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REPORT

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Swimming against the tide in implementing change in paediatric physiotherapy for asthma and dysfunctional breathing: stakeholder reflections through digital storytelling

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ABSTRACT

Physiotherapy management of childhood asthma and dysfunctional breathing across the UK is inequitable. To address this, a Theory of Change (ToC) model was developed and implemented at three NHS sites. Storytelling is recognized in the NHS as an accessible methodology presenting a narrative of lived experience in participants' own voices. This project explored multi-stakeholder experiences to identify barriers and opportunities from those asked to deliver change in NHS clinics and those receiving care during this time. Three stories were created from workshops with four physiotherapists delivering outpatient services and a teenage patient and their parent treated during the time of the innovations project. This resulted in three online videos comprised of illustrative/documentary images co-created with each story's participant: Physiotherapist story: https://youtu.be/Pd7vJlUpYMo?si=JOR0m3ZJolKrn-D. Patient story: https://www.youtube.com/watch?v=b6wn5ciNgto. Parent story: https://youtu.be/5-1SSexaD-M?si=mtphptpz-ja1Kpla. Whilst stakeholders reported paediatric outpatient physiotherapy intervention being greatly beneficial, their stories illustrate institutional and socio-economic barriers to accessing services. Staff reported frustration at fundamental requirements not being prioritized for services to run effectively. Patient and parent each described limited knowledge of dysfunctional breathing in community care, resulting in incorrect diagnoses and treatments. Service provider and recipient experiences of this innovation project highlight issues to investigate, thereby refining the ToC base assumptions before national implementation.

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Introduction

Physiotherapy to support the management of childhood asthma and dysfunctional breathing (DB) in the UK is intrinsically affected by issues of equity and inequality (Wells, Hepworth, and Barker 2022). Despite research demonstrating beneficial effects of physiotherapy for children with asthma and DB (Hepworth et al. 2019), services remain sparse and under-resourced (Wells et al. 2019). The role of the physiotherapist is to identify and support the management of any causes of asthma or asthma-like symptoms despite medical optimization. Innovative community-based projects and specialist physiotherapy clinics for children with asthma and/or DB have shown to benefit young people and their families with fewer emergency department visits (down from 47 to one) and hospital admissions (from eight to one) (Lilley and Turner 2016), reduction in asthma symptom scores (<001) and improvements in quality of life measures of both the young person ($p < .000$) and their care giver ($p < .000$) (Barker, Elphick, and Everard 2016). DB within paediatric asthma services ranges from 35 to 65% prevalence (Hepworth et al. 2019; Wells et al. 2020), due to its impact on asthma symptoms it is defined as a 'clinically relevant co-morbidity in paediatric asthma' (de Groot, Duiverman, and Brand 2013). Interventions within a specialist physiotherapist clinic for children with asthma can include breathing pattern retraining, graded exercise, postural realignment, sinus management, musculoskeletal treatments, education and symptom differentiation. Regulators (British Thoracic Society 2019; Global Initiative for Asthma 2024; National Institute of Clinical Excellence 2018) recommend physiotherapy for these children, however few healthcare professionals outside specialist clinics understand how to identify children who would benefit from these interventions.

Even within a similar geographical region, access to and service provision from three regional specialist paediatric respiratory physiotherapy outpatient services were inconsistent. To address this variation, a one-year innovation project was designed to improve access to and quality of, specialist paediatric respiratory physiotherapy services across three NHS sites. The project unfolded in three interlinked phases. First, a baseline review of staff knowledge, competence and confidence was undertaken, followed by tailored educational input including 1:1 supervision, group mentorship and the development of supportive learning materials. Second, a standardized specialist physiotherapy assessment template was developed and introduced across all sites. This phase tested the technical and operational feasibility of embedding shared documentation and referral criteria within existing service infrastructures. Third, an implementation strategy was enacted locally at each site. This involved stakeholder mapping, team visits and iterative problem-driven adaptation. Throughout the year, the Theory of Change (ToC) model was refined in response to emerging barriers and contextual constraints, with the longer-term intention of informing national scale-up.

Figure 1 illustrates the intended implementation pathway and the assumptions underpinning the ToC at project inception.

However, the enacted implementation diverged from the original design in important ways. The implementation of this project over a year had varying levels of success. Engaging frontline staff proved challenging as other than the project lead, none of the original physiotherapy team involved in the project development remained in

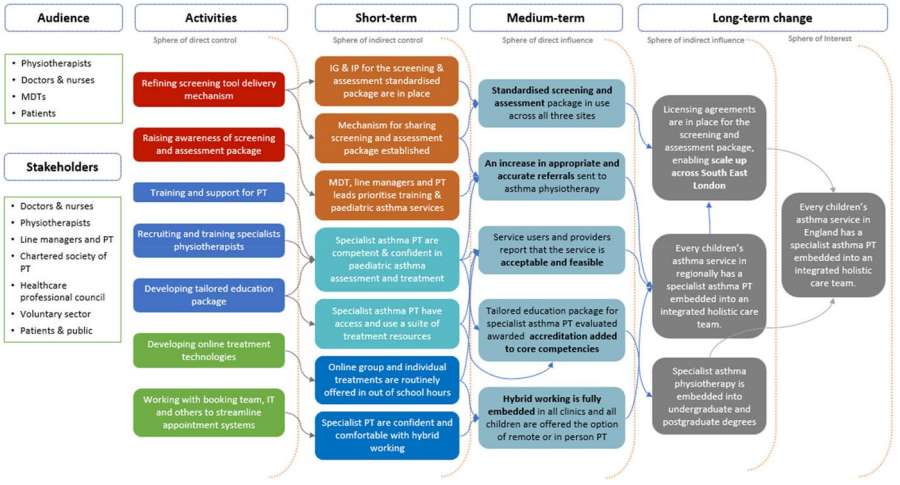

Figure 1. Theory of Change model: transforming national physiotherapy care for children with asthma or dysfunctional breathing. The activities are colour coded according to the different project activities: Developing the screening tool = red; staff training and development = purple and service development = green. The arrows indicate pathways to change. There are several assumptions underpinning the change pathways. As part of the project development, it is important to explore these assumptions and make them explicit. Designed by Ibidun Fakoya.

post. Although staff and services were keen to *receive* input in the form of education, patient resources and standardized assessment packages, there was a lack of 'buy in' and misalignment between staff daily workloads, the project priorities and the assumptions of the original ToC model was based on. Whilst mangers agreed with the objectives of the project, they did not demonstrate active support or meaningful engagement. Support services were not motivated in digital solutions for these services and patient facing physiotherapy teams did not engage with requests for *active* participation eg data collection, arranging or attending 1:1 supervisions, or setting up of clinics on a new online platform. This highlights the challenge of implementation of innovation and standardization of care across NHS services.

This project aimed to explore lived experiences following the one-year implementation phase of the innovations project, capturing reflections from physiotherapists who had been asked to enact service changes and from a patients and parents who accessed services during this period. The objective was to identify barriers and opportunities when implementing change within busy NHS services, thereby refining the assumptions underpinning the ToC prior to application in a national implementation research program.

This project was collaboratively delivered by a Specialist Paediatric Physiotherapist, a Patient Experience Lead and an Arts Manager.

Methods

Improving patient experiences of care is recognized as intrinsic to successful healthcare, yet a gap remains between measurement of experience and actionable improvement (Department of Health 2008; Locock et al. 2020). Storytelling in the NHS is

understood to provide an accessible methodology, presenting narrative of lived experience in participants' own voices and providing insight into what matters most to them (The Health Foundation n.d.). Digital storytelling was selected as the principal methodology because it is a participatory, co-creative approach that enables individuals to construct and share first-person narratives through facilitated story development, voice recording and image curation (Lambert and Hessler 2018). Within the healthcare context, digital storytelling has been used to surface experiential knowledge, challenge dominant professional narratives and create dialogic spaces between service users and practitioners (Stacey and Hardy 2011; Stenhouse et al. 2013).

Hardy and Sumner (2017, 2018) conceptualized digital storytelling as a co-production process in which participants retain authorship and narrative control, positioning storytelling not as data extraction but as collaborative meaning-making. Similarly, Lal, Donnelly, and Shin (2015) and Skarpaas et al. (2016) described its value within allied health education and research as a reflective method capable of revealing implicit understanding, experience-based knowledge and professional identity tensions. In this study, digital storytelling was employed not solely as a dissemination tool but as a reflexive design method, enabling stakeholders to interrogate assumptions embedded within the project's ToC.

Study design

This study adopted a design-informed narrative inquiry approach, using digital storytelling as a participatory method to explore lived experience following implementation of a service innovation. The storytelling process functioned as a reflective mechanism to interrogate and refine the assumptions underpinning the ToC, emphasizing co-production and participant ownership throughout.

Workshop 1 – staff

A face-to-face group workshop was facilitated with four NHS Band 7–8a physiotherapists delivering outpatient services for children and young people (CYP) with asthma and DB. Participants were involved in actioning the innovations, rather than its initial design. The ToC was presented, and discussions focused on implementation challenges and alignment with the project's assumptions. Given the limited engagement observed across the project, staff were remunerated for attending the workshop to facilitate participation. This workshop represented the only instance in which all staff members attended a session collectively.

Prior to the workshop each participant drafted a 300-word 'day in the life' story. During the session participants shared and discussed their stories, reflecting on commonalities and differences. A single script was collaboratively developed drawing on agreed themes to represent their shared experiences. Script development followed co-productive principles, with participants retaining the right to revise, reframe and emphasize their experiences (Hardy and Sumner 2018). Audio recordings and illustrative images were provided by participants and incorporated into the final digital story, with iterative review and consent ensuring full narrative ownership. The workshop employed a 'story circle' approach to create a safe, reflective space that facilitated

dialogue and meaning-making (Lambert and Hessler 2018). A two-stage consent process was used. Forms were signed by each participant to confirm that the hospital could retain their voice recording and images. The second form confirmed that the final video could be shown anywhere, including online. All participants were given several options including to Health and Social Care professionals, on the Trusts Charity social media/website and anywhere including online.

Workshop 2 – patient and parent

Children and parents accessing the three asthma and DB outpatient services during the innovations project were invited to participate. One teenager and their parent consented. Participants were provided with a £50 gift voucher each as a token of appreciation for their time and contribution. Although broader recruitment was anticipated, engagement in active service user recruitment varied across sites, which constrained participation. As the objective was to co-create a digital story illustrating personal experience, rather than to achieve data saturation, the smaller sample was acceptable within the scope of the project.

An informal online interview was conducted by the Arts Lead, capturing the experiences of service access, interventions and desired improvements. Transcriptions were used to draft narrative scripts, which were iteratively reviewed and revised by participants to ensure authorship and authenticity (Hardy and Sumner 2017; Stenhouse et al. 2013). Participants recorded their own audio and provided illustrative images for the final digital stories. Consent included permission for broad dissemination across NHS, charity and educational platforms.

Analytic integration with the Theory of Change

The innovations project had developed an initial ToC outlining assumptions regarding staff engagement, managerial support, feasibility of standardization and anticipated patient benefit. Digital storytelling workshops were designed as a reflective mechanism to test these assumptions against post-implementation lived experience.

Following story creation, the project team collaboratively identified key narrative themes (eg time pressures, barriers to access, advocacy through self-determination). These were mapped against the original ToC to examine alignment, tension, or contradiction (eg assumptions about managerial facilitation or staff capacity). The updated model highlights essential contextual preconditions, enabling assumptions and mechanisms of change co-designed with stakeholders, while clearly linking to short-, medium- and long-term outcomes. This streamlined ToC provides a clearer, more practical framework grounded in participant experiences and supports ongoing refinement of implementation strategies within NHS physiotherapy services (Figure 2).

The mapping process was undertaken by the project team (Specialist Paediatric Physiotherapist, Patient Experience Lead and Arts Manager), it was iterative and consensus-driven, positioning digital stories not as illustrative outputs but as narrative evidence informing the refinement of implementation assumptions (Hardy and Sumner 2018; Stacey and Hardy 2011).

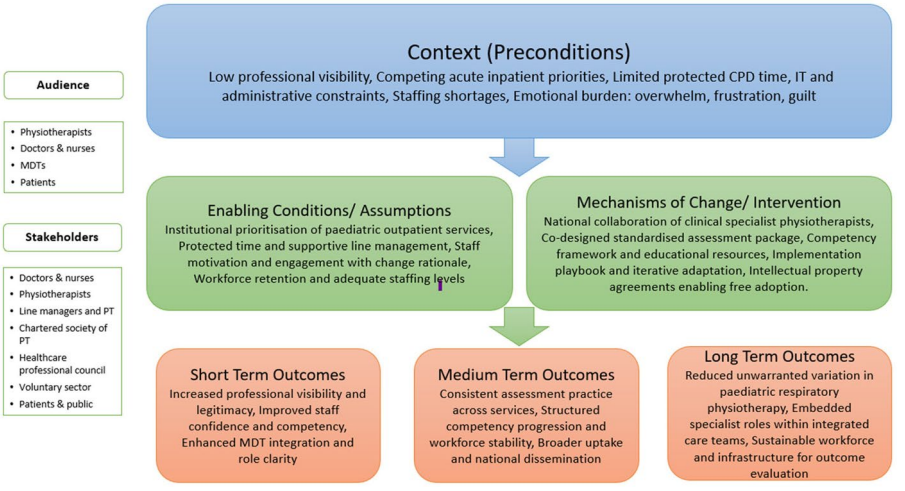

Figure 2. Revised Theory of Change model following story telling narrative analysis.

Results

Digital story outputs

Three co-produced digital stories were generated:

- Physiotherapist story: https://youtu.be/Pd7vJIUpYMo?si=JOR0m3ZJoIKr-n-D
- Patient story: https://www.youtube.com/watch?v=b6wn5ciNgto
- Parent story: https://youtu.be/5-1SSexaD-M?si=mtphptpz-ja1Kpla

All participants consented to sharing their stories widely, highlighting the accessibility and flexibility of digital storytelling as a medium for stakeholder voice. The stories revealed areas of commonality as well as difference in perspectives on service innovation, reflecting the nuanced realities of implementation within complex healthcare systems.

Emergent narrative themes

Analysis of the stories, conducted through collaborative review with participants, identified several key themes (Table 1).

Organizational Barriers: Despite enjoying their jobs, all physiotherapy staff reported frustration about fundamental needs for adequate service provision not being effectively allocated, including inadequate booking systems, clinic rooms, equipment and staffing levels. The physiotherapists felt that this, together with patient demand was contributing to high staff turnover. It was suggested asthma/DB services are undervalued, despite providing crucial ill-health prevention. Staff felt that without protected time to provide paediatric outpatient respiratory services, they would continue to struggle to deliver required care or engage in any new service changes through project work. Potential solutions identified through the innovations project could not be implemented due to lack of time and no

Table 1. Workshop 1: themes of physiotherapy experiences and feelings.

Themes of issues with fundamental service provisions	Themes of collective physiotherapy experiences working within their service	Themes of collective of institutional issues experienced by physiotherapy staff	Themes of feelings experienced by physiotherapy staff
Low visibility in the system	Providing patient centred care	Acute inpatient care takes top priority of all case load. This compromises teaching, staff and service development and outpatient services. With no protected CPD time	Overwhelmed
Frustrations with poor room availability	Being part of a multi-disciplinary team (MDT)	Teaching blocked by service managers and working systems eg shifts and 7-day working	Unseen/ unappreciated
Insufficient equipment to support the roles	Varied case loads	Not enough hours in the day to meet the high demand of the service	Guilt
Difficulties with IT and not enough administrative support	Providing education for patients on mind/ body connection with breath and holistic care	Working extra hours: coming in early, leaving late, missing lunches and still not enough time to get everything done	Chaotic/ busy/ dynamic
Difficulties with patient booking, causing appointment non-attendance rates to rise and slowing patient flow through the service	Satisfaction when working out the clinical puzzle with each patient for success/ achieved patient goals	So many balls to juggle and spinning plates to balance	Split roles/ juggling
Frustrations with poor patient attendance to appointments	Difficult to progress patients due to huge time gap between appointments	Having to race all over the place/ chaotic due to logistic issues with service	Frustrated

administrative support, leading to further feelings of hopelessness. These narratives revealed systemic constraints impeding service standardization and innovation, providing concrete examples of barriers that had previously been assumed to be minimal.

Equity and Access: Whilst all stakeholders reported paediatric outpatient physiotherapy intervention being greatly beneficial, their stories highlight institutional and socio-economic barriers to the running and access of services. While the patient reported long-awaited access to specialist services as being transformative, service providers reported daily issues affecting staff morale and service efficiency.

Conversely, apart from access, the patient and parent participants each described overwhelmingly positive experiences of the service. The participants highlighted inequities in accessing services and gaps in knowledge of DB in community care, resulting in incorrect diagnoses and treatments which the parent felt was 'wasteful for the NHS'. Specialist service referral was eventually obtained through self-funding, extensive travel and 'personal determination' and reliance on self-advocacy. They described an appreciation for and wish to raise awareness of, the positive impact specialist DB services had on their lives, to advocate for increased availability and access across the UK. The narratives illuminated gaps in community knowledge and

pathways, demonstrating how lived experience can reveal critical barriers overlooked in quantitative or policy-focused evaluation.

Professional Identity and Reflection: Storytelling prompted physiotherapists to articulate challenges, successes and frustrations in enacting service changes, surfacing experience-based knowledge about practice, team dynamics and adaptation strategies.

Co-Production as Insight Generation: The collaborative story creation process itself surfaced insights that would have been inaccessible through conventional interviews or surveys. Participants' control over narrative content encouraged reflection on both personal and systemic experiences, enabling the team to identify misalignments between project assumptions and lived realities.

The video outputs were shared with the key stakeholders of the innovations project across participating trusts as well as embedded in training delivered at national and international conference and workshops which focus on developing clinical skills and services for CYP with DB.

Mapping to the Theory of Change

The emergent narrative themes were mapped to the project's ToC assumptions. This mapping highlighted areas of alignment, tension, or contradiction:

Alignment: Patient and parent experiences confirmed that access to specialist services improves outcomes, supporting the ToC's intended benefits.

***Tension*:** Physiotherapist stories revealed that education and standardized tools alone were insufficient for practice change, challenging assumptions about staff capacity and managerial facilitation.

Revision: Insights from co-produced stories led to refinement of the ToC to incorporate organizational preconditions, such as staffing stability, protected time and active leadership engagement, emphasizing the structural context as critical to successful implementation (Figure 2).

Discussion

This study demonstrates how digital storytelling functions not only as a method for representation but also as an epistemic and reflexive tool capable of interrogating implementation assumptions. By prioritizing the voices of service providers, patients and parents, the co-creative storytelling process surfaced tacit knowledge, organizational realities and inequities in service delivery that might otherwise have remained invisible (Hardy and Sumner 2017, 2018; Stacey and Hardy 2011; Stenhouse et al. 2013).

Insights into implementation

Rather than generating generalizable findings, the stories operated as situated, experiential evidence, allowing core assumptions about capacity, facilitation and equity to be critically examined. The intention was not to achieve representational saturation but to produce in-depth, experience-led insights capable of refining implementation assumptions.

The narratives illustrate that innovation implementation is highly sensitive to organizational and contextual factors. Physiotherapists' stories highlighted structural constraints – high staff turnover, limited resources and passive managerial support – as primary determinants of project success. These findings mirror barriers reported in other contexts, such as stroke rehabilitation guideline implementation (Munce et al. 2017) and physiotherapy evidence-based practice adoption (Paci et al. 2021). For example, the complete turnover of frontline staff between project submission and initiation meant that initial project buy-in could not be leveraged, requiring engagement with new staff whose priorities and focus differed. Similarly, time pressure, lack of space and inadequate equipment were recurrent barriers, reflecting systemic challenges beyond the scope of individual motivation.

Table 2 outlines how these stakeholder experiences informed the refinement of the ToC, incorporating organizational preconditions and contextual constraints previously underrepresented.

Reflexive co-production

The co-production of digital stories encouraged participants to reflect critically on their own experiences while contributing to system-level knowledge (Hardy and Sumner 2018). Collaborative script development and participant-led representation ensured that insights were authentic and grounded in lived experience, strengthening both methodological rigour and ethical engagement. The process also revealed the limits of standardized interventions: despite access to education and tools, staff were constrained by organizational realities, highlighting that innovation often feels like 'swimming against the tide' when structural and managerial conditions are unchanged.

Implications for service redesign

The study demonstrates that service standardization and scale-up cannot succeed without concurrent structural and managerial support. Digital storytelling functioned as both a diagnostic and reflective tool, surfacing actionable insights into barriers, facilitators and contextual conditions critical for successful implementation. By explicitly mapping narrative themes to ToC assumptions, this approach enables evidence-informed redesign that is responsive to stakeholder experience.

Much implementation research within physiotherapy has focused on the acceptability and feasibility of interventions from the service user perspective, with the aim of addressing potential barriers – such as adherence – prior to clinical trial evaluation. Within paediatric asthma and dysfunctional breathing services, however, interventions are already established and generally well received (Barker, Elphick, and Everard 2016; Hepworth et al. 2019), a finding reflected in the patient and parent narratives presented here. In this context, implementation efforts may need to shift attention from intervention acceptability towards organizational barriers – particularly time constraints, resource limitations and insufficient structural support – which remain significant impediments to adoption and sustainability, consistent with wider evidence (Munce et al. 2017).

Table 2. Theory of Change development through the digital storytelling project.

TOC original assumptions	TOC additional assumption	What is needed	Barriers
People care about accurate asthma diagnosis and high-quality patient management both in society and within the healthcare system	Institutions prioritize paediatric outpatient care in line with inpatient acute care services	Time	Institutional barriers: lack of staffing, space, equipment. Lack of prioritization of services, difficulty with IT systems, difficulty in gaining support from administrative staff. Discrepancy between adult and paediatric services.
People are aware that how we breathe matters especially to those with respiratory conditions or respiratory symptoms.	Systems should be adjustable and staff cases put forward	Protected services	Societal: Lack of understanding about how to make an accurate asthma diagnosis. Lack of knowledge and understanding about dysfunctional breathing and complexity of breathlessness management beyond pharmacology.
Not all breathlessness is asthma and differential diagnosis is a key element in patient management	Staff have the capacity and motivation to implement changes	Supportive line management	Professional: small number of physiotherapists specializing in this clinical area across the country.
Physiotherapy staff are interested in this clinical area	Institutions support change, innovation for improvement in services and patient health outcomes	Access to specialism and training support	Project management: staff delivering any innovation project and quality improvement need to be engaged with the theory of why change is needed and what the outcome will be. They need the support of their line manager to be given time and space to implement any new service development.
Patients would want to access these services if referred into them	Staff would engage with education materials, mentoring and personal development opportunities.	Staff retention and appropriate staff numbers for the service demand	Staff retention: Strains on services lead to work dissatisfaction and staff not remaining in post. This continues the cycle of few physiotherapists specializing in this clinical area and services continuing with high demand and low service provision.

As noted by Paci et al. (2021), 'lack of time' often represents many potential barriers, including limited willingness to modify established practice and the low prioritization of ongoing engagement with up-to-date evidence-based knowledge and skills. In the present project, limited facilitation – whether through insufficient leadership engagement or lack of protected staff capacity – constrained uptake despite clear frontline

motivation. This reinforces the importance of formal organizational frameworks and structured support practices to enable effective implementation (Paci et al. 2021; Zwikael and Meredith 2019).

Organizational support practices that prioritize early-stage (front-end) investment, rather than focusing solely on end outcomes, are associated with improved overall project performance (Zwikael and Meredith 2019). The development of formal frameworks and support practices can equip project teams to articulate objectives clearly, set strategic goals and align project management processes with their achievement, consequently strengthening the conditions necessary for sustained implementation (Zwikael and Meredith 2019).

Conclusion

Digital storytelling enabled the research team to interrogate assumptions about implementation, equity and staff capacity, generating rich, experiential evidence that complements traditional evaluation methods. Integrating co-production principles ensures that the knowledge produced reflects authentic stakeholder perspectives, strengthening both methodological integrity and the practical relevance of findings for healthcare innovation.

By supporting the voices of all stakeholders – both those being asked to implement change or those receiving care – to be heard, we can better understand the subtleties of their experience and respond to them. This project demonstrates how digital storytelling can function not only as a vehicle for representation, but as a reflexive design tool capable of interrogating implementation assumptions and informing service redesign within complex healthcare systems.

Contribution of paper

1. Novel use of digital storytelling of lived experiences of physiotherapists involved in innovation initiatives.
2. Novel use of digital storytelling presenting patient and parent lived experiences accessing NHS physiotherapy services.
3. Review of a new model of change theory for NHS physiotherapy services for children and young people with asthma and dysfunctional breathing.

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Ethical approval

None required – service improvement project. Consent gained participating in the project and the sharing of the digital storytelling outputs.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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