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Experience-based co-design to develop innovative telehealth physiotherapy interventions and resources for children and young people with asthma and dysfunctional breathing

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ABSTRACT

Introduction: Healthcare requires new technologies to deliver hybrid services. Before embedding health-delivery transformations including physiotherapy in asthma clinics, it is essential to give young people and their carers a voice to facilitate co-designing of services.

Objective: To co-design hybrid telehealth physiotherapy services and online resources for, and in partnership with, young people with asthma and dysfunctional breathing, and their families.

Methods: Experience based co-design study undertaken at a specialist paediatric difficult asthma clinic, including online service user focus groups and electronic questionnaires for service providers. Eight children aged between 11 and 17 years and their families and 11 members of the multi-disciplinary team (MDT) managing children with difficult asthma were recruited purposively.

Results: A series of seven online videos were created, topics included: how to support a breathless child, education on how we breathe, breathing patterns, symptom differentiation, breathlessness, rescue breathing techniques, and exercise. Each video has downloadable resources. Five children and four parents wrote blogs to share their experiences. A live online 12-week physiotherapy program was developed on a web-based platform www.beamfeelgood.com called Asthma Kids.

Conclusion: Co-design enabled partnership working to develop hybrid telehealth physiotherapy services and prototype interventions to support home practice for children with asthma and dysfunctional breathing.

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CONTRIBUTIONS OF PAPER

- Service provider and service user insight into experiences of using digital healthcare technologies.
- Novel co-designed physiotherapy-based 12-week program of interventions for children and young people with asthma and dysfunctional breathing.
- Novel co-designed online resources to support physiotherapy home practice for children and young people with asthma and dysfunctional breathing.

Introduction

Asthma is a complex, life-long airways disease affecting 11% of children in the UK (Asthma + Lung UK, 2018), clinical features include reversible airflow obstruction, wheezing, breathlessness, chest pain and cough (Pavord et al. 2018). Physiotherapists can help identify and treat alternative, or contributory causes of poor asthma control (Global Initiative for Asthma 2023), for example dysfunctional breathing (DB) patterns, including Exercise Induced Laryngeal Obstruction (EILO), deconditioning, retained secretions and blocked sinuses (Barker et al. 2020).

Specialist physiotherapy interventions for children with asthma and DB, improve asthma symptom scores (Hepworth et al. 2019), quality-of-life measures for both children and carers (Barker, Elphick, and Everard 2016), and reduce emergency department visits and hospital admissions (Lilley and Turner 2016). The British Thoracic Society and Scottish Intercollegiate Guideline Network (BTS/SIGN) (British Thoracic Society 2019), and National Institute for Clinical Excellence (NICE) (National Institute of Clinical Excellence 2018) asthma guidelines, recommend physiotherapy for children with asthma, particularly for DB.

DB symptoms may be present in 35% of children in an asthma clinic (Hepworth et al. 2019), and the strong association between DB and asthma control suggest it as a "*clinically relevant co-morbidity in paediatric asthma*" (de Groot, Duiverman, and Brand 2013). Children with asthma and DB may misinterpret their symptoms particularly during exercise and then avoid activity, getting stuck in a cycle of deconditioning and worsening breathlessness. A recent meta-analysis has shown physical training helps relieve clinical symptoms of asthma in the paediatric population and should be recommended as a supplementary therapy, however relatively few children with asthma engage with regular exercise (Yin et al. 2019).

Specialist physiotherapy input for children with asthma and/or DB is not widely available because of a lack of specialist staff and reductions in outpatient services (Wells, Hepworth, and Barker 2022). More recently, the COVID-19 pandemic led to repeated lockdowns, school closures and those with difficult to control Asthma were encouraged to shield. These factors exacerbated the lack of engagement in physical activity (Stockwell et al. 2021),

poor emotional wellbeing (Idoiaga Mondragon et al. 2021) and further reduced access to face-to-face healthcare services. Clinical practice has had to adapt in unprecedented ways with increasing reliance on telephone or video conferencing style clinics (Nichols et al. 2022).

To review less resource intensive breathing retraining services in the adult asthma population, the BREATHE trial compared the effectiveness of physiotherapy-based breathing retraining delivered through face-to-face sessions or a self-guided programme (DVD plus booklet) (Bruton et al. 2018). They showed both programs improved quality-of-life, but the face-to-face group had a more positive perception of breathing retraining and more time practicing. Qualitative review of this trial showed the participants felt positive about physiotherapy and liked having the materials (DVD and booklet) (Arden-Close et al. 2017). The patient educational materials were collaboratively developed by healthcare professionals and patient representatives (Bruton et al. 2013).

Innovations in service delivery using new digital technologies (rather than DVDs and booklets) could be a viable option to overcome barriers such as access to specialist services and cost of travel. Online platforms and digital services preferred by children and young people (CYP), and their parents/carers need to be evaluated. Co-design of healthcare services with both providers and users can assist a more effective partnership by enabling users to act as experts, giving valuable insight into their needs and priorities (Marsten, Epston, and Johnson 2011). Successfully co-designing services may also increase engagement with healthcare, minimize waste and reduce costs (Batalden et al. 2016).

The objective of this study was to develop novel hybrid telehealth physiotherapy services, interventions, and online resources, with and for, CYP with asthma and/or DB, and their families. This study follows the international guidance for reporting patient and public involvement in health and social care research (GRIPPS2) (Staniszewska et al. 2017).

Methods

Study design and setting

Experience Based Co-Design (EBCD) (Point of Care Foundation 2018) methods provide an approach to include all stakeholders (patients, their families and healthcare providers) to explore gaps and tailor priorities for service development. It has been successfully used to include families in supporting the redesign of service delivery in a variety of healthcare settings (Piper et al. 2012, Blackwell et al. 2017, and Brady, Goodrich, and Roe 2020). Due to social constraints (national lock down and social distancing) and capacity constraints (research and healthcare teams) a modified EBCD process was

Table 1. Comparison of EBCD process and methods used in this study.

EBCD stages	Modified stages
Project set up	Project set up included site PPI group reviewing, editing, and feeding back on all ethics documentation.
Gathering staff experiences	Gathering staff experiences via digital questionnaire.
Gathering patient and carer experiences – filmed narrative-based interviews	Gathering patient and carer experiences through recorded virtual focus groups.
Initial codesign event bringing together staff, patients and carers.	Virtual recorded focus group with patients and carers with digital technology representatives to identify and prioritize service and intervention codesign.
Codesign workshop	Virtual focus group with patients and carers to collaboratively review and edit resources and iteratively redesign hybrid services.
Celebration even	Presentation of new resources and prototype hybrid service separately to service users and providers.

conducted aiming to closely align stages and ethos of the methodology (Table 1).

This was a single centre study in a tertiary paediatric difficult asthma clinic (Figure 1). Ethical approval was provided by East Midlands – Leicester Central Research Ethics Committee (IRAS No. 291850).

Project set up: purposive recruitment

It was critical to include a diverse group of people within the co-design process, including a range of people with lived experience and those who deliver the service (Moll et al. 2020). Purposive recruitment of both users and providers ensured the co-design group included children of varying ages and ethnic backgrounds, a range of learning needs, physiotherapy needs, geographic locations and socio-economic backgrounds. Service providers were recruited to represent a range of professions within the multidisciplinary team (MDT).

Study participants

All MDT members of the children's difficult asthma service were introduced to the study and given information leaflets. Eleven of fourteen MDT members provided informed consent to take part, including four consultants, two clinical nurse specialists, one physiotherapist, two physiologists, one pharmacist and one research nurse.

All patients that had undergone a holistic physiotherapy assessment as part of the difficult asthma service and were considered to have DB were included. Of those that were approached, eight of nine CYP and their parents agreed to participate in the co-design study focus groups. This included four girls and five boys with ages ranging from 11 to 17 (mean 14).

CYP and their carer participants (service users) all took part in three focus groups. These were held virtually during the national lockdown, after school, at a convenient, mutually agreed time. They were recorded and transcripts produced for retrospective analysis by the facilitator. The first sessions

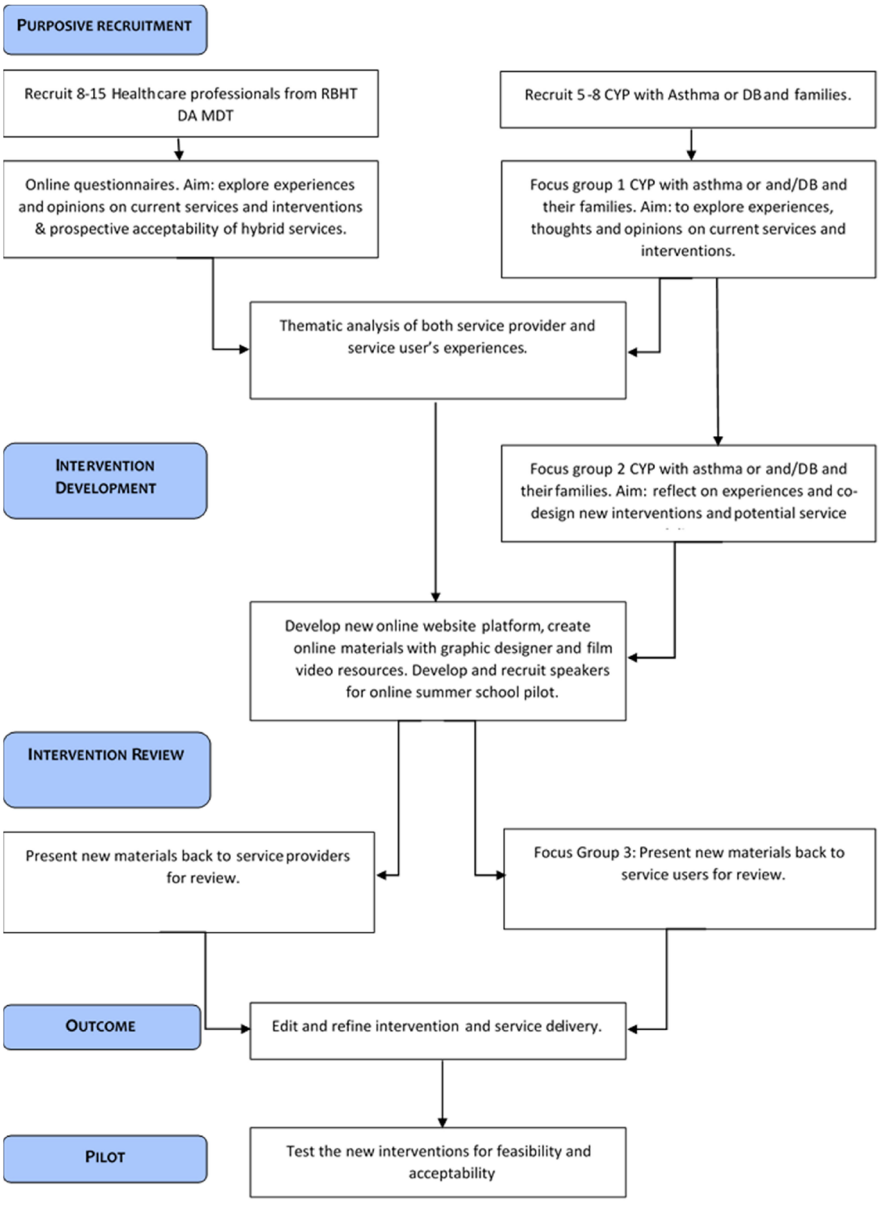

Figure 1. Research methods flow chart.

focused on patient and carer experiences, the second on co-designing solutions and the third to review and edit new resources, interventions, and service design.

Gathering staff experience

A semi-structured electronic questionnaire was designed and sent to the 11 participating service providers to obtain information about their experience

of working with children with asthma using telehealth service provision during the pandemic and physiotherapy services.

The questions were developed using the Theoretical Framework of Acceptability (TFA) (Sekhon, Cartwright, and Francis 2017). The TFA provides seven constructs on which to assess an intervention's acceptability including ethicality, affective attitudes, burden, opportunity costs, perceived effectiveness, self-efficacy, and intervention coherence. The initial question bank was reviewed by the research team for redundancy, clarity, and relevance to the project. The survey was then constructed within Microsoft Forms. The questionnaire included open free text questions and closed questions e.g. Likert scale, rating preference/ ordering answers and multiple-choice questions. The question design was chosen according to its purpose (Roopa and Rani 2012).

Gathering patient experience

To encourage all participants to share their experiences, clear ground rules and etiquette were emailed ahead of the first focus group and agreed by the group within the meetings, for example all opinions are valid and important to be heard, to be respectful to each person sharing their thoughts, feelings and experiences, and to be mindful that CYP are in the meeting, so all language should be appropriate for them to hear.

After an icebreaker activity the facilitator explained the aims and tasks for the focus group:

- Agree ground rules/ etiquette for group.
- CYP shared their experiences of their symptoms, journey of getting into the difficult asthma clinic and impact of physiotherapy.
- Parents shared their stories and experiences of having a child with asthma, DB or exercise induced laryngeal obstruction (EILO).
- CYP and parents reflected and shared their experiences of physiotherapy and considered what elements they found helpful/ unhelpful, easy/ hard.
- Answered the questions: 1/ Message in a bottle: what do they wish they could tell their younger self to help themselves with their asthma or DB journey? 2/ What are their top tips for other people with asthma or DB?

The group listened to each other as both parents and the CYP took turns to share their experiences. They were guided through the above tasks and together discussed similarities and differences in their experiences and journeys. Participants were encouraged to email additional thoughts or experiences that they did not feel able to share or remembered subsequently. After the focus group notes and recordings were

analysed by the facilitator using summative content analysis (Hsieh and Shannon 2005) to develop session themes, these were circulated to the members of the focus group to ensure accurate representation. Two CYP and six parents emailed after the session with added thoughts and reflections on their experiences. These were used when refining the themes for the session.

Co-design and intervention development focus group

A second service user focus group was held to design and prioritize service delivery for hybrid telehealth physiotherapy (including supportive online resources). The second focus group included:

- Agreement of themes from the first focus group.
- Development and prioritization of a list of physiotherapy interventions to be included in hybrid services to guide development of prototype services (Table 2).
- Participants developing content and design of new parent and patient supportive resources and ways to provide these (digital handouts and videos).
- Participants sharing ideas for new ways to answer the message in a bottle information and top tips from the previous focus group. They agreed to write blogs (parents and patients) to share with others entering the physiotherapy service.
- Participants were introduced to online platforms www.beamfeelgood.com, Attend Anywhere (NHS England) (Video Call Management (attendanywhere.com) and online clinics and the RBH webpages (Physiotherapy in the management of teenagers and young adults with asthma and altered breathing patterns | Royal Brompton & Harefield hospitals (rbht.nhs.uk)). They shared their thoughts on each and developed a hybrid tele-health physiotherapy service design combining all three platforms (Figure 2).

The focus group created a list of considerations for the development of new resources and hybrid services:

- They wanted separate resources for primary and secondary school aged children, reflective that teenagers may disconnect from resources designed for younger children. These resources should ideally filmed outside of the clinical setting.
- They wanted to allow for choice, so people can engage with resources and services at convenient times.

Table 2. Overview of idea's developed in co-design service user focus group 2.

Common physiotherapy interventions (Hepworth et al. 2019)	Focus group created topics for development of new resources	Focus group prioritization of topics (1-14)	Focus group suggested means of provision of this intervention or material
Education on a healthy breathing patterns and how DB can affect symptoms.	How to identify symptoms of 'normal' breathlessness. Telling your symptoms apart –A guide to help symptom differentiation (asthma, anxiety, breathing pattern, fitness). Ages 6–11 and age 12–16	1	On demand video and supportive digital leaflet/ flash card. Include within live online classes.
Establishing diaphragmatic breathing.	One minute – quick check of breathing pattern checklist	2	On demand video and supportive digital leaflet/ flash card. Include within live online classes.
Breathing techniques to help with functional activity and reduce symptoms.	Guided rescue breathing –during sport, anxiety or asthma	3	On demand video and supportive digital leaflet/ flash card. Include within 1:1 hybrid clinic sessions.
Education and practical on correcting DB.	Asthma: A guide to observe your breathing and how to start to correct it. Ages 6–11 and 12–16.	5	On demand video and supportive digital leaflet/ flash card. Include within 1:1 hybrid clinic sessions.
Parent/ guardian support to differentiate symptoms.	Parent video: how to support your child with their breathing and to differentiate symptoms.	6	On demand video and supportive digital leaflet/ flash card. Include within 1:1 hybrid clinic sessions.
Exercise interventions and how to exercise safely.	Exercise video including how to warm up, control your breathing and recover age 6–11 and 12–16.	7	On demand video and supportive digital leaflet/ flash card. Include within both live online classes and 1:1 hybrid clinic sessions.
Inspiratory muscle training may be considered for those exercising at a high level.	Inspiratory muscle trainer demonstration – how to do it correctly.	8	Include within both live online classes and 1:1 hybrid clinic sessions.
Physiotherapy management of EILO includes specific breathing techniques and vocal exercises to help manage these symptoms	EILO specific breathing exercises age 6–11 and ages 12–16	9	Include within both live online classes and 1:1 hybrid clinic sessions.
Patient and carer shared experience	Interview with older children who have been through physiotherapy.	10	Kids/ parents blogs.
Sinus management	Education and demonstration on sinus rinsing.	11	Include within both live online classes and 1:1 hybrid clinic sessions.
Musculo-skeletal and postural interventions	Posture and exercise. A guide on how your posture can affect your breathing.	12	Include within both live online classes and 1:1 hybrid clinic sessions.
Relaxation and anxiety management	Guided relaxation and body scan techniques to help ground patients and improve breathing pattern.	13	Include within both live online classes and 1:1 hybrid clinic sessions.
Airway clearance and cough management	To help manage airway secretions to reduce chest infections.	14	Include within 1:1 hybrid clinic sessions.

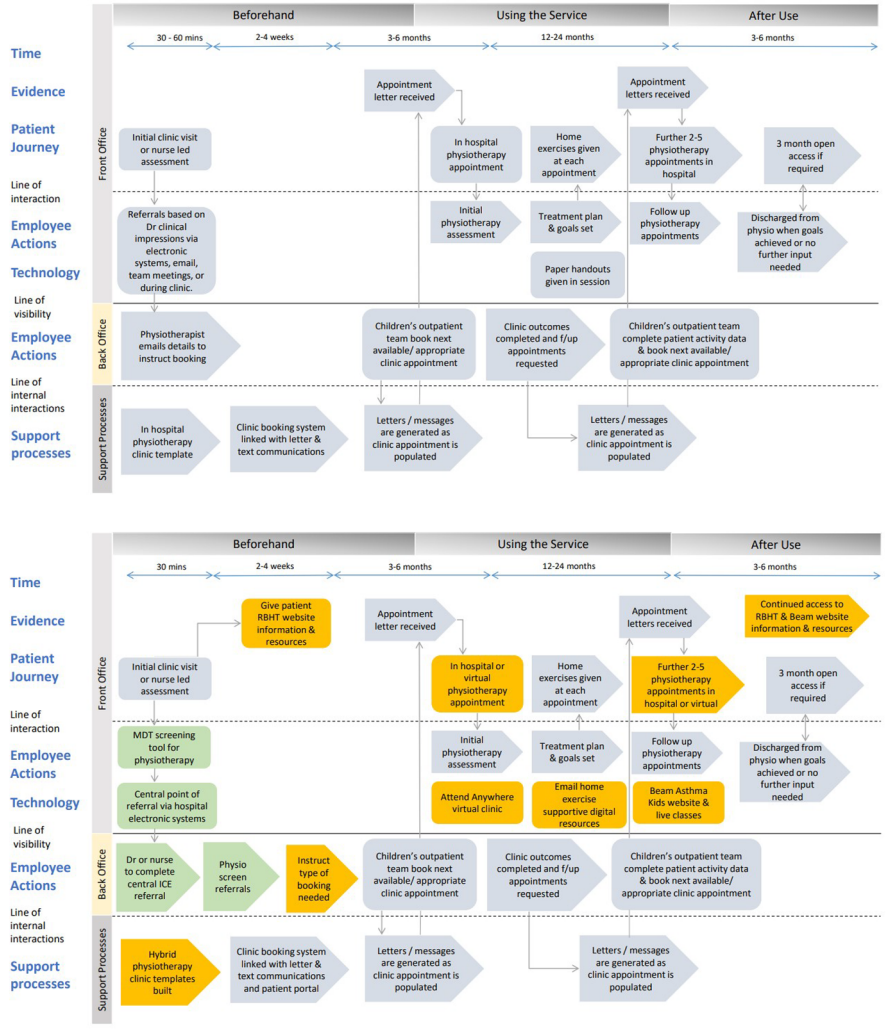

Figure 2. Service blueprint mapping patient flow through physiotherapy services pre and post co-design research.

- They highlighted CYP access resources on their phones so downloadable images may be more help than printed leaflets. They requested minimal text and more image-based resources.
- They reflected that some children have been put off live online classes after home schooling during lock down. Others may enjoy sharing experiences with others with similar issues. They wanted to provide choice for CYP.
- They identified some CYP are anxious to travel to the hospital, whereas others do not engage well with video appointments and benefit from hospital-based sessions.

- They wanted to develop a stock library of resources and guided programs accessible for when a CYP is ready to engage with them, available both on hospital webpages and new online Beam Feel Good platform.

The zoom recording for the focus group and facilitators notes from the session were reviewed to develop themes from the meeting, these were circulated back to the group to check they represented the session. Within the focus group CYP and parents reported they had benefitted from hearing each other's experiences and wanted to share this within the new resources. A blog template was emailed to the group, five CYP and four parents returned completed blog stories.

All focus group participants were invited to take part in filming new videos resources, all declined. CW filmed the stock video library and developed the downloadable materials in accordance with the focus group requirements with a film crew and graphic designer from the Beam Feel Good team.

The focus group proposed the idea of a physiotherapy course of online afterschool sessions. They wanted each session to have a theme and a specialist providing education followed by an activity. CW developed a twelve-week program incorporating all the themes proposed, speakers were recruited (supportive information) and the list was circulated to the focus group for review.

Collaborative review and edit focus group

A third focus group was undertaken with service users to collaboratively review and edit the newly recorded video resources and downloadable materials. The group explored and reviewed the layout, look, and usability of the new 'Asthma Kids' platform created on https://beamfeelgood.com/liveClasses/asthma%20kids.

The online summer school classes plan for both CYP and parents was finalized (full details are listed in the supporting information of this publication). These materials were also made available to service providers and two paediatric specialist physiotherapists to comment on content, layout, and usability. The resources were edited based on focus group feedback and service provider reviews.

Data analysis

Audio recordings of each focus group were anonymously transcribed, then analysed alongside log notes by the researcher (CW) using summative content analysis (Hsieh and Shannon 2005).

Online questionnaires with free text answers were analysed thematically. Likert scale, rating and multiple-choice questions were analysed using descriptive statistics (Cowles 2019).

Results

Staff experience

The staff questionnaires showed that online video physiotherapy appointments for children with asthma were acceptable to 10/11 as a hybrid service (online appointments and additional face-to-face). All participants agreed a good quality service using tele-medicine clinics and interventions could be provided.

> "Yes. The quality of the service provided is not dependent on the medium (ie F2F or remote) but on the provider and we are fortunate to have a physiotherapist who can deliver a high quality service" Consultant.

Service providers agreed virtual appointments give a choice to patients but felt this should not be a substitute for face-to-face services.

> "Yes, a quality service can be delivered to lots of the patients - for some however particularly those who find it easier to engage face-to-face [in hospital] is better. Sometimes families don't put the same level of engagement into a video call". Asthma nurse.

> "I still feel there needs some face-to-face contact to correct positioning and manoeuvres." Pharmacist

Experience from the first national lock down, and rapidly changing services reflected positively on video appointments as helpful in maintaining services.

> "Video appointments are a great way for more patients to access the services especially when many patients do not live locally". Physiologist.

> Virtual appointments are "a really useful resource and a great way of ensuring engagement and timely follow up". Consultant.

Most staff agreed that whilst a hybrid service is probably here to stay, face-to-face sessions are still important to engage families and maintain quality of hands-on physiotherapy treatments. Concerns were highlighted around missing subtle changes and difficulty building rapport using tele-medicine and digital technologies.

> "In physiotherapy I have always thought that the power of touch is important and being present to correct any bad habits." Pharmacists.

> "Establishing a rapport with the patient and family is challenging with telemedicine models of care" Consultant.

Table 3. Technical issues experienced with virtual clinics (attend anywhere) during the pandemic by service providers.

Technical Issue	Number of service providers experiencing these issues (n = 11)
Patients unable to find the link to log in to Attend Anywhere online clinic.	10
Patients unable to log in.	9
I (service provider) was unable to log in to the Attend Anywhere online clinic.	1
Internet speeds effecting the quality of the call.	9
Unable to hear the patient adequately.	7
Poor quality picture.	9
Lost connection with patient.	8
Accidental termination of video call.	2

> "Engagement with families may be better face-to-face as seeing them in person you get to interact with them in person and build a rapport more easily". Asthma nurse.

Many encountered logistical issues during the pandemic with online appointments (Table 3). There were concerns about equity of access to online services, with some families not having access to devices, unstable or poor internet connections and those who are not 'tech savvy', particularly the disadvantaged or very young.

> "It can be difficult to fully assess breathing pattern over video particularly with poor quality picture/ sound connection". Physiotherapist.

> "My only concern would be that people may not have equal access to the internet and device on which to access these services" Asthma nurse.

A potentially positive effect of online videos and resources to improve patient's self-efficacy with home exercise, less travel, increased convenience, more efficient model of care, and offering choice and flexibility for families was acknowledged.

> "This helps both the families work on exercises and tasks they have been given to do at home and practice and also help service in respect of waiting lists". Asthma nurse.

> "More accessible to families who come from further away, potentially less disruptive to patients' day." Consultant.

> "By offering video calls, appointments can be scheduled to cause minimal disruption to school and work commitments, fitting more easily around patients' lives…. if finances were tight, then this may have impacted on their ability to consistently attend and have continued support." Asthma nurse.

Most service providers (10/11) preferred to deliver care face-to-face initially, then by video appointment (Attend Anywhere, FaceTime or WhatsApp). Service providers preferred providing online resources compared to information in printed handouts or newsletters.

Patient experiences

Thematic analysis of CYP and their parents' experiences (Table 4) was undertaken using audio recording and notes from the first focus group session. These were reviewed by the focus group members and agreed in the second focus group session.

Co-design and intervention development

A hybrid physiotherapy service, enabling flexibility to patients and service providers using face-to-face hospital appointments and virtual online video appointments via NHS Attend Anywhere, was developed with focus group participants considering service provider feedback (Figure 2).

New resources to address the key themes prioritized by service users, included videos, text and image-based downloadable PDFs and printable leaflets (Supporting Information) were produced by CW and Beam Feel Good graphic designers considering the content given in Focus group 2 and edited in focus group 3. These educational and exercise-based resources were aimed at primary school aged children and their parents, or teenagers.

The hospital communications team were involved in developing new webpages for children and teenagers with asthma and/or DB. The information written for the webpages were drafted by CW, reviewed, and edited by the focus group participants. The communications team built pages for primary school aged children and their parents (https://www.rbht.nhs.uk/our-services/paediatrics/paediatric-rehabilitation-and-therapies/paediatric-physiotherapy/physiotherapy-management-children-asthma-and-altered-breathing-patterns) and one for teenagers (https://www.rbht.nhs.uk/our-services/paediatrics/paediatric-rehabilitation-and-therapies/paediatric-physiotherapy) with age-appropriate information. Each webpage was connected to a resource page which organized information by topic for easy access which included video resources and downloadable leaflets as recommended by focus group two and reviewed and edited in focus group 3.

A 'live' online summer school was developed in focus group three for delivery on the newly created 'Beam Asthma Kids' page on https://beamfeelgood.com/on-demand/asthma%20kids full details listed in supporting information. This platform hosted the focus group patient and parent blogs, on-demand library of videos, live online classes for CYP, pre-set programs guiding patients through selected videos on topics *e.g.,* breathing pattern retraining, exercise and EILO management, asthma control and health and wellbeing, and supportive downloadable resources.

The online summer school classes formed a version of pulmonary rehabilitation (PR) for children with asthma and/or DB. Each session had a theme with an education element, chance for discussion and sharing of experiences, followed by an activity or exercise. Each class could be joined "live", or it

Table 4. Focus group 1. Summary of themes from the child/ young people's and their parents' experiences.

Child/ Young person experiences		Parents experiences	
Importance of education sessions	"Education session really helpful – learning the mechanics and functioning of breathing helped – which helped visualize what was happening when breathing symptoms came on"	Connections with Anxiety and Panic	Anxiety and panic caused by recurrent cycle of A&E presentations. This was a hard time for parents and their children. They would like materials on hyperventilation, breathing patterns and their link with stress and anxiety
Importance of simple clear breathing checklist	"Breathing checklist really helpful - to help me stop panicking and helping work out what was causing the breathing symptoms"	Difficulty differentiating symptoms	Parents found helping their child differentiate their asthma, breathing and symptoms apart difficult.
Rescue breathing techniques	Rescue breathing techniques were helpful, particularly in school and during sport, so that when struggling they had 'funny/ random' memorable breathing exercises and pursed lip breathing on exercise (these were used often and helped stop panicking)	Nose breathing	Parents felt that their child switching to diaphragmatic nose breathing allowed them to detect symptoms much sooner at a mild stage (like allergies, wheeze, exacerbations) which meant they could start treatments sooner and stop it reaching crisis point.
Nose breathing	Children are often mouth breathers before physiotherapy and get short of breath quickly during sport. One child reflects learning that moving to nose breathing really helped him control his breathing. It took lots of practice (and support from parents) but in time he changed and now finds he does not get out of breath when running around	Breathing checklist allowed teamwork	Breathing checklist and flow sheets helped them (parents and children) work as a team – parents could support their child when experiencing symptoms. It gave them confidence in what they were doing and to work through the symptoms
Practise, Practise, Practise	With family support to help them remember and build the muscle memory so that their body knows what to do without them having to think about it. Motivation to do this was often being able to control symptoms during sports and helped by family reminding	Stop the panic	Physiotherapy helped parents themselves to stop panicking when their child got wheezy. Having support and guidance on 'what to do if your child is breathless and wheezy'.
1:1 exercise sessions	The 1:1 exercise session with the physio in real time, where corrections could be made was really helpful. It built confidence and was reassuring		

could be watched back at any time at the service users' convenience. Each week's 'live' classes, were uploaded to the website, split into two shorter videos separating the education and activity sections. This would then develop a bank of videos and resources available on Beam Asthma Kids as the program would run over 12-weeks.

Discussion

This study demonstrates how patients, carers and healthcare professionals co-designed a prototype model of care for physiotherapy services to address issues of accessibility, engagement, home efficacy with physiotherapy interventions, exercise, and education programs. This model is currently integrated into patient care at the specialist centre.

By facilitating better understanding of experiences from service users and providers, a new model of care was created including one-to-one hospital or virtual physiotherapy appointments, supplemented with online resources, videos and patient stories alongside 12-week live virtual group classes. Although nurse or doctor-led asthma tele-health clinics for children with asthma have been explored to help reduce the number of missed appointments (Van Houten et al. 2021) and adult physiotherapy services for the treatment of DB comparing face-to-face and virtual interventions have been published (Bruton et al. 2018), to date no hybrid physiotherapy services for children with asthma or DB have been developed.

When given creative licence to develop a new intervention, the children, their families, and healthcare professionals developed a holistic online body, breath, and wellbeing program specifically for patients with asthma and/or DB. It is a novel intervention for the treatment and management of CYP with asthma and DB, not dissimilar to virtual PR programs.

EBCD methods have been used to develop similar virtual adult PR services to address issues of low referral, uptake, and completion rates (Barker et al. 2021). Through the service provider and user feedback events a new model of care was designed to include a home-based eight-week exercise program for those who declined traditional outpatient-based PR. Both an in-home eight-week pulmonary tele-rehabilitation and a virtual rehabilitation program have been piloted in adults and found to be safe, feasible and practical, they demonstrated improvements in exercise tolerance and quality-of-life with no adverse events (Marquis et al. 2015 and Knox et al. 2019).

Virtual services have been piloted in other paediatric chronic respiratory conditions with successful outcomes. Chen Jen et al. (2018) piloted the feasibility and acceptability of a tele-exercise six-week program comprising three 30-minute live stream sessions each week for children with cystic fibrosis (CF). They demonstrated 85% overall attendance for ten participants aged between 8 and 20. Qualitative data indicated participants liked the tele-exercise program and wanted to continue.

Although hybrid paediatric asthma services or virtual group programs have not been studied, face-to-face PR programs for children with asthma have improved six-minute walk tests, lung function tests as well as shortness of breath and quality-of-life (Kirkby et al. 2018). An outdoor face-to-face two-week program for children and teenagers with asthma demonstrated

increased running distance, reduced fractional exhaled nitric oxide (FeNO) and exercise induced bronchospasm (Lipej et al. 2021). We anticipate the new model of service delivery, patient support with home exercises and group sessions developed in this study will have a similar effect.

This study provided an opportunity to facilitate collective ownership of physiotherapy services. Using modified EBCD we explored and reflected on experiences of virtual services during the COVID-19 pandemic and developed a new model of care for the future. This was the initial phase of a two-part study, to co-design then pilot the new prototype tele-physiotherapy service design and intervention for acceptability, feasibility, and safety, as such we needed to get ethical approvals for recruitment. This approval process enabled direct recruitment for the co-design study allowing for meaningful participation of both service users and providers.

Limitations

The relationship between the co-design facilitator (CW) and those participating in the study may have been a limitation as they acted as researcher, facilitator and was part of the specialist asthma service, treating the patients in the focus groups. This may have had an impact on responses. CW aimed to work reflexively developing an open, non-hierarchical, and trusting environment for service users and providers to share their experiences. They used mentoring arrangements and clinical supervision to review progress of the research, explore ideas and review qualitative data. We recognize the inclusion of both parents and their children in the same focus groups may have influenced discussion topics and group dynamics. For one older child the parent would leave the group for them to speak freely, for another younger participant who was too shy to speak himself, would whisper to his parent to relay the message.

Conclusion

Working in partnership with service users and providers to reflect on experiences of physiotherapy services before and during the COVID-19 pandemic we creatively reframed the service (Figure 2) and resources available to CYP with asthma and/or DB and their families. This resulted in a novel package of online resources and hybrid physiotherapy interventions, which we will be evaluated prospectively to investigate service user and provider feasibility and acceptability.

Ethical approval

East Midlands – Leicester Central Research Ethics Committee.

Author contributions

C.W conceived the original idea and carried out the project. C.W. wrote the original draft, S.S and J.C. contributed to manuscript development. S.S supervised the project. All authors discussed the results and agreed the final manuscript.

Disclosure statement

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References

Arden-Close, E., L. Yardley, S. Kirby, M. Thomas, and A. Bruton. 2017. "Patients' Experiences of Breathing Retraining for Asthma: A Qualitative Process Analysis of Participants in the Intervention Arms of the BREATHE Trial." *NPJ Primary Care Respiratory Medicine* 27 (1): 56. https://doi.org/10.1038/s41533-017-0055-5.

Asthma + Lung UK. 2018. "What is Asthma." *Asthma + Lung UK*. Accessed June 19, 2023. https://www.asthmaandlung.org.uk/conditions/asthma/what-asthma.

Barker, R. E., L. J. Brighton, M. Maddocks, C. M. Nolan, S. Patel, J. A. Walsh, O. Polgar, et al. 2021. "Integrating Home-Based Exercise Training with a Hospital at Home Service for Patients Hospitalised with Acute Exacerbations of COPD: developing the Model Using Accelerated Experience-Based co-Design." *International Journal of Chronic Obstructive Pulmonary Disease* 16: 1035–1049. https://doi.org/10.2147/COPD.S293048.

Barker, N., H. Elphick, and M. Everard. 2016. "The Impact of a Dedicated Physiotherapist Clinic for Children with Dysfunctional Breathing." *ERJ Open Research* 2 (3): 00103–2015. https://doi.org/10.1183/23120541.00103-2015.

Barker, N., R. Thevasagayam, K. Ugonna, and J. Kirkby. 2020. "Pediatric Dysfunctional Breathing: Proposed Components, Mechanisms, Diagnosis, and Management." *Frontiers in Pediatrics* 8: 379. https://doi.org/10.3389/fped.2020.00379.

Batalden, M., P. Batalden, P. Margolis, M. Seid, G. Armstrong, L. Opipari-Arrigan, and H. Hartung. 2016. "Coproduction of Healthcare Service." *BMJ Quality & Safety* 25 (7): 509–517. https://doi.org/10.1136/bmjqs-2015-004315.

Blackwell, R. W. N., K. Lowton, G. Robert, C. Grudzen, and P. Grocott. 2017. "Using Experience-Based Co-Design with Older Patients, Their Families and Staff to Improve Palliative Care Experiences in the Emergency Department: A Reflective Critique on the Process and Outcomes." *International Journal of Nursing Studies* 68: 83–94. https://doi.org/10.1016/j.ijnurstu.2017.01.002.

Brady, G. C., J. Goodrich, and J. W. G. Roe. 2020. "Using Experience-Based co-Design to Improve the Pre-Treatment Care Pathway for People Diagnosed with Head and Neck Cancer." *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer* 28 (2): 739–745. https://doi.org/10.1007/s00520-019-04877-z.

British Thoracic Society. 2019. "British Guideline on the Management of Asthma." British Thoracic Society Scottish Intercollegiate Guidelines Network. Accessed June 19, 2023. https://www.brit-thoracic.org.uk/quality-improvement/guidelines/asthma/.

Bruton, A., S. Kirby, E. Arden-Close, L. Taylor, F. Webley, S. George, L. Yardley, et al. 2013. "The BREATHE Study: breathing Retraining for Asthma—Trial of Home Exercises. A Protocol Summary of a Randomised Controlled Trial." *Primary Care Respiratory Journal* 22 (2): PS1–PS7. https://doi.org/10.4104/pcrj.2013.00047.

Bruton, A., A. Lee, L. Yardley, J. Raftery, E. Arden-Close, S. Kirby, S. Zhu, et al. 2018. "Physiotherapy Breathing Retraining for Asthma: A Randomised Controlled Trial." *The Lancet. Respiratory Medicine* 6 (1): 19–28. https://doi.org/10.1016/S2213-2600(17)30474-5.

Chen Jen, J., D. M. Cooper, F. Haddad, A. Sladkey, E. Nussbaum, and S. Radom-Aizik. 2018. "Tele-Exercise as a Promising Tool to Promote Exercise in Children With Cystic Fibrosis." *Frontiers in Public Health* 6: 269. https://doi.org/10.3389/fpubh.2018.00269.

Cowles, Ernest L. 2019. "Presenting Survey Results." In *An Introduction to Survey Research*, edited by Ernest L. Cowles and Edward Nelson, 2nd ed. New York: Business Expert Press. https://search.credoreference.com/articles/Qm9va0FydGljbGU6NTIxMDc=?aid=279773.

de Groot, E. P., E. J. Duiverman, and P. L. P. Brand. 2013. "Dysfunctional Breathing in Children with Asthma: A Rare but Relevant Comorbidity." *The European Respiratory Journal* 41 (5): 1068–1073. https://doi.org/10.1183/09031936.00130212.

Global Initiative for Asthma. 2023. "Global Strategy for Asthma Management and Prevention: Global Initiative for Asthma Report." Global Initiative for Asthma. Accessed June 19, 2023. https://ginasthma.org/wp-content/uploads/2023/05/GINA-2023-Full-Report-2023-WMS.pdf.

Hepworth, C., I. Sinha, G. L. Saint, and D. B. Hawcutt. 2019. "Assessing the Impact of Breathing Retraining on Asthma Symptoms and Dysfunctional Breathing in Childhood." *Pediatric Pulmonology* 54 (6): 706–712. https://doi.org/10.1002/ppul.24300.

Hsieh, H.-F., and S. E. Shannon. 2005. "Three Approaches to Qualitative Content Analysis." *Qualitative Health Research* 15 (9): 1277–1288. https://doi.org/10.1177/1049732305276687.

Idoiaga Mondragon, N., N. Berasategi Sancho, M. Dosil Santamaria, and A. Eiguren Munitis. 2021. "Struggling to Breathe: A Qualitative Study of Children's Wellbeing during Lockdown in Spain." *Psychology & Health* 36 (2): 179–194. https://doi.org/10.1080/08870446.2020.1804570.

Kirkby, S., A. Rossetti, D. Hayes, E. Allen, S. Sheikh, B. Kopp, A. Patel, et al. 2018. "Benefits of Pulmonary Rehabilitation in Pediatric Asthma." *Pediatric Pulmonology* 53 (8): 1014–1017. https://doi.org/10.1002/ppul.24041.

Knox, L., M. Dunning, C.-A. Davies, R. Mills-Bennet, T. W. Sion, K. Phipps, V. Stevenson, C. Hurlin, and K. Lewis. 2019. "Safety, Feasibility, and Effectiveness of Virtual Pulmonary Rehabilitation in the Real World." *International Journal of Chronic Obstructive Pulmonary Disease* 14: 775–780. https://doi.org/10.2147/COPD.S193827.

Lilley, A., and L. Turner. 2016. "Assessing the Benefits of Having a Specialist Paediatric Pharmacist and Physiotherapist in the Community to Improve Childhood Asthma Outcomes." *Archives of Disease in Childhood* 101 (9): e2. https://doi.org/10.1136/archdischild-2016-311535.6.

Lipej, M., D. Plavec, J. Živković, O. Malev, B. Nogalo, R. Magdić, R. Lulić Jurjević, and M. Turkalj. 2021. "Effect of Pulmonary Rehabilitation in an Allergen Safe Outdoor Environment on Children and Adolescents with Mild to Moderate Persistent Allergic

Asthma." *The Journal of Asthma: Official Journal of the Association for the Care of Asthma* 58 (10): 1377–1383. https://doi.org/10.1080/02770903.2020.1784192.

Marquis, N., P. Larivée, D. Saey, M. F. Dubois, and M. Tousignant. 2015. "In-Home Pulmonary Telerehabilitation for Patients with Chronic Obstructive Pulmonary Disease: A Pre-Experimental Study on Effectiveness, Satisfaction, and Adherence." *Telemedicine Journal and e-Health: The Official Journal of the American Telemedicine Association* 21 (11): 870–879. https://doi.org/10.1089/tmj.2014.0198.

Marsten, D., D. Epston, and L. Johnson. 2011. "Consulting Your Consultants, Revisited." *International Journal of Narrative Therapy & Community Work* 3: 57–71.

Moll, S., M. Wyndham-West, G. Mulvale, S. Park, A. Buettgen, M. Phoenix, R. Fleisig, et al. 2020. "Are You Really Doing 'Codesign'? Critical Reflections When Working with Vulnerable Populations." *BMJ Open* 10 (11): e038339. https://doi.org/10.1136/bmjopen-2020-038339.

National Institute of Clinical Excellence. 2018. "Asthma: Guidance and Guidelines." NICE. Accessed June 19, 2023. https://www.nice.org.uk/guidance/qs25/chapter/Quality-statement-5-developmental-Suspected-severe-asthma.

Nichols, A.-L., M. Sonnappa-Naik, L. Gardner, C. Richardson, N. Orr, A. Jamalzadeh, R. Moore-Crouch, et al. 2022. "COVID-19 and Delivery of Difficult Asthma Services." *Archives of Disease in Childhood* 107 (3): e15. https://doi.org/10.1136/archdischild-2021-322335.

Pavord, I. D., R. Beasley, A. Agusti, G. P. Anderson, F. Bel, G. Brusselle, P. Cullinan, et al. 2018. "After Asthma: redefining Airways Diseases." *Lancet (London, England)* 391 (10118): 350–400. https://doi.org/10.1016/S0140-6736(17)30879-6.

Piper, D., R. Iedema, J. Gray, R. Verma, L. Holmes, and N. Manning. 2012. "Utilizing Experience-Based co-Design to Improve the Experience of Patients Accessing Emergency Departments in New South Wales Public Hospitals: An Evaluation Study." *Health Services Management Research* 25 (4): 162–172. https://doi.org/10.1177/095148481247424.

Point of Care Foundation. 2018. "EBCD: Experience-Based Co-Design Toolkit" Point of Care Foundation. Accessed June 19, 2023. https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/.

Roopa, S., and M. S. Rani. 2012. "Questionnaire Designing for a Survey." *Journal of Indian Orthodontic Society* 46 (4_suppl1): 273–277. https://doi.org/10.1177/0974909820120509S.

Sekhon, M., M. Cartwright, and J. Francis. 2017. "Acceptability of Healthcare Interventions: An Overview of Reviews and Development of a Theoretical Framework." *BMC Health Services Research* 17 (1): 88. https://doi.org/10.1186/s12913-017-2031-8.

Staniszewska, S., J. Brett, I. Simera, K. Seers, C. Mockford, S. Goodlad, D. G. Altman, et al. 2017. "GRIPPS 2 Reporting Checklist: Tools to Improve Reporting of Patient and Public Involvement in Research." *Research Involvement and Engagement* 3 (1): 13. https://doi.org/10.1186/s40900-017-0062-2.

Stockwell, S., M. Trott, M. Tully, J. Shin, Y. Barnett, L. Butler, D. McDermott, et al. 2021. "Changes in Physical Activity and Sedentary Behaviours from before to during the COVID-19 Pandemic Lockdown: A Systematic Review." *BMJ Open Sport & Exercise Medicine* 7 (1): e000960. https://doi.org/10.1136/bmjsem-2020-000960.

Van Houten, L., K. Deegan, M. Siemer, and S. Walsh. 2021. "A Telehealth Initiative to Decrease No-Show Rates in a Pediatric Asthma Mobile Clinic." *Journal of Pediatric Nursing* 59: 143–150. https://doi.org/10.1016/j.pedn.2021.04.005.

Wells, C., C. Hepworth, and N. Barker. 2022. "Lennon, Marley and the Paediatric Asthma Physiotherapist: All Things We Lost in the 1980s." *Paediatrics and Child Health* 32 (3): 110–112. https://doi.org/10.1016/paed.2021.12.006.

Yin, G., Z. Xie, P. Wu, Q. Zang, C. Xu, and G. Lu. 2019. "Appropriate Physical Training Helps to Relieve Clinical Symptoms of Pediatric Asthma. A Meta-Analysis." *International Journal of Clinical and Experimental Medicine* 12 (3): 2079–2087.

New resources freely available

Webpage for parents and primary school aged children with asthma and breathing pattern disorders:

Physiotherapy in the management of children with asthma and altered breathing patterns | Royal Brompton & Harefield hospitals (rbht.nhs.uk)

Resource's webpage

Physiotherapy in the management of children with asthma and altered breathing patterns - resources | Royal Brompton & Harefield hospitals (rbht.nhs.uk)

Webpage for teenagers with asthma +/- breathing pattern disorders:

Physiotherapy in the management of teenagers and young adults with asthma and altered breathing patterns | Royal Brompton & Harefield hospitals (rbht.nhs.uk)

Resource's webpage

Physiotherapy in the management of teenagers and young adults with asthma and altered breathing patterns - resources | Royal Brompton & Harefield hospitals (rbht.nhs.uk)

www.beamfeelgood.com/asthmakids is not yet publicly available, but please contact corresponding author for information and details.