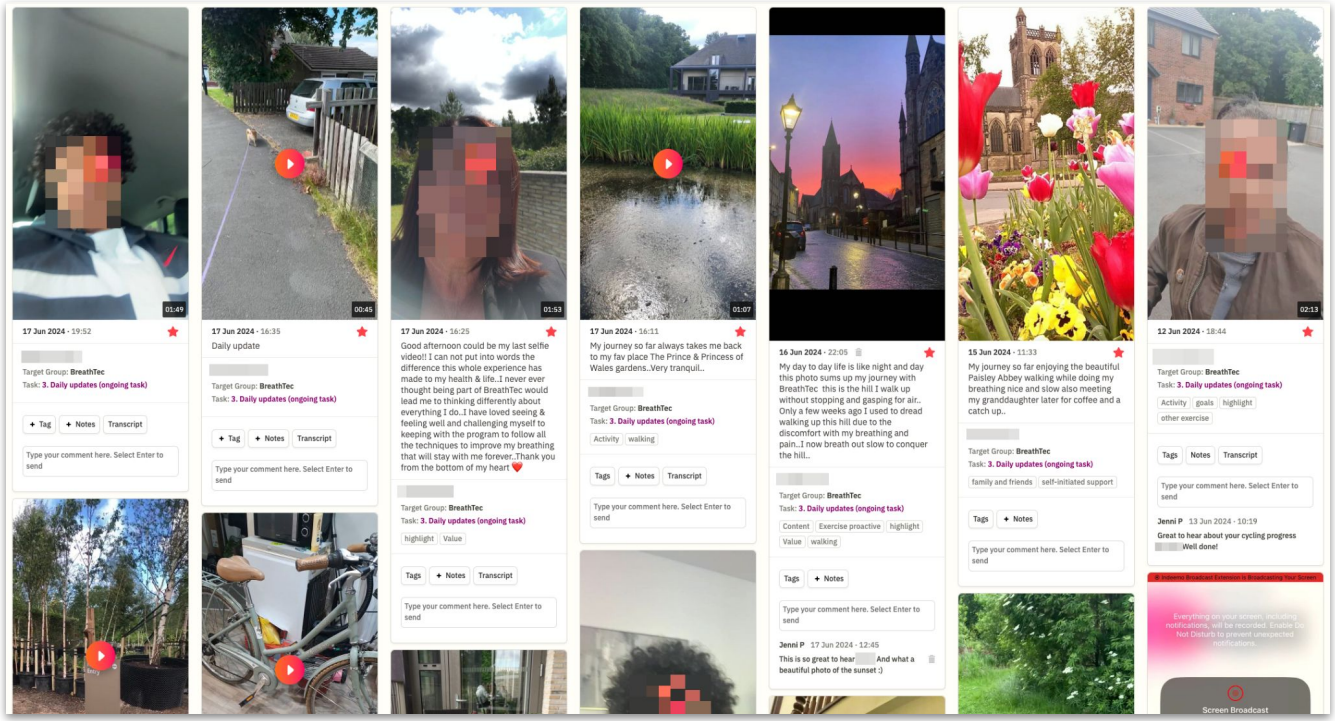
Representation of
- Neurodiversity
- LGBTQIA+ identities
- English as an additional language



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8 weeks of product testing and mobile ethnography



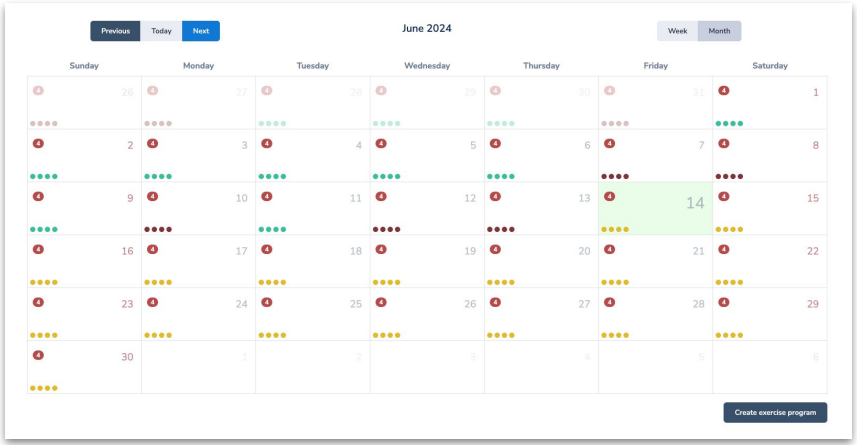


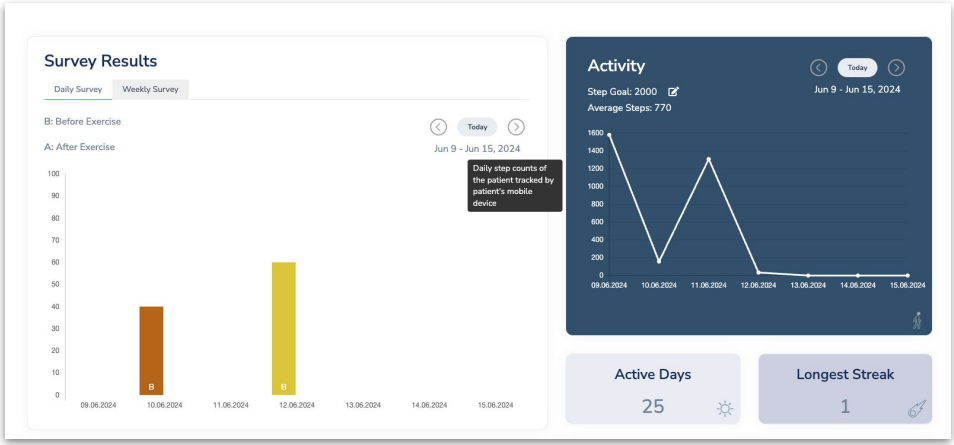
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Product testing

Analysis of usage data to compare to reported usage and identify trends





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31

Research participants

60

In-depth entry / exit interviews

15

Tasks to explore key features and experiences

1,317

Total uploads to mobile ethnography platform

903

Videos and screen recordings shared

58+

Hours of footage analysed

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Impact:

‘Usability testing is amazing – the way you think and what people actually do is a different world!’

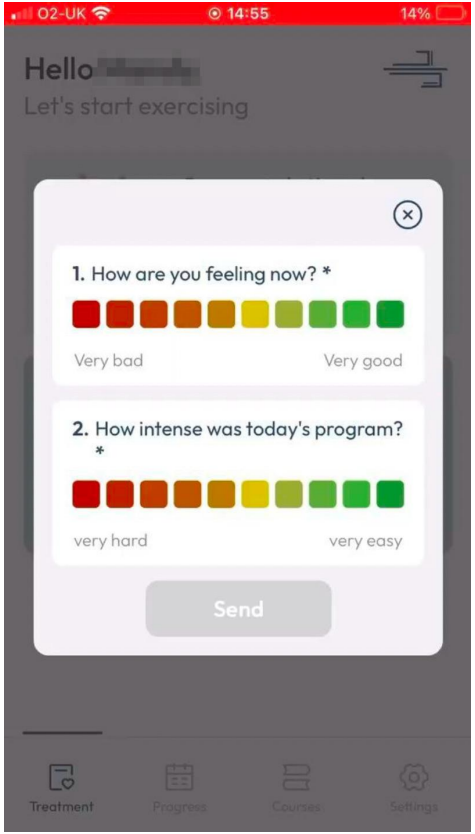
Product owner

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Learning you could never get from interviews

Example: Sally was unable to recognise that Breathment had had a positive impact on her health despite being able to identify improvements in breathing and ability to be more active.



‘What with them **asking before you started how you felt, and after how you felt**, I thought it should be making a difference… **I never felt no different, if I struggled with them I sometimes felt worse**, I never felt no better’

Testing participant

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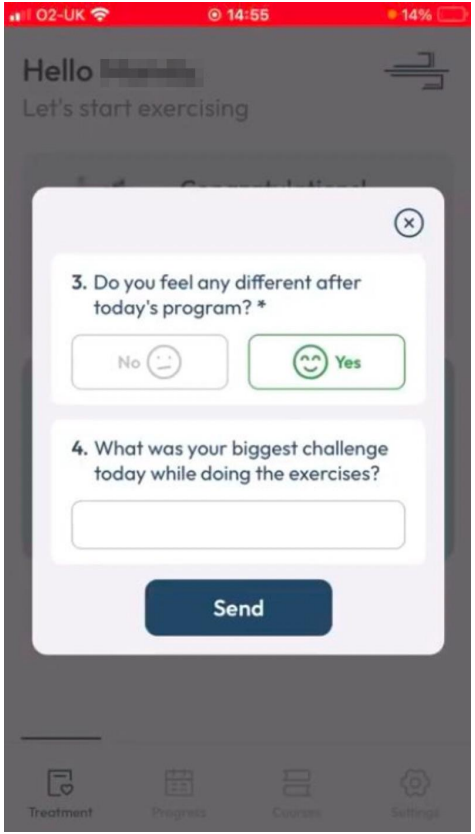
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Learning you could never get from interviews

Example: Sally was unable to recognise that Breathment had had a positive impact on her health despite being able to identify improvements in breathing and ability to be more active.

‘The insights around the pre- and post- exercise surveys [creating misconceptions around immediate relief] were the **most unexpected learning** for me. **I would never have thought of this**, but it makes sense when you put it this way.’

Product co-founder



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Seeing the context of people's broader daily lives





24 May 2024 · 23:45

Today I went for a walk with my grandad. I really enjoy walking with him as we go at a similar pace.

At the end of the park near my house there's a bit of an incline which usually tires us both out at the end. Instead of pushing through it as we usually would, we used one of the Breathtec tips and paced ourselves instead. We know we always get out of breath and instead decided to slow down and take breaks as we needed.



'My **day to day life is like night and day**. This photo sums up my journey with BreathTec - this is the **hill I walk up without stopping and gasping for air**. Only a few weeks ago I **used to dread walking up this hill**.'

Testing participant

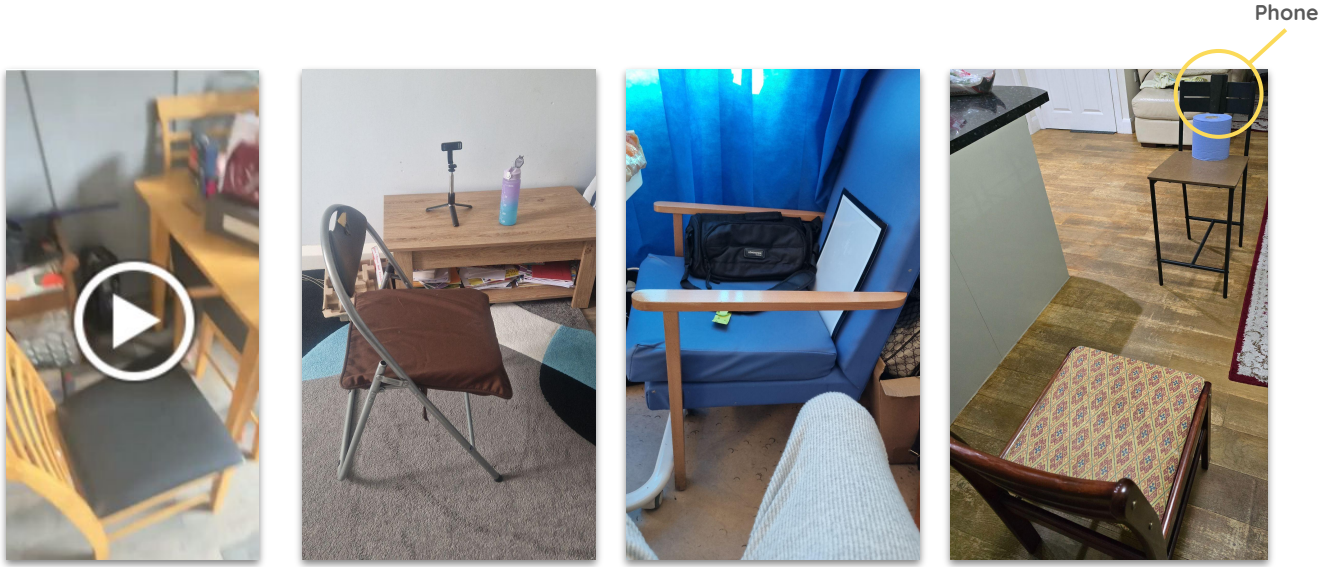
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Challenging assumptions

Hypothesis:

Setting up the phone will be a barrier to using the app



Finding:

People found very creative solutions in practice!

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3 rounds of co-analysis



Session 1

Mid-way learning check-in



Session 2

Interpreting the big findings



Session 3

Ideas and recommendations

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Co-analysis

Mid-way learning

Does what we're learning resonate with your experience?

What should we capture in the second half of the research?



'Do they see these tips and advice from the app staying with them without using the app?'

Research question suggested by a co-designer living with a lung condition

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Co-analysis

Interpreting the big findings

How do the results compare to our product evaluation criteria?

‘The best part was being able to see the results, especially the positive ones’

Co-designer living with a lung condition



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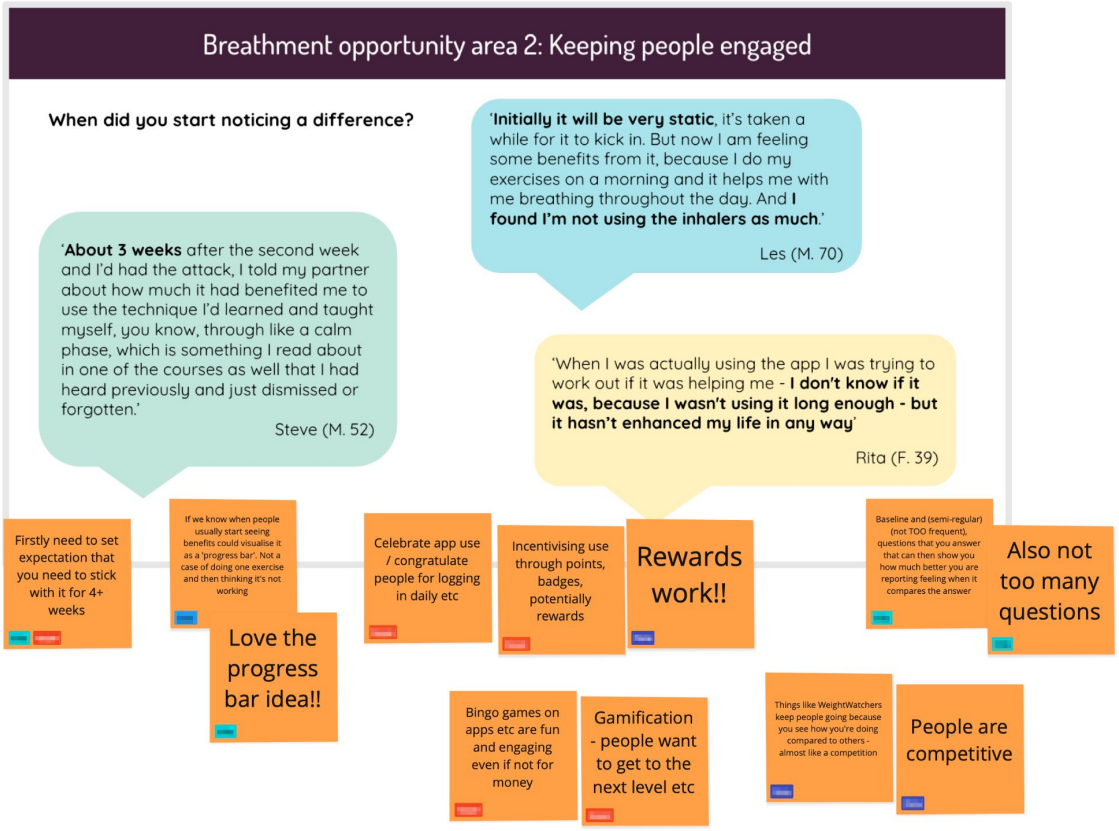
Co-analysis

Ideas and recommendations

Exploring opportunities for new features

‘My opinions felt very valued.’

Co-designer living with a lung condition



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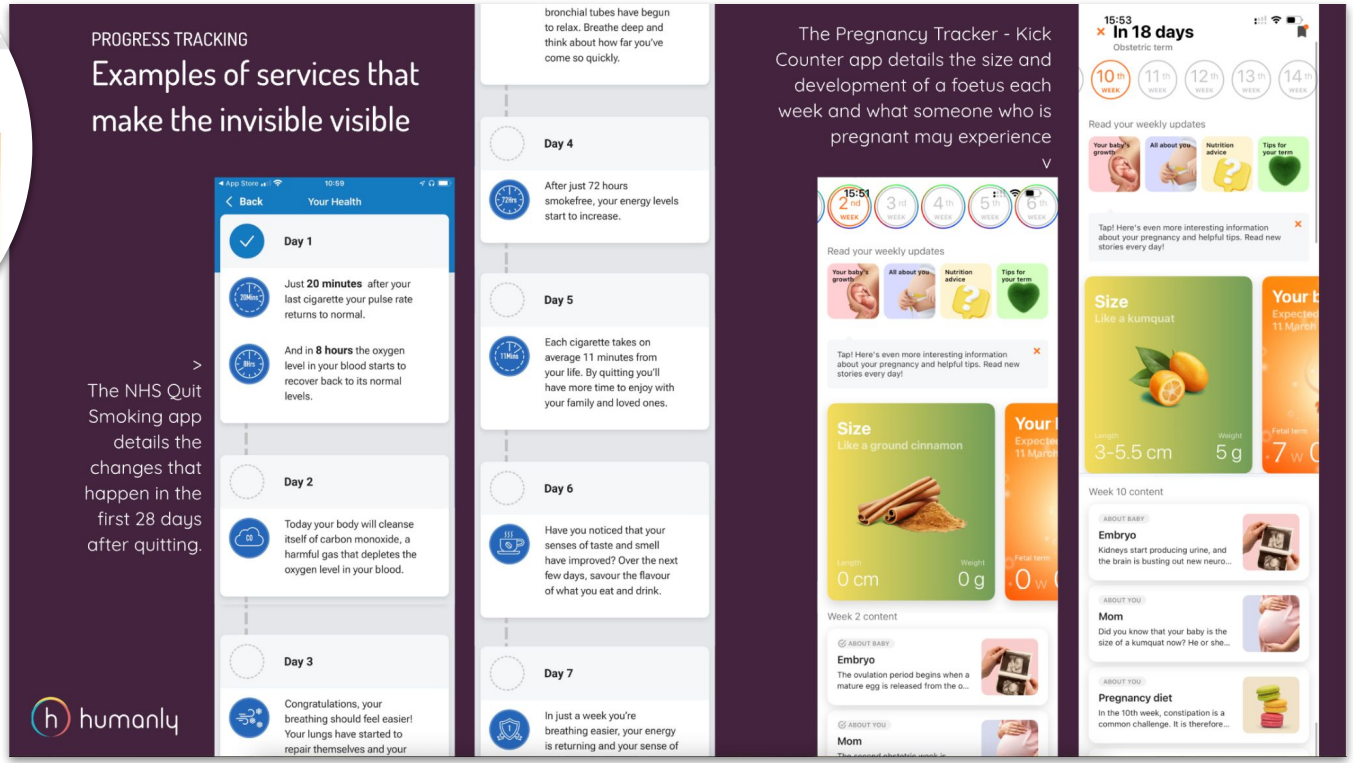
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Shaping recommendations for the products

If we know when people usually start seeing benefits could visualise it as a 'progress bar'. Not a case of doing one exercise and then thinking it's not working

Love the progress bar idea!!

> The NHS Quit Smoking app details the changes that happen in the first 28 days after quitting.



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Presenting back to product teams



'You **miss all of that key information when you interview them** 3 months later'

Product co-founder

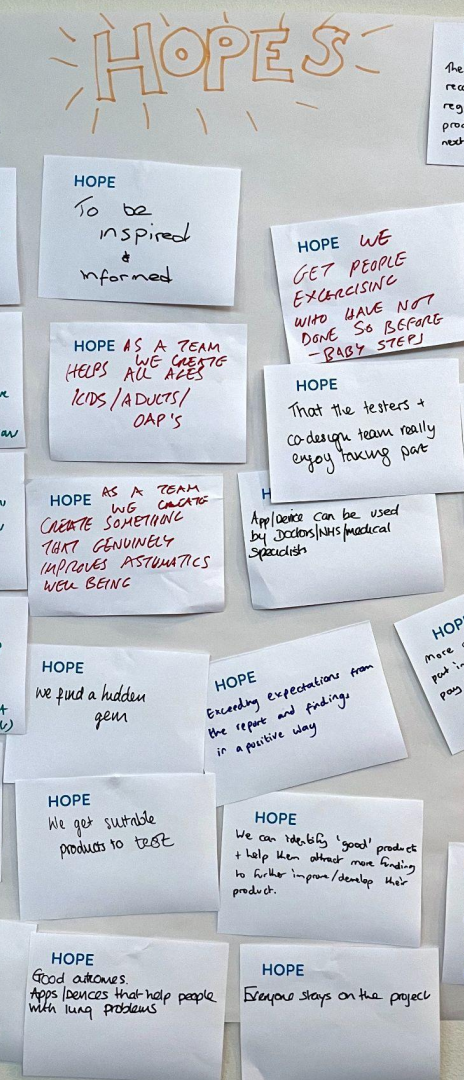
'So much information and so much thoroughness, I would certainly recommend that you do this process again'

Product co-founder

'Thank you all for your support, understanding and effort throughout the entire process. We got **amazing feedback**'

Product co-founder

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A few things we've learned along the way

Use time wisely

- Always make time for care + relationships
- Focus on achieving objectives, rather than getting through planned activities
- Check what co-designers want to spend their time on

Decision making

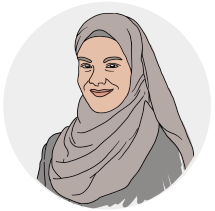
- Sometimes took a 'blank canvas' approach, other times drafted a proposed approach + took to the team for discussion
- Most important thing is to pause and sense-check thinking before going ahead

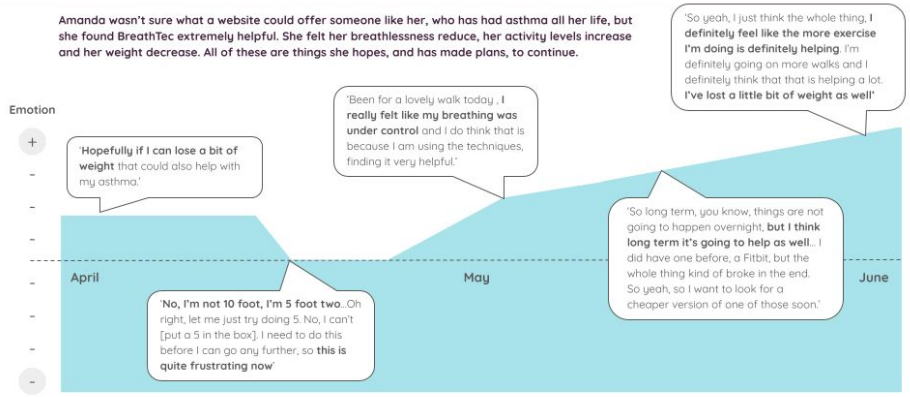
Flexibility

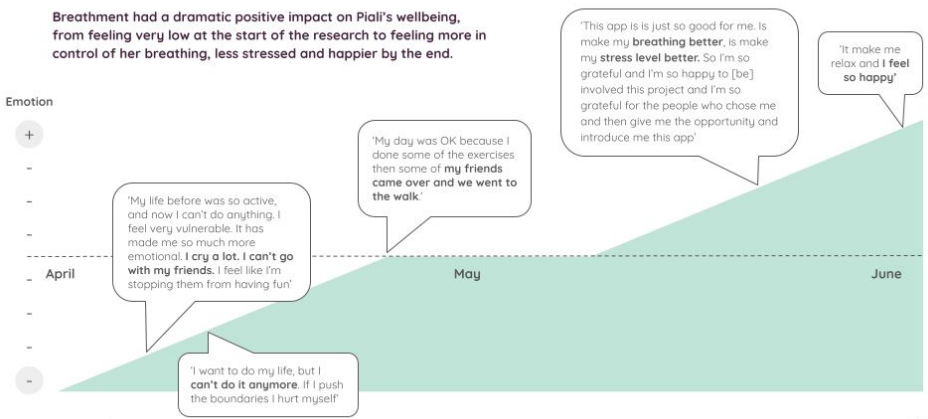
- Diverse ways of working and collaborating, not just meetings
- Being flexible + adaptable without shifting the goalposts all the time

Is 8 weeks necessary?









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Impact:

How this will add value

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Better insights into **real-world user experiences** in the context of **people's everyday lives, goals and challenges**

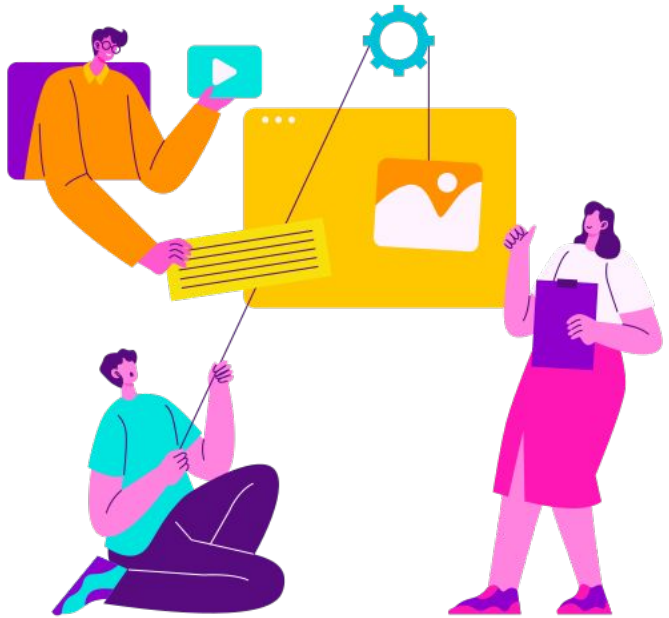
Better products that are **more usable, desirable and effective** for the **diverse population** of people living with lung conditions

Better product development practices that marry **usability and desirability** with **clinical efficacy**

Better outcomes for **all people with lung conditions**

Next Steps

- **Celebration event** bringing together co-design team and product teams
- **Short film** documenting the project, being made by a co-designer
- **Independent evaluation of the programme** - can this process ‘accelerate’ products? Is there anything we could change to make this process even better?
- **Ambition for future accelerators** addressing other unmet needs



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Wider influencing

- Where does innovation intercept with NHS, and what is A+LUK's role in this?
- Is there a justification for a third category of evidence?

  - Does it work (clinical efficacy)?
  - How much does it cost (the NHS)?
  - **Can and will people with lung conditions actually use it?**



Find out more:

bit.ly/innovation-accelerator-blog

Co-designing the future of respiratory innovation

Jenni Parker
Published in Humanly
3 min read · 5 days ago

Listen Share More



Humanly is working with Asthma + Lung UK, the UK's largest charity for people living with a lung condition, to launch an exciting Innovation Accelerator to find and support the best respiratory innovations in the UK.

Why are we doing this?

Asthma + Lung UK wants to see high-quality, user-centred products in the hands of 2 million people with lung conditions. The Innovation Accelerator aims to give respiratory innovations a boost towards this goal. We hope that through this process we can contribute to the development of products that really meet the needs of people with lung conditions and truly make a difference to their lives.

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Thank you!

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