



# Transforming Local Systems TEC Pathfinder Programme Evaluation

**Final Report**

**Appendix 4: Midlothian Pathfinder**

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

# Appendix 4: Midlothian Transforming Local Systems Impact Report

**AIM: To transform traditional models of care to enable the increasing numbers of people living with frailty to achieve their best possible quality of life.**

## Overview

**The Midlothian Pathfinder is working with Digital Health and Care Innovation Centre (DHI), the Glasgow School of Art, the Red Cross and VOCAL to develop a long-term digital solution to improve people’s access to services, and to improve connections and the flow of information between services. This is with the aim of improving the experience of care and support for people living with frailty, their family, carers, and staff.** The findings from user research and the Discover phase led the Pathfinder to focus on ‘hubs’ in the system to overcome barriers people face in accessing support and in navigating the complexity of the health and care system. Hubs can be ‘professionals’ (for example third sector organisations) who guide people through the health and care system; carers who navigate on behalf of the person; and people living with frailty who prefer to navigate for themselves. Hubs were placed at the centre of the solution, as they were identified by people as the kind of support that was most valued. Hubs were identified as helping ‘the digitally anxious’ to use technology, access person-centred care, and to enable self-reliance. This builds on the concept of the ‘Circle of Care’, which has been explored in variety of ways across health and social care. The Circle of Care “re-envision[s] compassionate healthcare by placing it in a broad social and interpersonal context, describing a multi-directional flow of care between healthcare professionals and their colleagues, patients and carers.”<sup>45</sup> The Pathfinder sought to bring in new thinking, new approaches, and new capabilities, to incorporate Technology Enabled Care and design thinking as transformation enablers in a person-centred system of frailty care. The Pathfinder’s solutions were developed in recognition of the following problems:

- Effort and data are siloed, with no readily available method to resolve this;
- Our current operating model ‘puts’ the citizen at the centre but is not patient centred;
- Governance constraints limit systems integration.<sup>46</sup>

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 SATSD and how (‘who with’), the value of the project to them (‘how they feel’)

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<sup>45</sup> Circle of Care. (n.d.). Available at: [link](#)

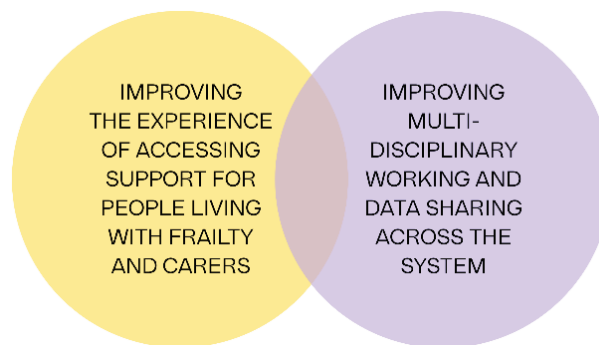
<sup>46</sup> Midlothian Pathfinder Summary (Jan 2023), internal document.

- 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 throughout the project.** User engagement was facilitated by DHI staff from the Glasgow School of Art, who had specialist expertise in participatory design approaches. User engagement during the Discover/Define stage took place at several different levels. The first stage involved a service mapping workshop, which was held with staff from across the health and care system to get a better understanding of the complex system, and the current pathways for care for people living with frailty in Midlothian. Two key themes emerged:

Figure 1. Key themes



The Pathfinder also intended to engage the public through pop-up stands in public spaces and at events. However, due to Covid-19, this was redesigned, and greeting cards shaped as flowers were designed, with three questions aimed at understanding more about getting older: “What keeps you well?” “What is good about aging in Midlothian?” and “How might we support you?” One hundred and twenty greeting cards were sent out to people living with frailty, included in British Red Cross packs. Seventeen responses were received, in addition to the eight responses that were submitted online.

**The tools used by the Pathfinder to interview people with lived experience have been very valuable. They have been used both as a means of gathering information but also for feeding back research to participants. Follow-up conversations to discuss the output of the research were also an opportunity to point people to useful services that they may have been unaware of. The role of third sector partners in engaging people and in conducting interviews was also important here.** Overall, the Pathfinder undertook nine in-depth two-stage interviews with people

with lived experience of frailty and five with carers, to understand what supports people to feel valued, and to identify challenges or unmet needs. Due to Covid-19, the interviews took place over the phone. Interviews were carried out by two people, one from the voluntary sector (whom the participant knew) and one from DHI. The two-stage interview process was a useful way of reflecting findings back to participants. After the first interview, Pathfinder members created a Circle of Care map, which they then shared back with the participant in the second interview to identify if anything was missed or misunderstood. This was a valuable process as in the second engagement the interviewers from the voluntary sector (Red Cross/VOCAL) were able to suggest services, products or organisations that might help the individual. Additionally, one stakeholder noted, that the representation of the system using the Circle of Care visual was appreciated by many participants and it was also seen as a valuable tool by carers.

“ So for each citizen interviewed we created a map and a visual ... an overview of everything that they talked about as their ‘Circles of Care’. We posted that back out to them and used it to have a follow-up conversation ... We also asked people ‘what did you think of it?’ and we had people sharing it with their families and talking about it ... quite a reflective thing ... but overwhelmingly positive ... it enabled conversation [but] we were [also] able to say you talked a little bit about this [challenge] ... have you thought about these things [as supports] because it was a paired interview with an advisor [who] knew what supports were available in Midlothian ... When [we also] showed [the visuals] to professionals like VOCAL advisors they just looked at it and said ‘this would be fantastic for talking to our carers and for us to be able to have a holistic conversation, to see the whole person’.”

- Pathfinder team member

“ The work we did with [citizens] through Glasgow University. We went back to them with their story laid out in a visual way. And what people were coming back with was ... They didn't realize how many people were involved with them, and what had been achieved over that period of time ... And it also helped them recognise where the gaps were, but also who they could go to to support them. So for the individuals the feedback we were getting was they loved participating in it and it gave them something back and something visual that they could keep and share with their family.”

- Third sector partner

Figure 2. Circle of Care example for an interview participant who chose the pseudonym Georgina



**As well as people with lived experience, the Pathfinder has also engaged closely with other users, including professionals from the third and independent sector as well as other healthcare practitioners.** The final stage of engagement during the Discover/Define stage involved engaging professionals to reflect on the interviews that had been conducted with people with lived experience. In interviews with citizens, people had highlighted supports such as social activities, family, and friends, as well as the support provided by the third sector, GPs, nurses, and carers in navigating the complex health and care system. Barriers to navigating support included form filling, bureaucracy, waiting times, lack of awareness and confidence. Professionals were able to reflect on this information to support the Pathfinder's overall understanding. It also encouraged professionals to reflect on how they work and to identify opportunities for new ways of working.

“ It's brought to life the issues that people are experiencing and so a big part of the work that we've undertaken is the engagement with carers and ... it also informed internally as well. It had a double benefit.”

- Third sector partner

## Knowledge, skills, relationships and capacity

**As described in the previous section, the process of user engagement undertaken by the Pathfinder was as important as the research and information produced.** The methods and data visualisation approaches were helpful in engaging people in good conversation about services and supports available. It also provided a deeper understanding of the issues, challenges and barriers faced by people living with frailty among the third sector partners directly involved in the Pathfinder, as well as other professionals.

“ I think there will absolutely be a legacy. I think it's generated some really useful conversations locally about our systems and how we share information and the experience for the people that we're supporting who get passed between service to service to service and how do we try and overcome that to give a better experience for the individual.”

- Third sector partner

“ It was quite an eye opener the way that it was done through the Glasgow School of Art and I think brought to our service that a) we were doing a good job and b) there were multiple partners involved and [made us think] how we could work better together for the benefit of the client. I felt it was very worthwhile. And then to share that with a wider audience in the [healthcare and] voluntary sector on the outcomes of that. It gave you a tool to use to show your work.”

- Third sector partner

“ So service users, you know, from two years ago ... they've come back to us. They knew if they couldn't find it themselves, they could come back to us and we would be able to find them an answer or be able to help them directly ourselves.”

- Third sector partner

**An important outcome of the Pathfinder has been to enhance the relationship between the two third sector organisations involved in the Pathfinder, VOCAL and the Red Cross.**

“ We have now created a formal partnership and we have a dedicated carer connector who works for the Red Cross but links in with VOCAL very closely.”

- Third sector partner

**Third sector partners also described the strengthened relationship with Midlothian HSCP as extremely valuable.** Stronger engagement with the HSCP and the Pathfinder was described as leading to changes in internal organisational processes.

“ I think it's been very valuable ... to ourselves, it's made us think about how we approach assessment of clients and we've increased that assessment and taking in things like how important anticipated care planning is, emergency care planning. So that's already been put into assessment and support planning [strategy].”

- Third sector partner

A stronger relationship has also led to a third sector partner being able to support the HSCP more effectively. One partner described being more heavily involved in supporting the Council's strategic planning processes, including feeding in relevant statistics related to falls and hospital admissions.

“ And it's giving us a clearer idea of what the Local Authority want in the way of ... what stats do they actually need. So a big one was the number of falls ... and because of Covid ... the mobility has reduced so there's a higher fall rate, which means higher admissions to hospital. So we are able to report back on a number of these things every quarter which to me helps the Council plan for the future. [Previously] we didn't have any way of directing it into the Council ... We've been involved in a lot of the strategic planning going forward, such as falls, such as carers, older people's planning group and Council staff are more aware of what we can produce to support them.”

- Third sector partner

### **Third sector partners described new connections they developed resulting from their engagement with the HSCP and the Pathfinder.**

“ I've just been invited to Health Improvement Scotland under the frailty [work] because [an individual] at the Council is leading on a piece of work.”

- Third sector partner

“ There's been off spin off as well with SCVO [Scottish Council for Voluntary Organisations], there's been training that I've attended that I've been made aware of [by my contact in the HSCP] so that's actually enabled me to make links with other organisations or opportunities.”

- Third sector partner

**DHI, who are key partners in the delivery of the Pathfinder solutions, have also assessed the relationship they built with the Midlothian Pathfinder and its third sector partners as hugely valuable.** DHI has specifically benefited from the health and care knowledge and expertise brought by the partnership and the third sector organisations Red Cross and VOCAL.

“ The Innovation Centre became more holistic and person-centred in our thinking and strategy as a result of the contact.”

- Pathfinder stakeholder

**Reflecting this change in focus and understanding of integrated care, DHI have developed a new strategy in which, as a direct result of the project, ‘integrated co-managed care’ is one of the four core pillars, expected to comprise a quarter of the innovation centre’s workplan over the next ten years.** DHI described the strong relationship between Midlothian HSCP and Red Cross and VOCAL as significantly contributing to this change in focus, resulting in DHI gaining a greater understanding of integrated care and a hugely valuable data set born from the co-design phase with users.

**Overall, the co-design activities undertaken in the Discover/Define stage have enabled the Pathfinder and DHI to get a better understanding of what a ‘future state system’ facilitated by digital tools might look like.** “Key challenges identified were repetition of information at multiple interactions with services; lack of agency (for cared for people and their carers) though the system relies on their support; repeated failures to access benefits/services to which people were entitled; confounding processes causing stress either resulting in giving up or wasted effort through duplication of information from support services or both. These activities helped DHI refine their process for collaborative service mapping in Health and Social Care and generated a vision or blueprint for future care...This blueprint and refined process have been applied and iterated in subsequent DHI projects<sup>47</sup>

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

**The co-design work in the Midlothian Pathfinder continues to contribute to ongoing work by DHI on developing the so-called ‘Collaborative Care Architecture’.** DHI has created a first-generation blueprint for the “Collaborative Care Architecture” which demonstrates a ‘future state story’ facilitated by new digital tools. This moves beyond the normal focus on user interfaces, to consider an ecosystem of software systems that integrate and extend. Several elements of this blueprint are being developed into prototypes.

**Within this, DHI has been exploring the Circle of Care concept. This builds on findings from several of its projects in a broader national portfolio.** The concept rests on the idea of citizen-owned data, where citizens have access and control over their data and can permit others, family, health and social care staff or carers to access and share relevant information and data across the system to ensure they receive better care. Midlothian Pathfinder has specifically contributed a significant amount from the health and care perspective to the Circle of Care concept, through its co-designed user journeys and the engagement work in the Discover phase. The next phase of work to be completed before March 2023, is the completion of a non-functional, clickable prototype of the Circle of Care, which will enable people to have the illusion of experiencing the Circle of Care interactions of a future state system.

**Resources from the Pathfinder have enabled DHI to commission Mydex, who in early 2023, will develop a set of apps integrated into a Personal Data Store that will later power the Circle of Care concept.** This will be undertaken using the first third of the overall target story from the co-design phase. For this portion a full data dictionary has been developed, alongside a ‘simulation story’ (a data sharing focused version of the future state story) to support development. Using this data,

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<sup>47</sup> ibid



Mydex will produce a set of functional prototype apps integrated into a personal data store. This will show how the individual apps held by citizen, carer, and various professionals will support the generation and reuse of the person's story. DHI has noted that there is still more work to be done on the data set that will sit under the full end to end story. The Glasgow School of Art is planning to undertake another round of co-design with citizens to feed into the next version of digital tools which is expected to be "significantly more sophisticated but not more complicated." This story data can then be used to power future 'Circle of Care' functional prototype development.

**In the short-term, a pilot supporting integration across VOCAL and Red Cross's CRM systems is planned as part of the work leading to the development of the functional prototype.** The long-term aim of the functional prototype of the Circle of Care is to allow information to be shared across the health and care system more easily, with permissions given by the citizen. While it is expected that the pilot will enable designers to test the model and identify real world challenges, it isn't anticipated that a fully functional integrated system between Red Cross and VOCAL will be developed in the short term. The pilot will feed into the overall learning for the development of the functional prototype and may involve some basic short-term improvements in the way Red Cross and VOCAL systems can communicate.

“ The proposal when you see that mapped out, you can actually see the work that's gone into it not just from one organisation, but collectively and you can potentially see the impact it would make for carers in particular to be able to engage with something that get them through systems so much easier than they're experiencing at the moment.”

- Third sector partner

**There are plans for beyond the Pathfinder. DHI will undertake further development of the prototypes and personal data store.** They will undergo further phases of testing, simulations and integration into wider health and care systems (for example GP systems).

“ Everyone who has been shown the first generation prototype as an example of a more holistic navigation based thought process ... has reacted very positively.”

- Pathfinder stakeholder

**In addition to the Circle of Care prototype, the knowledge outputs from the Pathfinder have also been assessed as extremely valuable and some of these outputs have already been integrated into national strategies.** The scenario and personas developed from the user research gathered during the Discover phase of the Pathfinder is being integrated via DHI into several national strategies including the Digital Health and Care Strategy, the National Care Service, the National Health and Care data strategy and the Digital Front Door. Overall, DHI has provided a suite of nine personas across three scenarios, where frailty is one scenario, to anchor national delivery and strategy to the needs of real people based on co-design. Aspects of this are expected to be published soon.<sup>48</sup>

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<sup>48</sup> Interview with DHI

## Scalability and spread of the solutions or new approaches and the impact on people

**Developing the Collaborative Care Architecture is a long-term investment, with several technical development phases still to occur, as well as information governance (IG) barriers to be overcome before it can be implemented in practice and at scale.** The next phase of the implementation of the Collaborative Care Architecture is yet to be determined. DHI is currently determining if the solution can be brought into a national development process, providing greater potential for its scalability, and spread. The Pathfinder is contributing to the critical mass that is needed to drive a digital solution with truly transformative potential in the long term. In the short term, there are indications that the ‘high value/impact’ data set that is being developed in the Pathfinder is likely to inform national strategy as well as support other local transformation projects due to its robustness as a data set, and its reusability.

**Building on the co-designed outputs of the user engagement phase of the Pathfinder, DHI is creating a harmonised data model for the Red Cross, VOCAL and Midlothian HSCP.** The data model shows a single user journey for a person and their carer, including all typical, non-unique interactions, assessments, processes, and conversations that take place over a period of time.

“ Our working hypothesis is that the person who is frail in this story and the carer, that over the course of their engagement of a year, that 50% of that data is repeated. They are answering the same questions, with the same answers over and over again. And this is typical as people move within and between health and care services.

- Pathfinder stakeholder

“ Some of the remaining 50% of the data then appears unique ... [But] really they are trying to get the same outcome from the system. They are asking questions to generate the same insight or decision. We’re trying to figure out what the ‘high impact data set is’ [telling story once].”

- Pathfinder stakeholder

A high impact data set, with methods for its storage and sharing, would be very beneficial to support development of the National Care Service data platform, and DHI is having early conversations with key strategic partners involved in its development, who have all indicated the value of the well-evidenced data model, and its potential to be foundational for their work. In addition, DHI is creating a ‘pattern recognition board’ with Mydex, who are also DHI’s supplier supporting other health and care related projects (the Promise and the Moray HSCP). A pattern recognition board identifies the common components between the projects to enable aspects from the Midlothian project to be replicated in other projects.

“ It will go blazingly quick if people leverage what we have done because they will be able to do three months of translation work as opposed to deep participatory user design, because they have such good foundations [Midlothian data set] and confidence of rigour ... and it is very translatable.”

- Pathfinder stakeholder

**There is good evidence indicating that the outputs from the Pathfinder project are scalable and sustainable.** There are strong indications that the outputs from the Pathfinder will inform the future development of national strategies and are of 'high value' with significant potential to support other research, service design and transformation projects.