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Participatory design of service innovation to support people and their carers in Moray

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This paper describes the findings of a participatory-design project focussed on the use of modern, digital technologies to support people and their carers. In particular, to improve access to services, better co-ordinate services and to make support packages more resilient (more likely to reduce a crisis situation and more likely to last longer before needing changes). The design activities were: a focus group and three participatory design workshops, all with health and care professionals, and several interviews with unpaid carers. The work all took place in Moray, Scotland. The findings are presented as designed concepts and insights that should help health and care delivery, in particular, by supporting unpaid carers. The paper contributes four concepts alongside insights from the unpaid carers. The concepts are (at the time of writing) being developed for future use in the region and so the paper also describes the process of procuring simulated healthcare services in order to increase learning and improve the adoption of innovative service changes. Ultimately this work, the resulting commissioned innovative services and the long-lasting benefits in terms of service innovation should benefit Moray economically.

Keywords: participatory design; digital health and care; innovation

1 Introduction

This paper describes a participatory design project focussed on the innovation of care services provided by Health and Social Care Moray (H&SC Moray). The paper contributes to IASDR 2023's Organizations and Policies theme in that it describes participatory design activity that aims to transform the way in which a partnership of public organisations works, through innovative service design. Health & Social Care Moray are one of Scotland's health and care partnerships responsible for the delivery of health services (through NHS Grampian, a much larger region than just Moray) and care services, through Moray Council. According to preliminary discussions with the relevant stakeholders (unpublished), H&SC Moray are currently under pressure due to care service demand that has been exacerbated by COVID-19. Currently much of the care delivered in Moray is actually undertaken by unpaid carers (often family and friends and often in-home settings) who, in turn, face

many challenges (H&SC Moray, 2022). The project is funded by Scotland's Digital Health & Care Innovation Centre (DHI) and is part of their Rural Centre of Excellence activity in turn funded by the Moray Growth Deal (Moray Growth Deal, 2022). The DHI is part of the "Scottish Funding Council's Innovation Centre Programme, which is designed to support transformational collaboration between universities and businesses." (DHI, 2023). We know that digital innovation in health and care services is difficult (Greenhalgh, 2017) and that a participatory design approach should help with 'strategic, and systemic service redesign' (Chute & French, 2019).

The authors ran a focus group with management staff from H&SC Moray, three participatory design workshops with professionals from H&SC Moray and 6 interviews with unpaid carers in the region. We present the participatory design methods used and findings from these activities here in the form of insights and concepts for near-future innovative care service changes in Moray. At the time of writing, the concepts have been and/or are currently being procured. This development work is funded by the DHI through their funding as part of the Moray Growth Deal (Moray Growth Deal, 2022). The chosen industry partners will work alongside the H&SC partnership and other pertinent local partners such as third-sector organisations to implement and deliver the new service innovations in Moray over time to further learn and demonstrate efficacy. This industry involvement in the implementation of co-designed service innovation sits within a broad area of work that the DHI calls 'simulation' and is described later.

Home care services play a critical role in ensuring the health, well-being, and quality of life for individuals in need of support to remain at home. However, the growing demand for such services, coupled with a reduction in capacity in the existing workforce, has resulted in several pressing challenges for care providers. Prior to the work described in this paper, the DHI engaged in 'an initial desktop review of performance information, current strategies, and recent service developments within the H&SC Moray partnership. Over the months from January to March 2022 a series of 1-1 sessions with key management staff in the partnership including the third-sector have taken place also attending a range of strategic and operational partnership meetings. Also, conversations were held with external providers who are currently working with Moray to manage change.' This resulted in a problem definition document (unpublished) that was source material for the research described herein. Challenges listed in the problem definition document were: 'long waiting times for care assessment and waiting lists for care packages; reduced capacity in the existing workforce to sustain the level of service required; the need to prevent crisis – both in relation to health issues and breakdown in care arrangements; and, support for unpaid carers - reducing pressure and providing flexible support.' These challenges reflect the increasing demand for home care services, which has outstripped the capacity of the existing workforce.

The aim of the Care in Place research project is to gain a comprehensive understanding of the current state of, and future aspirations for, pertinent services that support a person in their home such as telecare, occupational therapists, GPs, social work assessment, etc. for people in Moray. The DHI conducted preliminary engagement with the H&SC Moray partnership, identifying key challenges facing the care services in the region. Considering these challenges facing service provision and experience, the Care in Place research project aims to explore the future aspirations of health and care professionals and recipients (citizens). Through stakeholder engagement and the analysis of relevant data, the project will identify the preferred future for home care services in the region. The

findings of the research project will provide valuable insights into the future direction of care services in Moray and inform the development of innovative and sustainable solutions to address the pressing challenges.

2 Methods

Our approach could be described as research through design (Giaccardi, E., Stappers, P. J., 2017). That is, something needed designing and it is this need that is the primary motive for the work, but we use methods from design research and produce new knowledge relevant to design research.

The authors took a participatory design approach, supporting those pertinent people to design the innovative services themselves. A participatory design approach utilises the experience and opinions of people who are experts by training and/or experience in collaborative design activities (Broadley & Dixon, 2022). This co-creation of new, shared concepts supports the emergence of outputs such as prototypes (Manzini, 2015). This design approach benefits from social engagement to inform the design outcomes (Bixter, et al., 2018, Shore et al., 2018, Shore et al., 2022). All participants and interviewees were people with pertinent experience living in Moray.

The design activities are described in Table 1. The design activity was facilitated by the authors. The design activities underwent a peer-reviewed institutional research ethics approval process before commencement. The authors prepared visual, meaning making activities for the participants before each workshop. Findings from each workshop were identified following an 'analysis on the wall approach' (Sanders and Stappers, 2012). That is, the authors identified the significant and pertinent points that participants had proposed and that had gained consensus in the workshops. Value judgements on what was or what was not significant, desirable or not were made in the workshops with the participants. Diagrams summarising and communicating the participants ideas and designs were prepared for the next workshop.

The authors took a mostly hermeneutic phenomenology (Patton, 2020) approach in that they freely interpreted the expertise of participants and interviewees according to their own expertise as designers in the health and care context. The authors have run many such participatory design research projects and have built up a knowledge of commonly seen lived experience to draw upon (Chute et al., 2022). However, after introducing an activity at a workshop or running a semi-structured interview the authors try to 'bracket' their experience and adopt a descriptive phenomenology approach (Patton, 2020). That is, they listen to and respect the experience of the participant fully.

Table 1. Description of design activities

Focus group (n=25)	Semi-structured focus group with management staff from H&SC Moray, held online using Microsoft Teams. An online shared whiteboard was used to show the topic structure and notes made during the focus group. Topics covered: Project scope: functions of the to be design service innovation(s); who is willing and/or necessary to be involved; pertinent digital and paper systems. Project goals: internal appetite and capacity for change; expected benefits of the innovation(s); evaluation. Project practicalities: preferred dates and activities.
1st workshop (n=10)	A participatory design workshop with staff from H&SC Moray. Activity 1: An 'icebreaker' exercise to consider the needs of citizens. Activity 2: a backcasting exercise to consider things that have worked well before and why things are different now – according to the experience of the participants.

	Activity 3: a timeline-based mapping exercise to describe the current care service according to the participants.
2nd workshop (n=10)	A participatory design workshop with staff from H&SC Moray. Activity 1: structured discussions around the possible areas of service innovation identified in Workshop 1 and the focus group. Activity 2: Designing a person-owned record. What would be in it and who would share what information with whom. Activity 3: the further development of those possible service innovations and ranking of which concepts are desirable.
3rd workshop (n=10)	A participatory design workshop with staff from H&SC Moray. Exercises to co-design the person-owned record and interfaces for the concepts previously rated as useful in workshop 2.
Interviews (n=6)	Held with informal carers recruited by H&SC Moray. Semi-structured interviews with the topics: experience of being a carer; things that help; when do carers have to share the fact that they are a carer; information that is stored to support caring; accessing services on behalf of the person they care for; what could be improved; and anything else. Either held over the phone, online using Microsoft Teams or in-person at the interviewee's preference.

2.1 Simulation

The DHI has seen relatively successful impact in Scotland with activities we call simulation (DHI, 2019). We use the term simulation to refer to digital services and systems which run and are real in terms of software and other technical and information systems but are only used with mock data. The simulated services are used to show 'what good looks like' and to prove that technically, 'it can be done'. Often the technical challenge is not significant in terms of complexity or magnitude software. Instead it is issues such as fear of change/failure, information governance and associated service change that are the primary challenge addressed by the simulation. The DHI uses simulation as a way to commission industry-built solutions that are exemplary in terms of the DHI's remit and the preferences of Scotland's citizens and professionals as identified in other participatory design projects. These simulations show clear evidence of somewhat de-risked, viable service innovations and have sometimes progressed to procurement (Mark et al., 2021). The DHI does not deliver services and procurement is between other parties.

The DHI has focussed on data-exchange mechanisms and person-owned records in the past (DHI, 2019). This is in line with Scotland's Digital Health and Care Strategy plan to deliver smaller, joined-up systems rather than a monolithic single system (Digital Health and Care Directorate, Scottish Government, 2021). Data-exchange mechanisms are services that send data between data stores belonging to organisations and/or individuals. They provide rules for the exchange of data and provide consent models.

Person-owned records can be used by individuals to store and more importantly share their data with other people such as friends and family and other organisations. In some models the person themself can become a point of integration between the services they use (Mydex, 2022). This is particularly interesting where statutory services do not do a good job of integration or when the citizen themselves wants to control the integration. By providing individuals with control over their own health and care records, they can better make informed decisions about their care, improving the quality and efficiency of care services. Additionally, consented person-owned records sharing can provide statutory care providers with information about the status and needs of care recipients.

There are, of course, many other issues around digital innovation such as digital identity, delegation of access, cross-organisation data-sharing, etc.

The findings of this research as shown in Sections 3.2 and 3.3 are, at the time of writing, going through internal procurement processes run by the DHI. Several simulations will be procured by the DHI. If feasible and desirable by all implementation partners then some of these service innovations will be used by professionals and citizens for a significant but limited period of time e.g. 6-18 months. Further design activities are planned after the period of real-world use.

3 Findings

3.1 Current state

Other than the service challenges taken from the DHI's problem definition document as described above there are a number of significant points that effect this research. The partner, Health and Social Care Moray is a partnership responsible for all statutory health and care services in Moray. There are multiple organisations represented within this partnership but the two most significant are NHS Grampian and the Moray Council. NHS Grampian operates across three local authorities, of which Moray is one, alongside Aberdeen City and Aberdeenshire. Service delivery is split between the NHS and the council. There are other organisations within the partnership with Quarriers, a third-sector charity, being most pertinent here. Quarriers are a national charity and in Moray they have been commissioned by H&SC Moray to provide the Adult Carer Support Service as is required by The Carers (Scotland) Act 2016 (legislation.gov.uk, 2016).

During the work, Moray Council were part-way through an innovation exercise to adopt a new form of assessment. The new method that could replace the existing assessment processes is called the Three Conversations (Partners4Change, 2023). This research was independent of the council's existing plans and the opinions of the participants were paramount in our methods and findings. The Three Conversations model is a holistic approach to understanding people and their service needs and is a move away from what could be considered traditional models of assessment, i.e. assessment for the sole purpose of determining service provision eligibility. At the time of the work the Three Conversations model was a paper-based process. The findings do not affect the adoption or success of the existing Three Conversations model in Moray but the findings presented later are broadly supportive of more holistic and person-centred approaches. You can see the Three Conversations appear in Figure 1.

The following significant points were raised at the focus group with health and care professionals (including administrative and management roles) from H&SC Moray:

1. A lack of service integration between health and care services is clear.
2. This work should be a practical step towards shared care records.
3. There is a need to reduce duplication of data gathering across the health and care systems as a whole.
4. Participants said that citizens expected them to know more than they actually knew (in terms of knowing information about the service users).
5. The benefits of this concept would be long-term and holistic and may not be perceived as worthwhile or achievable in the short-term.

6. There are overlaps with the Scotland Government's Digital Identity group's work on digital identity provision and person-owned records (Digital Identity Scotland, 2019).
7. The introduction and understanding of the person-owned records concept to professionals and citizens.

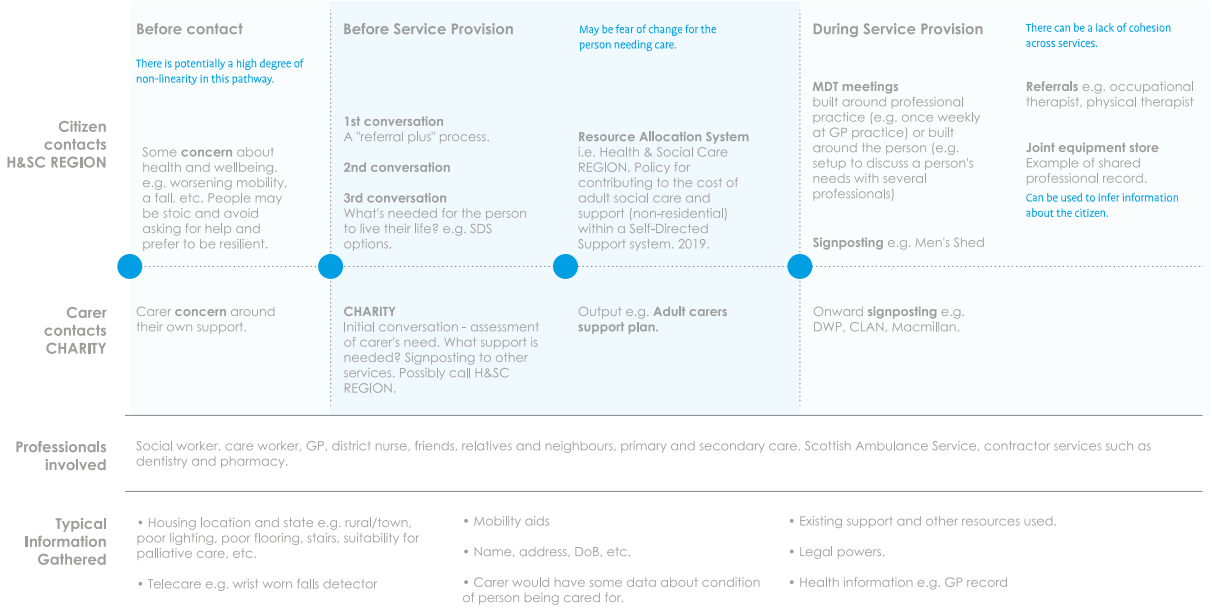

Figure 1: A highly abstracted version of the current state of care service assessment processes and provision co-designed by participants at the first workshop.

3.2 Preferred future state participatory design with professionals

3.2.1 The preferable future design concepts

Four concepts were co-designed by the participants and agreed to be desirable. One further concept was designed but then considered by the participants to be undesirable during the final workshop. These concepts are assumed to be built on some form of person-owned records so that the person is not reliant on statutory organisations to share their data.

3.2.1.1 Earlier communication

The earliest point of contact between the H&SC partnership and citizens and/or carers should be moved earlier using digital methods. This should reduce pressure on the H&SC partnership by making contact and offering non-resource intensive help. The access team phone call handlers were identified as a significant bottleneck. Also, conversation one (from the Three Conversations) would ideally be had before any crisis as that would be a better time to get to know the person and avoid an assessment for services situation. A single point of service entry should be used by all parties (e.g. GPs, in-patient discharge staff, carers, etc.) as early as possible to avoid any accidental misinformation being given.

3.2.1.2 Recognising carers

Unpaid carers are a hugely significant section of the caring workforce in Moray (as elsewhere presumably) and they should be supported to be more effective. Delegation is hugely important for carers and the person they care for as often the person being cared for will not have capacity to use the innovative digital tools themselves. The recognition of a carer through a digital identity should

allow carers to more easily act on behalf of the person they care for. Furthermore, forms such as the Adult Carer Support Plan and emergency planning forms should be digitised and owned by the person. Sharing the carer's identity between members of the H&SC partnership should allow delegated digital access to provide information or share their data onwards where it would support them.

3.2.1.3 Citizen's timeline

The participants felt that citizens would benefit from seeing a timeline of significant events related to their health and care and the relevant service provision. The professional participants were familiar with their own version of a timeline – which they knew as a chronology – that they maintain for each person using services to store information about the person and service delivery details. Participants said that a timeline showing, for example, appointments, progress, and prognosis over time would help with transparency and communication. There are many moving parts to Moray's health and care provision and this would help a person to understand, plan, self-manage and feel more in control. The following interviewee quote from an unpaid carer illustrates how a timeline might help with understanding:

> *"The hospital told me that there was a care package going into place for [husband]. A year later, I'm still waiting. I was even told I was top of the list." – Interviewee, unpaid carer*

Presumably, the 'hospital' in this quote gave their advice in the best possible faith but it is easy to see how citizens would benefit from having a timeline of events to aid their understanding and empower them to act in their own interests. Ideally, all relevant people and organisations would automatically share data to a person's timeline but NHS Grampian and Moray Council would be the most important providers. Participants suggested that it would be good to use Moray Council's care team timetabling software as a source of information for the timeline so that people could see their care visits and any changes to it. It should be noted that participants said that even basic information on the timeline such as who and when (e.g. Moray Council, occupational therapist on Wednesday at 13:40) would allow people to plan better. If a person shared even a simple timeline between two or more services (possibly including unpaid carers, friends and family) then it should help coordination. The level of data shared does not need to be significant in terms of depth for the timeline to be beneficial. Participants cited the joint equipment store as one existing resource which, although a highly specific part of service provision, allows staff to see whether some other professionals are involved in a person's care. This is an example of the council and NHS board sharing data around service provision though it is a workaround.

3.2.1.4 Digital Communication

Participants envisaged modern, digital, two-way communication channels between those being cared for and H&SC Moray, and between Quarriers and unpaid carers. The council, for example, still requires wet-ink signatures on many forms and this may require an extra visit to get the signature. One such digital channel would be a two-way chat. The authors have seen this request from a number of current and recent participatory design projects for other similar service areas. Recently implemented two-way chat functionality for COPD services in one territorial healthboard in Scotland has shown highly promising service benefits (unpublished). The mechanism has great potential to reduce visits, and improve self-management where a person can manage with a small amount of input, etc. Note that one of the interviewed unpaid carers said that the ability to ask a quick question would enable unpaid carers to perform their roles better with less involvement from statutory healthcare. So, although two-

way messaging might be perceived as adding to workload, it should support the unpaid carers to work more efficiently.

3.3 Design implications from the interviews with informal carers

The interviews with unpaid carers highlighted the importance of care provision and support from, for example, family members and friends for the cared for. During some interviews there was emotional narrative shared in relation to duties and tasks performed and experiences of engagement with health services and day-to-day activities. The interviews were recorded and transcribed verbatim. The authors identified four significant themes through thematic analysis (as shown in Figure 2) (Braun & Clarke, 2006) and are summarised here:

3.3.1 Family Relationships and support

The interviewees expressed a need (or greater need) for education and training programs for carers (also seen in the earlier initial communication concept from the workshops); a need to offer regular respite care services to relieve caregiver burden; to provide financial support to offset the costs associated with providing care (this partially relates to the concept of recognising carers from the workshops); to improve communication and collaboration between unpaid carers and health and care professionals in order to help unpaid carers access to information and resources. This point on better communication to support collaboration fits with the digital communication concept designed during the workshops by professionals. Here are two quotes taken directly from the interview transcripts that illustrate this:

> *"There used to be; and this is a point that I think I'd like to make is in terms of points of contact in the health and social care system to help me sort out things Umm has gone from reasonable to nothing I would say - I now just happen to have numbers or e-mail addresses that I know that if I want to go and get occupational health for instance." – Interviewee, unpaid carer*

> *"But I get good support from the GP that deals with my father. She's very understanding and she said, I can, if ever I need to go and talk to her about what's going on?" – Interviewee, unpaid carer*

3.3.2 Mental Health

Interviewees said that they would like better mental health care and support. This is particularly the case for: improving access to mental health services for those who have limited financial resources or live in remote areas; and primary care mental health services in order to improve identification and treatment. Participants suggested developing awareness campaigns to reduce the stigma associated with carers seeking help with their mental health. The idea to address mental health was not directly pursued in the workshops though the carers mental health and mental wellbeing was inherent and was a topic raised in many of the activities. There are third-sector charities that work specifically in the area of mental health and these may be targeted for some of the DHI's planned procurement in Moray. The following two quote from interviewees reinforce the obvious issues around the mental wellbeing challenges for carers:

> *"My mental capacity was such that it was shattered." – Interviewee, unpaid carer*

> *"Until [father-in-law] went into the care home, it got to a stage where it was too much." – Interviewee, unpaid carer*

3.3.3 Devices and technology

Interviewees said they would like better use of digital devices and technologies to provide care and support, and furthermore to ensure that people have access to the needed devices (e.g. for those who cannot afford smart phones or Internet connection). Interviewees suggested education and training programs for carers and healthcare professionals to ensure that they are proficient in using the latest pertinent technology. This interview theme broadly relates to the entirety of the DHI's Rural Centre of Excellence program of work.

> *"…getting information online and being able to look up support, look up...for help, is all looking online. The problem is nowadays that not everybody is online. And elderly people don't know – I mean, really elderly people – don't know how to use the Internet." – Interviewee, unpaid carer*

3.3.4 Diarising and documenting care and support

The interviewees would like support to document and diarise their carer role, to provide information to others and have access to information they need to make informed decisions. This theme reinforces the concept of a timeline from the workshops.

> *"I also keep a diary or I did when [mother-in-law] was here, and I still do when I go to visit her in the hospital. So, if anything happens and you need a record of when [mother-in-law] started doing that or she said that, you've actually got it down." – Interviewee, unpaid carer.*

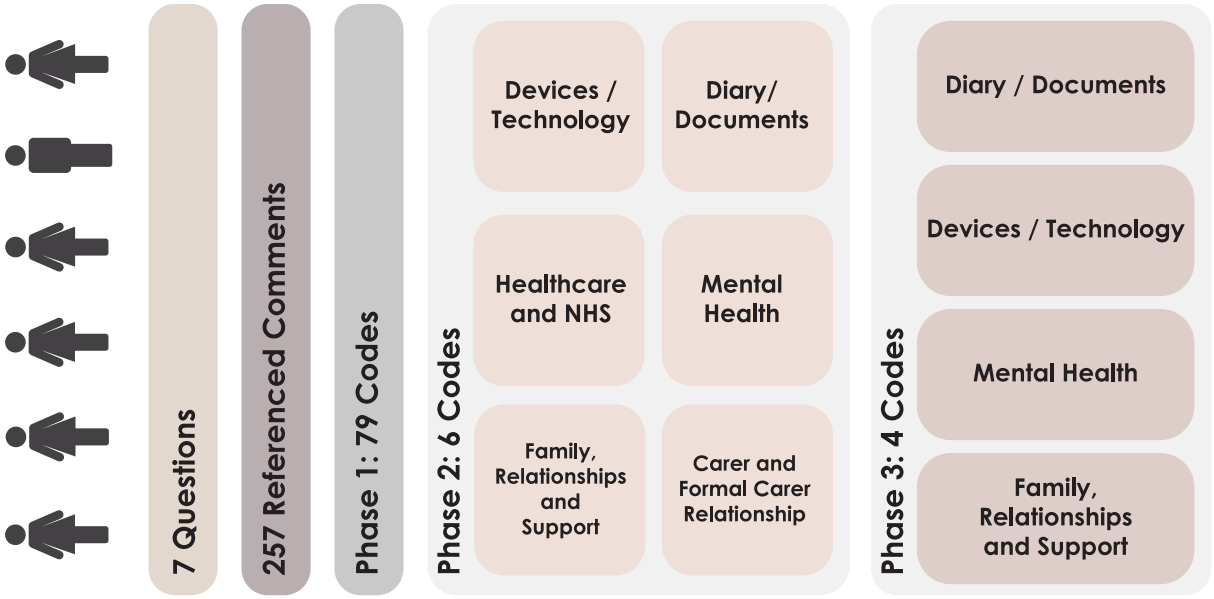

Figure 2: The thematic analysis process for the interviews with unpaid carers.

3.4 Early access prototype

At the time of writing, one prototype has been procured by DHI and partially developed (by an external company). This prototype has been dubbed the 'Early Access' web-site and represents some of the findings already presented. It is a web-site that citizens can use to access many health care services in Moray from one common starting point. It includes services typically used by people being cared for as well as carers. This prototype is currently being used to gather feedback before hopefully being used by H&SC Moray and health and care partners within Moray for a period of time to further learn

and assess suitability. The DHI's funding can only support innovation activities and so cannot be used to deliver part of a service as business-as-usual.

The prototype represents the following significant features:

- earlier communication with, and access to, health and care organisations, particularly 3rd sector organisations as per the findings in Section 3.2.1.1. This reduces pressure on the H&SC Moray access team.
- a single point of service entry as per Section 3.2.1.1.
- the prototype is for people requiring care and for informal carers to seek services for themselves – treating both groups equally when seeking help. Partially as per the findings in Section 3.2.1.2.
- is an online resource supporting people to self-manage and/or access relevant services without bottlenecks as per Section 3.3.3.
- the prototype leads the user to find relevant services first showing immediate utility, but always offers the opportunity to create a personal data-store so that any data entered can be kept (owned by the person in their own data store) for future sharing/use without re-entering the information. This aligns with point 7 of Section 3.1 and supports (or potentially supports) most of the findings presented. The use of person-owned records will potentially lead to a systemic transformation of health and care services, particularly in terms of integration of disparate services around the person's need.

4 Discussion

Upon conclusion of the design activities, the authors, alongside other professionals at the DHI created a number of procurement activities in order to develop technologies and services that match the generated requirements (single, early example described in Section 3.4). Each procured service or technology should run for a short but significant period of time in Moray e.g. 6-18 months to be agreed with all stakeholders and possibly in conjunction with other service innovations. These services will be run by the relevant stakeholders in Moray. The DHI has no service delivery role and can only procure for the purposes of innovation. The DHI will commission external evaluation partners to record the effect of the service innovations.

At the time of writing, the DHI have and are procuring innovative digital services to support the concepts as design by the professionals and insights from the unpaid carers as shown in Section 3. One such prototype is described above in Section 3.4. The authors will run further design activities after the period of real-world use. Two more participatory design workshops to firstly, understand how the service innovations have work and then, to co-design future changes. There are further interviews planned with unpaid carers who have used the service innovations. Afterwards, all relevant stakeholders should have a good understanding of what service innovations are desirable to Moray's healthcare professionals and unpaid carers, how the services work in practice (including implementation details for industry), what the innovations bring to the local authority, what has been collectively learned and what should change before procurement decision can be made.

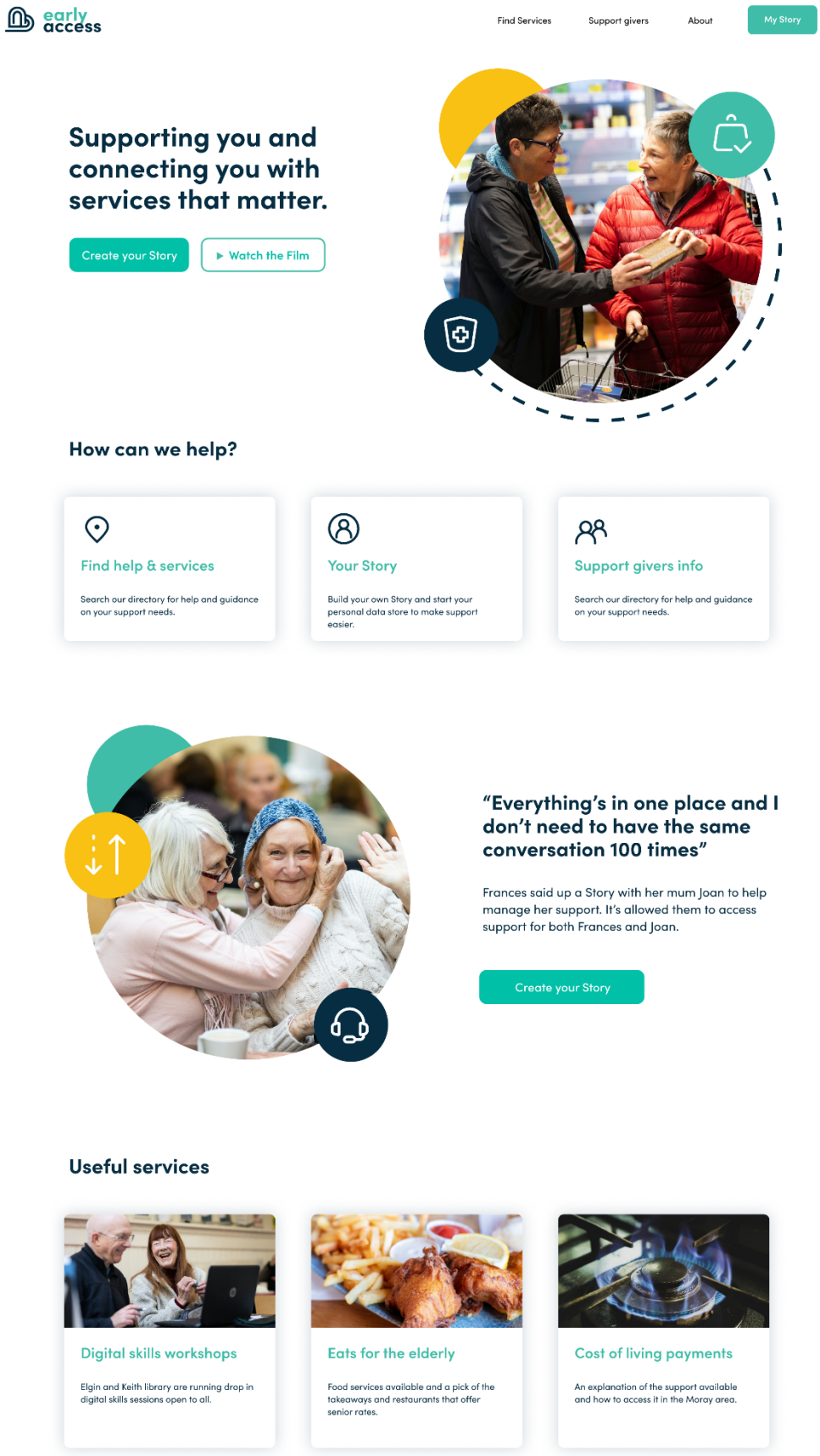

Figure 3: The Early Access prototype web-site representing some of the findings from Sections 3.2 and 3.3. The services and logos shown are fictional.

This paper contributes a case-study of participatory design applied within a partnership of public organisations for the benefit of their service innovation. At the time of writing, the design activities appear to have been successful in that they have generated sufficient concepts to inform the procurement of innovative services from industry that match a subset of the requirements of pertinent professionals and citizens. Case-studies, although not offering new methodological contributions, are sometimes useful contributions to the knowledge-base, 'because they detail specific experiences in particular contexts, offer the opportunity to learn more about the relationship of organisational processes and context to the success or failure of quality improvement efforts' (Baker, 2011). In particular this paper contributes to the understanding of innovation within a health and care partnership in Scotland and contributes concepts that should serve as exemplars for what should be done to improve the health and care 'quality chasm' (Institute of Medicine (US), 2001) in Scotland and beyond. The service innovation concepts should serve as exemplars that show 'what good looks like' that have had a reasonable level of genuine participatory design contributions from those that will use the future services or have them used on their behalf (Raman, S. & French, T., 2022). The work is relevant to the Scotland Government's recently promised Digital Front Door commitment (Scotland Government & COSLA, 2022) and Scotland's ongoing work on their Digital Health and Care Strategy (Scottish Government, 2021).

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