



Transforming Local Systems TEC Pathfinder Programme Evaluation

Final Report

Appendix 3: Highland Pathfinder

April 2023

Bouchra Atkinson

Dr Ailsa Cook

**This is an excerpt from a larger report.
The full report can be viewed [here](#).**

Appendix 3: Highland Transforming Local Systems Impact Report

AIM: To transform the Highland Respiratory Care pathway towards a pathway that is truly patient centred, by co-designing it with patients and all those who either use or provide respiratory services from the outset.

Overview

The Highland TEC Pathfinder is delivering many solutions aimed at transforming the Highland Respiratory Care pathway. Twelve solutions were developed in response to the priority areas of change identified through user engagement in the Discover phase. Specifically, qualitative research undertaken with patients and healthcare professionals indicated that there were four priority areas for change. Firstly, improving patients' access to information on all aspects of the respiratory pathway, including about their condition itself. Secondly, improving patients' access to support and additional services. Thirdly, improving healthcare professionals' confidence, knowledge, and ability to effectively diagnose, manage and make referrals on behalf of patients with respiratory conditions. Fourthly, improving secondary care processes and systems that enable patients to experience person-centred and streamlined care and support either as inpatients or outpatients, as well as the developing integrated systems for better data sharing and information flow to enable healthcare providers to effectively support patients.

The Highland TEC Pathfinder has developed solutions to address each of these priority areas. In this section we will assess how well the Pathfinder is making progress towards impact or is positioned for impact, by examining four key questions. Evidence is drawn from data collated by the Pathfinders in OutNav against three pathways (Discover/Define; Develop; Deliver - see Appendix 6).

- Which stakeholders did the Pathfinder engage across all four phases of the SAAtSD and how ('who with'), the value of the project to them ('how they feel')?
- To what extent are there changes in (or progress made towards changes in) knowledge, skills, relationships, capacity to support the intended changes in the system ('what they learn and gain')?
- To what extent is there evidence of the application and adoption of the solutions, or new ways of working ('what they do differently')?
- To what extent is there evidence of the scalability and spread of the solutions or new approaches, and the impact on people ('what difference does this make')?

Stakeholder engagement and the value of the project to them (‘who with’ and ‘how they felt’)

The Pathfinder has undertaken extensive user engagement in all phases of the Scottish Approach to Service Design (SAtdS). The Pathfinder engaged with patients and healthcare professionals through workshops, informal interviews, and discussion groups in the Discover phase, to gather views and to develop a systems understanding of the respiratory pathway from the perspective of users. Despite a good overall level of engagement from patients, one member of the Pathfinder described challenges in ensuring people with lived experience were engaged. Covid-19 and the move to online engagement was cited as one factor affecting the numbers of people with lived experience that were included in the process. Overall, one hundred and thirty-four patients were engaged either in workshops, surveys, focus groups, or informal interviews in the first phase.

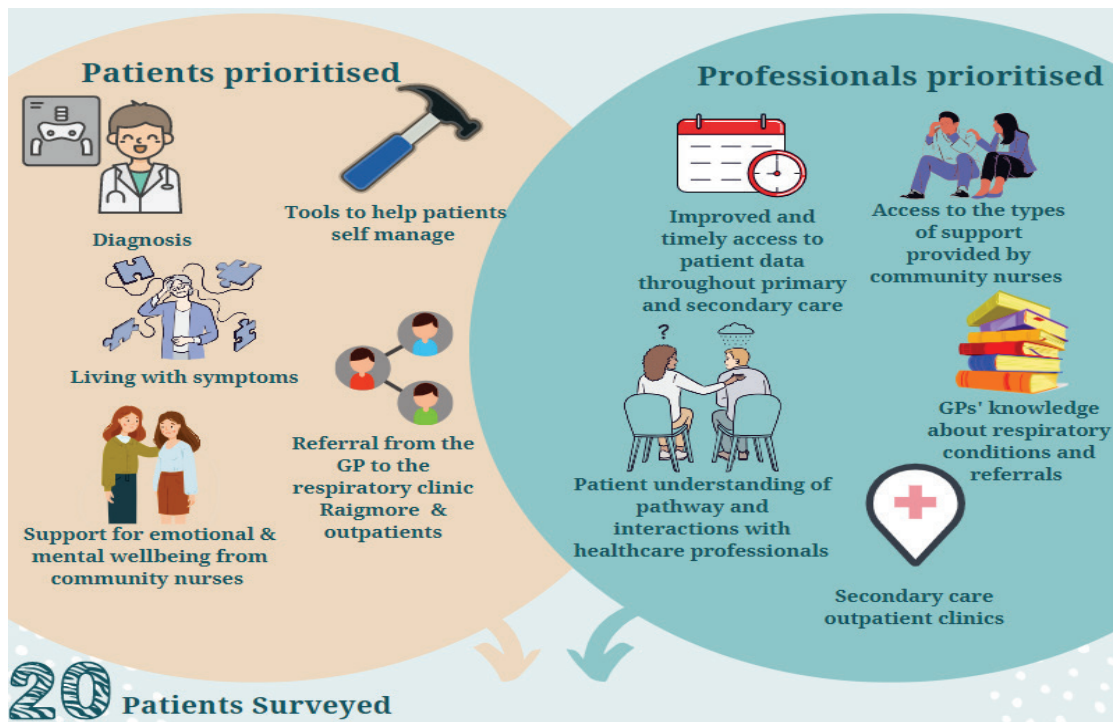
Figure 1. Highland Infographic



During the Define and Develop phase, the Pathfinder continued to have a good level of engagement with patients and healthcare professionals. This informed the analysis and prioritisation process undertaken to extract key themes, priorities and to refine the problem statement. The Highland Pathfinder’s third sector partners Chest, Heart and Stroke Scotland (CHSS) and Let’s Get On With It Together (LGOWIT) were critical to ensuring people with lived experience were engaged in these early phases.³⁴

³⁴ Stakeholder interview

Figure 2. Areas of change identified by patients and professionals during the Define phase



During the Develop phase, the Pathfinder delivered a well-attended stakeholder workshop, patient surveys, and several ideation workshops with healthcare professionals, to ideate and develop several solutions which were further refined over the course of three short-life working groups.

During the Deliver phase the Pathfinder worked with healthcare professionals, several different teams within NHS Highland (including the respiratory team, e-Health and TAM), its third sector partners as well as the Digital Health and Care Innovation Centre (DHI), Public Health and representatives from Primary Care to take forward and implement the solutions.

Figure 3. Highland Pathfinder 1.2 solutions

Patient information	Patient support	Clinician knowledge	Data sharing & flow
<ol style="list-style-type: none"> 1. Respiratory Resource Hub – online and on paper 2. Online open learning and Q&A sessions 3. Digital access to patient's own medical records 4. Improved secondary care letters 	<ol style="list-style-type: none"> 5. Improved access to specialist respiratory nurses 6. Improved access to and uptake of pulmonary rehab 7. Embed 3rd sector (CHSS & LGOWIT) within the respiratory pathway 	<ol style="list-style-type: none"> 8. Improved Respiratory Guidelines on TAM 9. Improved opportunities for learning & knowledge exchange through: <ul style="list-style-type: none"> • Online teaching sessions • Multidisciplinary team meetings • Joint clinics • Mentoring 	<ol style="list-style-type: none"> 10. Improved secondary care systems and processes 11. Improved clinical applications and data sharing for healthcare professionals 12. Implemented COPD pathway & improved data sharing with SAS

The broad engagement of stakeholders across all phases of the SATSD has been central to ensuring the solutions designed are relevant, person-centred and address identified needs.

There are early indications that this approach is supporting the actionability and uptake of the research and solutions. Specifically, there has been consistent usage of the Respiratory Resource Hub. A feedback survey embedded in the Resource Hub between January and August 2022 shows nearly a quarter having been referred to the Hub by their respiratory nurse, primary care, or peer support group. Additionally, 57% of the respondents noted they came to the Hub through social media. The Pathfinder has indicated the Respiratory Hub was mainly promoted through social media and via the Your Breathing Matters (YBM) learning events which have proved to be popular. Each of the four YBM sessions run between February and August 2022 were well attended, indicating a clear need for the support and information provided in the session. One participant noted “I’m just so relieved to finally get some information and help”.³⁵ The topics of the sessions are informed by patient views, and the Pathfinder has indicated that co-designing the sessions with the patients was a key driver for the success of YBM. Furthermore, the Pathfinder has buy-in from the Specialist Community Respiratory Team (CRT) in NHS Highland, who have agreed to manage the YBM platform and the delivery of the sessions, ensuring sustainability. Specialist Respiratory Nurses from CRT were engaged in the Pathfinder from the outset and formed part of the Core Group.³⁶

Core partners involved in the Pathfinder have reported that the experience has been valuable to them.³⁷ One third sector partner noted that the “project has probably been relatively transformative for us as a charity”.³⁸ Other core partners noted:

“ What took over was the collaborative approach, a lovely gel, it felt really friendly ... In a way I think that validated us and gave us a bit of motivation for keeping on with the project and making things better.”

- Specialist Respiratory Community Nurse, NHS Highland

“ The Pathfinders group have given us a resource ... we now have a plan for the way forward which has been created with patients and staff.”

- Respiratory Consultant

The Pathfinder has evaluated and obtained feedback from users of some of the solutions it has implemented. Feedback on the value of the Respiratory Resource Hub has generally been positive, with 66% of respondents to an embedded feedback survey agreeing they found it useful and 53% agreeing they were likely to use it again.³⁹ Feedback obtained by the Pathfinder on the Your Breathing Matters sessions and on the educational sessions delivered through ECHO for healthcare professionals indicate that participants have found these resources useful.⁴⁰

³⁵ Padlet. (n.d.). Highland Pathfinder Final Report. [online] Available at: [link](#) [Accessed 21 Apr. 2023].

³⁶ Padlet. (n.d.). Highland Pathfinder Final Report. [online] Available at: [link](#) [Accessed 21 Apr. 2023].

³⁷ Stakeholder interview

³⁸ Stakeholder interview

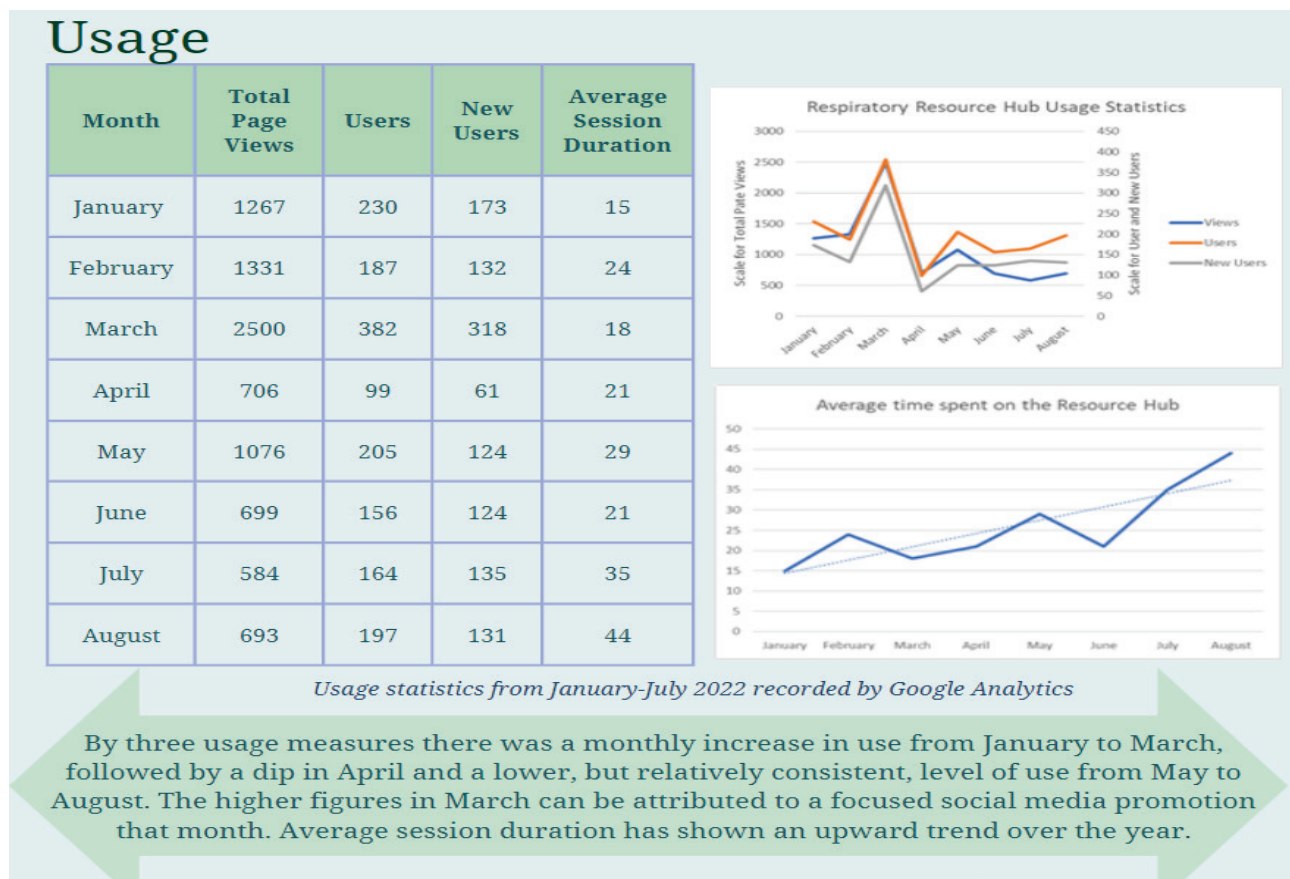
³⁹ Padlet. (n.d.). Highland Pathfinder Final Report. [online] Available at: [link](#) [Accessed 21 Apr. 2023].

⁴⁰ Padlet. (n.d.). Highland Pathfinder Final Report. [online] Available at: [link](#) [Accessed 21 Apr. 2023].

Knowledge, skills, relationships and capacity (‘what they learned and gained’)

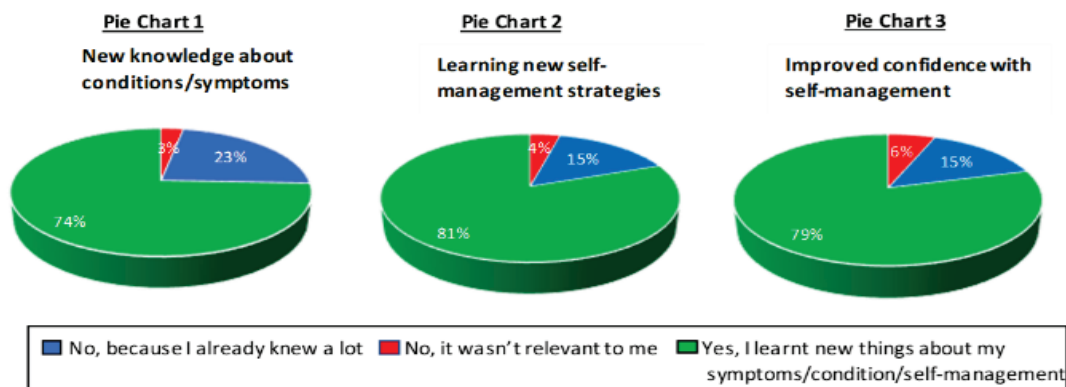
The Highland TEC Pathfinder has made significant progress in improving patients’ access to information. Usage statistics are shown for the Respiratory Resource Hub below.

Figure 4. Usage statistics for the ‘Respiratory Resource Hub’



There is good evidence showing that the Highland Pathfinder is effectively improving knowledge and strengthening capacity of people to manage their own conditions and prevent exacerbation. The Pathfinder is delivering open learning sessions, branded ‘Your Breathing Matters’, for patients and carers, which are run bi-monthly online using a Near Me Group Consultation platform. These are demonstrations or talks facilitated by a Specialist Respiratory Nurse. The talks are also made available open source on the Respiratory Resource Hub. Feedback obtained by the Pathfinder from participants of the Your Breathing Matters sessions shows that of the fifty-eight people who registered for the sessions between February and August 2022, the vast majority learned something new about their symptoms (74%) and learned new self-management strategies (81%), while 79% reported improved confidence with self-management.

Figure 5. Feedback on Your Breathing Matters



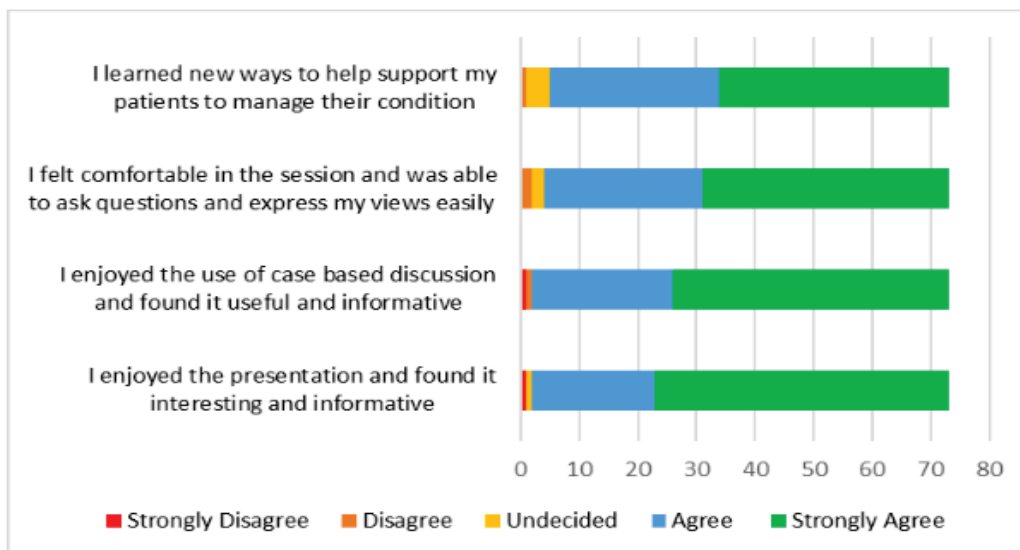
“ Another brilliant session. I learnt a lot from both speakers but particularly the respiratory physio (I think she was). I did not know it was possible to move your cough from your lower respiratory to upper respiratory tract yourself!”

“ Have been singing the 1 121 12321 in the woods whilst walking my dog as well as doing the diaphragm breathing and am feeling in a much better place than I was before.”

The Pathfinder has created new processes at an organisational level in NHS Highland (NHS) to ensure capacity strengthening of healthcare professionals is embedded. The Pathfinder has partnered with Project ECHO (Extension of Community Health Outcomes)⁴¹ to deliver a regular series of online respiratory learning sessions via ECHO to healthcare professionals in community, primary or secondary care. The structure of the sessions involves presentations made by respiratory specialists, facilitated by a specialist respiratory nurse, followed by case-based discussion with participants. The sessions are intended to improve healthcare professionals’ knowledge and confidence managing patients with respiratory conditions, as well as improve relationships between primary and secondary care, and referral pathways. The Pathfinder obtained feedback on the online ECHO learning sessions, aimed at building the confidence and capacity of those involved in diagnosing, managing, and making referrals for patients. One hundred and twenty-one healthcare professionals signed up to the sessions, which were held fortnightly between April 2022 and June 2022. Most of the participants who attended agreed or strongly agreed that they learned new ways to support patients to manage their condition.

⁴¹ Hospice, H. (2023). PROJECT ECHO. [online] Highland Hospice. Available at: [link](#) [Accessed 21 Apr. 2023].

Figure 6. Feedback from ECHO sessions



The Pathfinder has also improved and developed new respiratory guidelines made available in NHS Highland’s online system ‘TAM’ - ‘Treatment and Medicines’. The Pathfinder has developed a set of standardised respiratory guidelines, linked to national guidelines, for clinicians to support the diagnosis, management, and referral of patients with respiratory conditions. These guidelines are hosted on NHS Highland’s current online information system and app known as TAM (Treatment and Medicines). A clinician has been appointed to TAM for one year to support the development of these guidelines. The Pathfinder plans to evaluate the effect of the guidelines on respiratory referrals one year after the publication of the guidelines.

Individuals interviewed from the core Pathfinder team indicated that the project had resulted in strengthened relationships. The strong partnerships built with the third sector were highlighted. One third sector partner noted they went from feeling like they were initially included in the proposal to “tick a box” to feeling like they were consistently listened to and that they were equal partners in the project.

“ We worked really well as a team and there was an inclusive listening approach ... We as a third sector organisation felt equal in the development of the project ... So we felt listened to and included.”

- Third sector partner

“ So part of it was that relationship. So speaking to people, respiratory consultants, getting known and ... the double diamond approach. I generally think that’s going to be transformative ... I hope so.”

- Third sector partner

Application or adoption of the solutions or new ways of working ('what they are doing differently')

The Pathfinder's core solutions intended to improve access to information and strengthen capacity have been implemented by NHS Highland with steps taken to ensure longevity and sustainability. The Respiratory Resource Hub initially integrated into NHH's current online resource website and app TAM is now being adopted by The Right Decision Service (RDS) (part of DHI). NHH have been offered – at no additional expense – access to RDS's own iteration of Quris software, and migration of the Resource Hub to RDS was planned for the end of 2022. This option will improve functionality of the Hub and provide a long-term option for hosting the site. The Your Breathing Matters learning sessions intended to support patients and carers are delivered using the Near Me Group Consultation platform. The Community Respiratory Nursing Team (CRT) have taken full ownership of this solution, and it has been embedded in their operational processes. They will fully undertake the planning, delivery and evaluation of these sessions. The online knowledge exchange and learning sessions for healthcare professionals have been taken on by the Highland Hospice ECHO team, and a curriculum has been co-developed and sessions embedded in the respiratory calendar.

The Pathfinder has come up against several barriers to data sharing and information flow, hindering progress in improving secondary care processes and systems within NHH (NHH). The problem of the lack of integrated systems impeding healthcare professionals' ability to access all relevant medical data (from both primary and secondary care) was highlighted as a priority issue during the 'Discover' phase. An original key aim of the Pathfinder was to support work that has already been underway for some time in NHH to integrate systems to enable a single point of access to data. However, limited progress has been made. A key issue complicating the task was that IT system changes cannot be implemented for the respiratory department alone. The Pathfinder has however provided additional evidence and weight towards the creation of a data sharing agreement between primary and secondary care being progressed by the e-Health department in NHH.

Despite the limited progress in overcoming data sharing barriers at the organisational level in NHH, the Pathfinder has effectively raised awareness of the importance and desirability of citizen-owned data, as expressed by users. Most significantly, the Pathfinder has gained the support of DHI, which is drawing learning from the Midlothian Pathfinder to support, in the long term, the creation of a digital access solution for NHS Highland to enable citizens to access their personal data. The Pathfinder's recommendations and learning have been shared with the DHI team. In 2021, the Pathfinder surveyed 26 patients, gathering their views on the healthcare records and functionality they would like to be able to access digitally. Most popular were test results, with explanations of the results; clinic letters summarising the clinic appointment; primary care notes and outpatient notes. The announcement of the Scottish Digital Front Door project shows the priority identified by the Pathfinder for patients to access their own data has also been identified at a national level.

Figure 7. 'Test' interface prototype of a patient digital record



The Pathfinder has recognised that due to financial and technical limitations it will be unable – in the time frame of the project – to sustainably implement other solutions it has defined and developed. But it has successfully influenced other organisations and programmes to adopt its solutions. In December 2021, the Scottish Government funded the Interface Care Programme, aimed at reducing hospital stays by delivering alternative safe and high-quality care. The Interface Care Programme will provide funding for an additional specialist respiratory nurse as well as an administrator to support the CRT and additional educational activities undertaken by them. The importance of administrative support to ensure the effectiveness and efficiency of the CRT was highlighted in the Pathfinder’s recommendations and will ensure there is additional capacity to support the solutions developed by the Pathfinder that have been taken up by the CRT. Furthermore, the Pathfinder recommended developing an early supported discharge (ESD) service. This will be taken up by the Interface Programme, which will fund the development of a virtual ESD service, involving a remote ward on ‘TrakCare’ and a remote monitoring platform.

Learning and recommendations from the Pathfinder on pulmonary rehabilitation will be taken up by the Interface Care Programme. The Pathfinder has highlighted the importance of pulmonary rehabilitation for patients with pulmonary conditions and the need to move to a co-ordinated rehabilitation service with its own funding, management and common processes, including funding for specialist respiratory physiotherapists. A pulmonary rehabilitation service would improve provision, access and awareness of tools to self-manage pulmonary conditions, including courses and classes to support pulmonary rehabilitation. While the Pathfinder has not been able to develop a pulmonary rehab service, the recommendations and lessons from the Pathfinder have been taken up

by the Interface Care Programme. The Pathfinder will feed into the Programme via a rehabilitation steering group set up in NHS Highland.

The Pathfinder also has the potential to contribute to enabling people to self-manage their respiratory conditions in the long term by co-developing courses of pulmonary rehabilitation health classes, to be run in leisure centres in Highland. The Pathfinder held discussions with High Life Highland about holding Active Health classes at their leisure centres to support people who do not yet meet the criteria for pulmonary rehab. The Leisure centre has agreed to hold these sessions as part of the suite of online classes that it runs on a variety of long-term health conditions to support people towards active self-management.

Scalability and spread of the solutions or new approaches and the impact on people ('what difference is this making')

There is promise that the solutions implemented and recommended by the Highland Pathfinder will have a significantly greater reach over the long term than that currently achieved. Several solutions are well-embedded in the existing processes and structures of NHS Highland and are no longer tied to the Pathfinder per se, ensuring greater sustainability. Additionally, these solutions could be taken up by other specialities within NHS Highland and also by respiratory services within other health boards across Scotland. The Pathfinder has disseminated the outputs of its project widely through its End of Project event and has made all its resources and outputs available in an electronic library on Padlet (www.bit.ly/RespiratoryPathfinder).

Importantly, NHS Highland also has raised awareness of the essential role played by specialist respiratory nurses. The Community Respiratory Team has been fully embedded in the Pathfinder's work; specialist respiratory nurses are involved in the Your Breathing Matters and ECHO sessions and in providing expert knowledge for the Respiratory Resource Hub. Moreover, the Scottish Government funded Interface Care Programme has taken on the Pathfinder's recommendations to support the Community Respiratory Team. The Interface Care Programme will provide funding for an additional specialist respiratory nurse as well as an administrator to support the CRT and additional educational activities undertaken by them.

An important achievement of the Highland Pathfinder has been in creating a new pathway with the Scottish Ambulance Service. The Pathfinder established a new pathway for Scottish Ambulance Service and NHS Highland whereby COPD patients who called out an ambulance, but did not need to be taken to hospital, could be referred for follow-up by the specialist respiratory nurses, thereby providing a safety net for these patients. The pathway is intended to reduce hospital admissions and improve patients' access to specialist respiratory nurses and third sector organisations, as well as improve patients' confidence and ability to self-manage. The Pathfinder, however, noted in its final report "By September 2022 only 2 patients had been referred via this pathway. The reason for this is unclear, it is possible patients have not met the criteria or that individual SAS paramedics are not sufficiently aware of or confident using the pathway". While the importance of creating successful data-sharing agreements, given the significant barriers, should be recognised, this example illustrates that while data sharing is an important 'gateway' to ensuring more person-centred and efficient services, it is not, in itself, a sufficient criterion for success. Additional work needs to be done to ensure that the channels of communication opened by data-sharing agreements are well publicised, understood and used. However, if the pathway is effectively

communicated and implemented, it will support the sustainability of the Pathfinder's solutions and its ability to contribute significantly to enabling people to self-manage their long-term respiratory conditions.

While some of the Pathfinder's solutions have been taken up by other providers with the resources and technical know-how to implement them at scale, their sustainability and their successful future implementation is not guaranteed. Some solutions, such as the creation of a Digital Access solution by DHI for citizen-owned data, are not constrained to respiratory alone and therefore have potential to transform the patient experience across all specialities. This is a long-term goal as described in the Midlothian Pathfinder, but with significant potential. However, there are still many barriers towards wider implementation.

The adoption of the Pathfinder's solutions for the CRT and pulmonary rehabilitation service by the Interface Care Programme will improve patient experience, their ability to access information and self-manage their condition. However, funding for these solutions from Interface Care is for only two years.

“ They were asking people who were already relatively pressured. They were asking health professionals, GPs etc, who had already given time to the project but they needed to look at more sustainable ways of setting up.”

- Third sector partner

The Pathfinder has also increased awareness of the support and role played by the third sector.⁴² The Pathfinder highlighted the importance of third sector organisations to the respiratory pathway in the Together We Care strategy consultation.⁴³ However, NHS Highland was unable to commit to providing additional funding for these organisations from its budget outwith the project. One stakeholder noted that the challenge lay in the siloed team structures in NHSH, which meant that financial decisions were driven by teams less bought in and involved in the Pathfinder project.⁴⁴ The implications of this is that the third sector will have to continue to self-fund, and this will limit their ability to reach a greater number of patients (including from primary care) who would benefit from their support for self-management, education and rehabilitation.

⁴² Stakeholder interview.

⁴³ Padlet. (n.d.). Highland Pathfinder Final Report. [online] Available at: [link](#) [Accessed 21 Apr. 2023].

⁴⁴ Stakeholder interview