# DHI Demonstration & Simulation Environment

## DHI Phase 1b Report - Lessons Learned

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## Abstract

***This paper outlines the rationale behind, and delivery of, a series of simulation projects to explore how digital health and care systems can better integrate to support innovative, co-managed models of care. The lessons learned will inform a second phase of DHI simulation projects over the course of the next two years.***

## Contents

# 1. Executive Summary

The DHI Demonstration & Simulation Environment (DSE) is a Scottish Government funded innovation asset composed of two main capabilities. A) A physical place that can act as a place to bring together people, products and services to demonstrate the 'art of the possible'. B) A virtual sandbox in which multiple consumer and statutory digital products and platforms can interoperate and demonstrate their contribution to person-centred health and care service delivery. The facility and virtual toolkit are continuously developed to support Scottish Government policy using digital capabilities to enable co-managed, integrated care in the community. The DSE is fuelled by over five years of DHI co-design activities with the people of Scotland. As citizens co-managing care services, people want to:

- Tell their story once
- Have a meaningful dialogue with professionals
- Access and understand the data that might help them manage better
- Do things on their own terms
- Be able to use their data to unlock or unblock care they need

DHI's purpose in undertaking simulation activity is to provide assets and thought provocation that help meet these citizen needs in collaborative innovation and service redesign activities.

Through broader project delivery, market analysis and literature review activities, DHI has determined that the UK is punching below its weight on accessibility and use of digital health and care services. DHI proposes that this is largely due to organisation-centric design and delivery processes which do not align with modern user expectations for flexible, adaptable and portable approaches seen in other sectors.

Other countries that are doing well on these accessibility and use measures have benefited from enlarging the public sector 'walled garden' to encompass and interoperate with a larger number of assets and services. However, in most cases public sector systems are struggling to move from a predominantly centralised approach to the kind of decentralised or even fully distributed system required to handle a diverse and growing set of needs – chiefly for social care, independent, third sector and citizen access and control.

To support the shift to distributed systems, DHI's innovation model attempts to balance the short-term need for application of organisation-centric technologies at scale today (first horizon) with the need for more fundamental and system changing innovations for person-centred care in the longer term (third horizon).

The 'first horizon' work DHI have delivered over the last two years builds on the learning from a range of digital health and care projects that supply key principles for co-management at scale and key capabilities that can be used to help the ecosystem mature. The core capabilities explored in this work are for the statutory health and care provider to collate someone's clinical information and give them access to it (a tethered record) and to link this to an individual's ability to collect a range of data from across many sectors and services and make it available to services of their choice in a trusted way (an untethered record). This would allow co-management services to thrive with both the care provider and user being able to generate, collect and combine clinical and life context data sets to create more personalised and preventative ways of working.

DHI began this work with extensive engagement events and workshops, codesigning new service models based on this co-managed data set. Two of these were taken forward into simulation activity – in which DHI and industry partners developed the 'untethered record' capabilities and NHS Greater Glasgow & Clyde and Atos developed the 'tethered record'. 'Digital persona' were created to simulate the datasets and these were used to develop digital services aimed at helping people co-manage their care. These were created on top of several open data sharing platforms in such a way that the user had one 'statutory' account and one 'consumer' account that were linked. The users could either pass data into the statutory system and use the core clinical services, or they could extract clinical data into the consumer systems to self-manage more. This was all done using globally recognised API based standards and approaches, meaning that many additional services could connect to these open platforms to collect new data, or reuse the existing data to give the user better value. Many groups across Scotland are now using this approach in their own follow on activity.

DHI then developed interactive walk throughs for these new services and their policy and market context. These 'demonstrations' were given fifty times over a year in the physical DSE space in Glasgow to a range of groups across most sectors and services. The feedback was captured and used to both refine the demonstrations to help enhance the knowledge exchange for later participants, but also to set the scope for DHI's phase two simulation work.

Key lessons included:

- Many health and care professionals have a hard time believing that people can manage their own data in this way. This is mitigated when people can see the degree to which users manage and gain value from their own data in modern digital consumer services outside of health and care.
- The system must be able to support people to manage their own data across wide spectrum of personal ability and interest. Trust brokerage services must be developed to help them stay safe and see the benefit from their data, with options outside of government or commercial boundaries.
- Despite attempting to focus on integrated care use-cases, the simulation work was still inherently clinically focused, and future work must broaden out more to include more of the persons' lived experience.
- When open platforms are used in this way, there are many more possibilities. This is good for choice and innovation but can lead to an increasingly complex and confusing web of services. Normally, proprietary products focus the offer and coordinate background services to make it work for the user. New forms of orchestration must be explored when using open platforms to help people make sense of what is possible and ensure it works.

DHI set out to demonstrate that is was possible to create a set of infrastructure that follows and is controlled by a person, not and organisation, and that this could interact with health and care provider systems. Through this it is possible to rebalance the power dynamic, which at the moment favours organisational objectives at the cost of personal ones, to help achieve the desired objective of co-managed, integrated, person centred services. The existing simulations and the positive engagement to date highlight that is indeed possible, but that there are trust and orchestration issues that must be addressed to allow this approach to scale up.

DHI will seek to address these lessons its Phase 2 simulation work from September 2019. Requirements for an extended set of consumer / untethered digital infrastructure are being set with reference to the lessons found in this report, with the intention to release a PIN Notice in June 2019 and undertake procurement activity in September 2019.

# 2. Intro to the DHI Demonstration & Simulation Environment (DSE)

## 2.1. The Aim

The DHI DSE is a composed of two main components.

- A physical place that can act as a place to bring together people, products and services to demonstrate the 'art of the possible'.
- A virtual sandbox in which multiple consumer and statutory digital products and platforms can interoperate and demonstrate their contribution to person-centred health and care service delivery.

The facility and toolkit are continuously developed to support the following government policies and strategies:

- Citizen centred, proportionate and co-managed care. (Realistic Medicine, Scottish Government, 2014).
- Changes in approach so that the balance of care is delivered closer to the citizen's home – preferring a mixture of community services vs default dependence on hospital based medical care (Health & Social Care Delivery Plan, Scottish Government, 2016).
- The integration of care centred around the citizen, so that they and a full range of formal and informal carers can coordinate more effectively for the citizen's benefit (Health & Social Care Delivery Plan, Scottish Government, 2016).
- The delivery of this new care system, supported by digital services that are commercially sustainable and exportable by Scottish industry to the rest of the world (A Digital Strategy for Scotland, Scottish Government, 2017).
- To support the service transformation and digital platform work streams of the Scottish Government Digital Health & Care Strategy (2018) as an enabling programme of work to support overall policy objectives.

This is done by fusing co-design, market / academic research, industry engagement and technical experimentation to de-risk new service and business models to help DHI's partner organisations take more transformative steps using digital.

## 2.2. Unmet Citizens Needs

The DHI DSE activities are driven by the following citizen needs relating to data sharing surfaced through DHI Phase 1a literature review, market analysis and co-design work[1]. These needs are relatively consistent across several care groups including healthy ageing, mental health, cardiac, diabetes, and multiple sclerosis.

***As a citizen co-managing health and care services, I want to:***

- ***Tell my story once***
    - Be able to hold and share this story and have care services use this to personalise my care.
    - Feedback on my experience and outcomes – and for this to effect care for myself and others in the future.
- ***Have a meaningful dialogue with professionals***
    - Have conversations with professionals that focus on my priorities.
    - Have conversations with the necessary information or test results gathered ahead of time.
- ***Access and understand the data that might help me manage better***
    - Visualise clinical and personal data together to help me and others to see the patterns.
    - See a timeline / route map of my care interactions (past and scheduled) and understand the content and purpose of them – before and after they happen.
- ***Do things on my own terms***
    - Use my own technology to access services and monitor myself to support my own care.
    - See all the people supporting me and help them work together for me.
- ***Be able to use my data to unlock or unblock care I need***
    - Trust in how my personal information is used by others.
    - Share relevant, trusted data with people can help me.
    - Have the authority to activate services I am entitled to myself.

DHI's purpose in undertaking simulation activity is to provide assets and thought provocation that help meet these citizen needs in DHI & partner innovation and service redesign activities.

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[1] Digital Diabetes (2017), IDDEAS (2017), GDS (2017), DUDES (2017), Backpack (2017), Mental Health Coop (2017), Revolutionising the Outpatient Experience (2015), Next Generation Digital Records (2016), Digital Empathy (2016).

## 2.3. Systemic Challenges

The DHI, through its project portfolio activity over the last five years, has determined that:

- The UK is punching below its weight on access to and use of digital health and care services. This is largely because current organisation-centric design and delivery processes do not align with modern user expectations for flexible, adaptable and portable approaches seen in other sectors, including banking, which is also heavily regulated.
- Other countries that are doing well on these measures have benefited from enlarging the public sector 'walled garden' to encompass and interoperate with a larger number of assets and services. This had led to marked improvements in how data moves around centralised systems – which in turn creates a better user experience as the different systems coordinate around the shared data.
- However, in all cases formal healthcare systems are struggling to move from a predominantly centralised approach to the kind of decentralised or even fully distributed system required to handle a diverse and growing set of needs – chiefly for social care, independent, third sector and citizen access and control.
- Scotland has recent history of many digital products not achieving scale – mainly due to:
  - A lack of health and care service redesign to leverage digital fully – resulting in poor cost-benefit and therefore few decisions are made to scale.
  - Poor interoperability between systems – mainly due to the lack of clear standards for data sharing, existing public-sector systems being pre-dominantly closed, siloed and proprietary, and public-sector teams not being resourced to support integration with emerging industry capabilities.
  - A lack of commercial business model viability, largely due to (1) and (2).

## 2.4. Market Trends / Emerging Capabilities

### Emerging capability

Analysis of the rapidly evolving digital market identifies the following trends:

- Best practice is emerging around data sharing as a driver of better digital public services.
- The market is beginning to pivot towards more open, interoperable and consumer focused approaches seen in other sectors.
- Fundamental changes to infrastructure are underway, with a mixture of new connectivity options driving a fourth industrial revolution based on the Internet of Things (IoT) and increasing adoption of public cloud technologies by the public sector.
- Equivalent changes are taking place in the information architecture space – with new ways of securing, governing and trusting in distributed networks of information creators and users.
- Advances in machine learning to support data mining, predictive analytics and computer vision offer increasing degrees of automation for making sense of large volumes of data. Where previously concerns around 'information overload' on a stretched clinical workforce may have stopped citizen's directly contributing to decisions, now these additional tools can offer decision support to care teams to make informed decisions.
- There is an increasing market capability focused on the citizen having ownership and control of their personal data – adjusting for the New General Data Protection Regulations (GDPR).

## New health and care delivery / business models

The sustainability of health and care services is increasingly expected to be achievable only with digitally supported change. The fundamental pillars of this change will be:

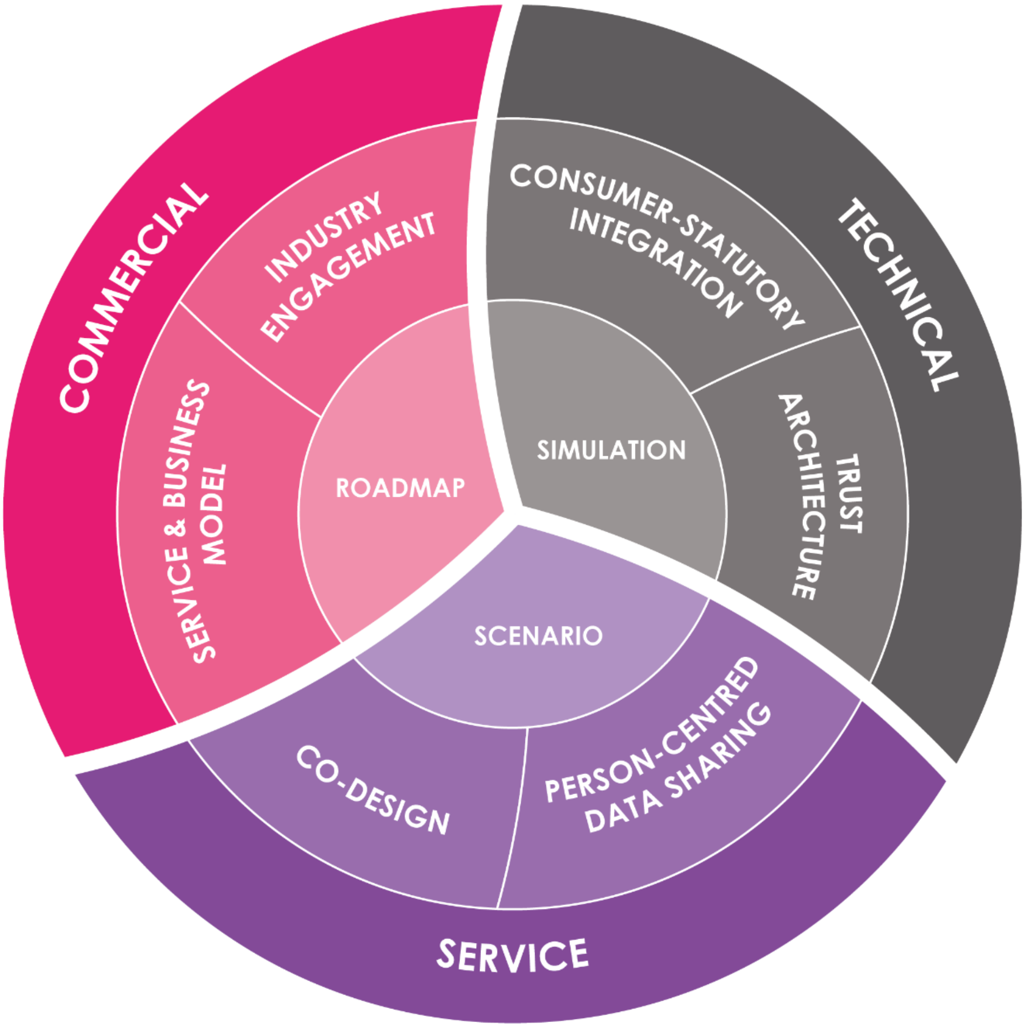
- **Management of Risk, Prediction & Prevention:**
    - **Low effort monitoring -** Creating new, low cost, convenient and ideally passive ways of self-monitoring using widely available and familiar technology.
    - **Automation -** developing predictive analytics and machine learning techniques to translate this data into insight that can be used to drive intervention in the community.
    - **Formal Care Management by Exception -** using citizen generated data and subsequent insight to focus on predictive models that activate proportionate responses – starting with the most local / informal, and then escalating up to formal / clinical when appropriate – reducing both routine contact and emergency action.
    - **Tailored interventions –** using the context and outcome data generated by citizens in this way to personalise care journeys and develop new services and treatments that can support more holistic benefit to the citizen.

- **Empowerment, Communication & Planning:**
    - **Self-management -** Allowing the citizen to control their own data - enabling the citizen and their informal care network to be more responsible and resilient in the management of their own care.
    - **Co-management -** Developing communication / coordination tools using data generated by both the citizen and the system to power meaningful dialogue and joint planning.
    - **One Version of the Truth –** Creating data once and reusing it, with all relevant actors contributing to and using the same version of the truth.
    - **Personalisation –** Allowing the citizen to hold this single version of the truth and use it to activate personalised services on their own terms.

- **Trust in Distributed Data:** The first two pillars are dependent on trust in data shared across an increasingly complex and diverse set of actors, which can be built through providing:
    - **Data provenance, integrity and consensus –** emerging technologies (e.g. distributed ledgers) can support the automation of governance to build trust in vast quantities of data generated outside of well-governed health and care service processes.
    - **Sustainability, reliability and timeliness of data communication –** new connectivity capabilities – such as Low Power Wide Area Networks, can improve the reach and consistency of information from lower cost sensors.
    - **Co-managed data to support co-managed care -** in this increasingly distributed world, attempting to govern permissions solely on an organisation to organisation basis is no longer viable. The more informal care providers – be they third sector, independent or members of the public – cannot participate effectively within this approach. It is also no longer desirable from a policy perspective as it excludes the citizen and perpetuates a patriarchal model that health and care services are trying to move away from. There will always be core and critical health and care data that has to move between organisations for individual and population health an safety purposes, but for the more informal and distributed data sets, the citizen is a more appropriate point of integration, supported by increasingly person-centred privacy policy and regulations (e.g. GDPR).
    - **A means to ensure only those permitted can access the data –** distributed and messy nature of informal care networks mean that previous organisation centred 'walled garden' approaches to data security will not be viable. Data will need to be encrypted 'end to end' with the 'keys' to read the data ultimately controlled on an active citizen consent basis in line with the GDPR.

## Key areas of exploration: DHI Demonstration & Simulation Environment

*Figure 1: DHI DSE – Areas of Exploration*



DHI's Demonstration & Simulation activity is focused on answering the following questions. How can:

- new connectivity options support a more passive, seamless and cheaper way to gather data?
- the citizen actively manage their own data to activate services on their own terms?
- this citizen-centred data sharing approach vary for different levels of citizen interest and skill?
- governance and trust in data be automated in a 'many to many' network of care providers and users – especially in a 'Massive IoT' context?
- citizen and system curated data be used together to support new predictive, preventative and proactive care models that support co-management?
- emerging capabilities fundamentally change the basic business model to support commercially sustainable services? Can the approach be scaled beyond Scotland?
- Citizen generated health data be combined with longitudinal care records to support research and population health studies.
- How can all of the above drive service transformation to create a more sustainable and effective health and care system?

# 3. Three Horizons

## Moving at Three Speeds

Innovation centres must be able to balance the short term need for application of relatively simple technologies at scale today with the need for more fundamental and system changing innovations for the longer term. DHI works to a 'three horizons model' to manage this.

**What the horizons depict:**

- How to move towards delivery of some unmet citizen needs.
- Several digital infrastructures under development and in many cases commercially available
- A working hypothesis as to how these developments can be aligned and integrated in stages to provide a fertile environment for service redesign.

**What the horizons do not depict:**

- a programme plan or ideal set of steps towards a known and agreed future state.
- a technical schema or solution for next generation information architecture.
- a set route that must be followed to completion.

## Horizons Summary

**Horizon 1 -** The world as it can be right now – DHI rationalising existing capabilities and offering a proxy of some of the user-oriented / consumer digital health infrastructures on the market. This then helps us to explore ways of adding value to existing public-sector initiatives with a view to moving towards more open and dynamic infrastructure in future iterations.

**Horizon 2 -** An extension of the world as it can be right now – anticipating how existing public-sector initiatives and emerging market forces might be blended into Horizon 1 simulation to enhance the scalability and applicability of the infrastructure. This moves beyond single sector, looking at environmental and broader 'life' data to support more integrated care.

**Horizon 3 -** Looks forward to a potential future state that may support more sustainable deployment of digital at scale than H1 and H2. This would use the platforms from H1 & H2 as 'anchors' for more distributed trust architecture approaches. At this stage this is more speculative and would be dependent on lessons learned from the first horizons and additional resources to move beyond concept work.

DHI has initiated activity in all three horizons simultaneously – with the Horizon 1 activity being the most practical and deployable, Horizon 2 work is practical at a proof of concept stage, and Horizon 3 being mostly conceptual and dependent on additional resources.

Horizon 2 and 3 proof of concept reports and academic papers will be available separately. For example, the application of fourth industrial revolution capabilities in care – Care 4.0.

**The remainder of this report outlines the simulation activities DHI has undertaken to progress Horizon 1.**

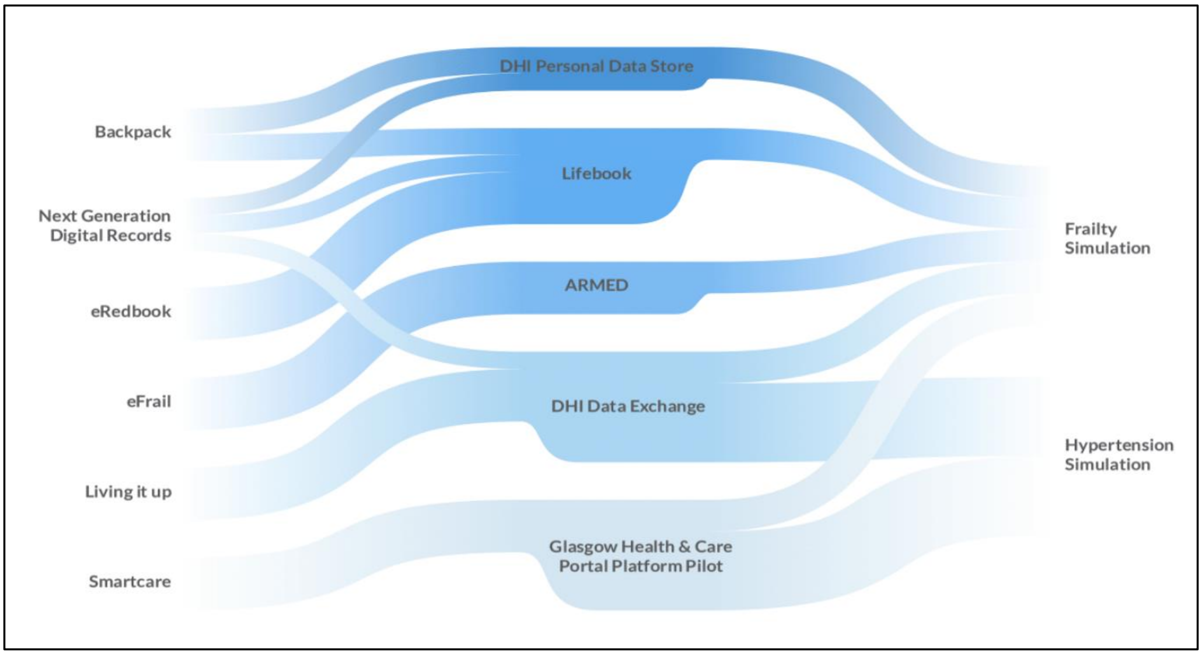
# 4. Horizon 1 Report

## 4.1. Horizon 1: Building on Previous Lessons

### Foundation Projects

DHI's Horizon 1 simulation activity integrates existing learning and technologies.

*Figure 2. Provenance of Horizon 1 simulation activities*



The foundation projects undertaken over the last five years include:

**Backpack** - The overall aims of this co-design project were to explore how people living with Multiple Sclerosis (MS) would like to manage their personal information, via a Personal Data Store (or 'Backpack') to improve the experience of accessing services and understand the potential of the Backpack to support health and care professionals to deliver more integrated and person-centred care. Several initiatives and commercial offerings have emerged across the world in parallel, promoting 'untethered' personal data stores in which the data is owned and ported by the user – as opposed to the more common 'tethered' offerings which allow a user to view and amend a subset of their data held by a care providing organisation.

**Next Generation Digital Records** – DHI facilitated a consortium of public, private and third sector organisations to consider emerging data sharing best practice and market trends. DHI undertook knowledge exchange trips to European countries leading on this agenda, as well as academic literature review and market engagement activities to understand global, cross-sector and general market trends. These exercises led to extensive lobbying to shift the public policy debate in Scotland from one focused on a centralised Patient Portal user experience to one that instead prioritised digital identity, data exchange infrastructure and the services that could be built on top of these capabilities.

**eRedbook** - The traditional paper Redbook is the personal health record given to all new parents to manage their child's health between 0-5 years that has been in use for over 50 years. NHS England is piloting the digitisation of Redbook maternity records for 100,000 women by the end of 2019. The eRedbook, provided by a Scottish business called Sitekit, includes information on immunisations, weight and height charts, developmental firsts and important contacts. It also contains practical, personalised information for new parents, including links to relevant information from local sources. The underlying platform behind eRedbook is called Lifebook – a Personal Health Record (PHR).

**eFrail** – The eFrail project between DHI, Edinburgh Napier University and CM2000 (now CM) combines pioneering predictive analytics modelling with innovative consumer wearable technology, and health and social care data, providing a powerful tool to identify risks (including risk of falling), earlier in the care cycle. This capability was commercialised by CM, aimed at helping people living in sheltered housing that may be at risk of frailty related events. It has demonstrated how people can self-manage, or co-manage, using readily available, consumer technologies, to deliver personalised and preventative services for their own wellbeing.

**Living it Up (LIU)** - LiU was a DALLAS project focused on promoting and supporting independent lifestyles and improvements in health, wellbeing and lifestyle. It focused on keeping older adults strong and connected, through an online marketplace of content, products and services. Lessons that have emerged as key learning points include the need for flexible and trusted working environments to support multi-sector working partnerships and the need for policy to support innovative business models (Agbakoba et al, 2015).

**Smartcare** - This project developed a series of innovative online tools to improve the health and wellbeing of people aged 50 plus who are at risk of a fall or recovering from a fall:

- The Falls Assessment Tool - To support good general health, to provide safety tips and signpost to useful resources that can help to prevent falls.
- The Person Held File – A safe and secure place to record health and social care information and to share this with those involved in providing care and support.
- A Calendar/Diary - A safe and secure place to record, manage and coordinate appointments including health and social care visits.
- Community Connections -Supporting healthier, active lifestyles through Living it Up (LIU).

## Capability & Knowledge Transfer

The core knowledge drawn forward from this work includes:

- Common principles of user co-designed health and care service models.
- Dealing with the challenges of recruiting and retaining groups of people for self and co-management services.
- Understanding of the systemic barriers to integrating technologies to support new services.
- Perspective on whole system innovation that is required to create change at scale.
- The need for a safe place to develop and test approaches between sectors and organisations.

The key capabilities drawn from this work includes:

- Data storage exchange capabilities – both for statutory and consumer data sets.
- Personal Health Record (PHR) systems to help individuals use their data, engage with services and with other people easily.
- Wellbeing and risk tools that are more accessible and easier to use / interoperate.

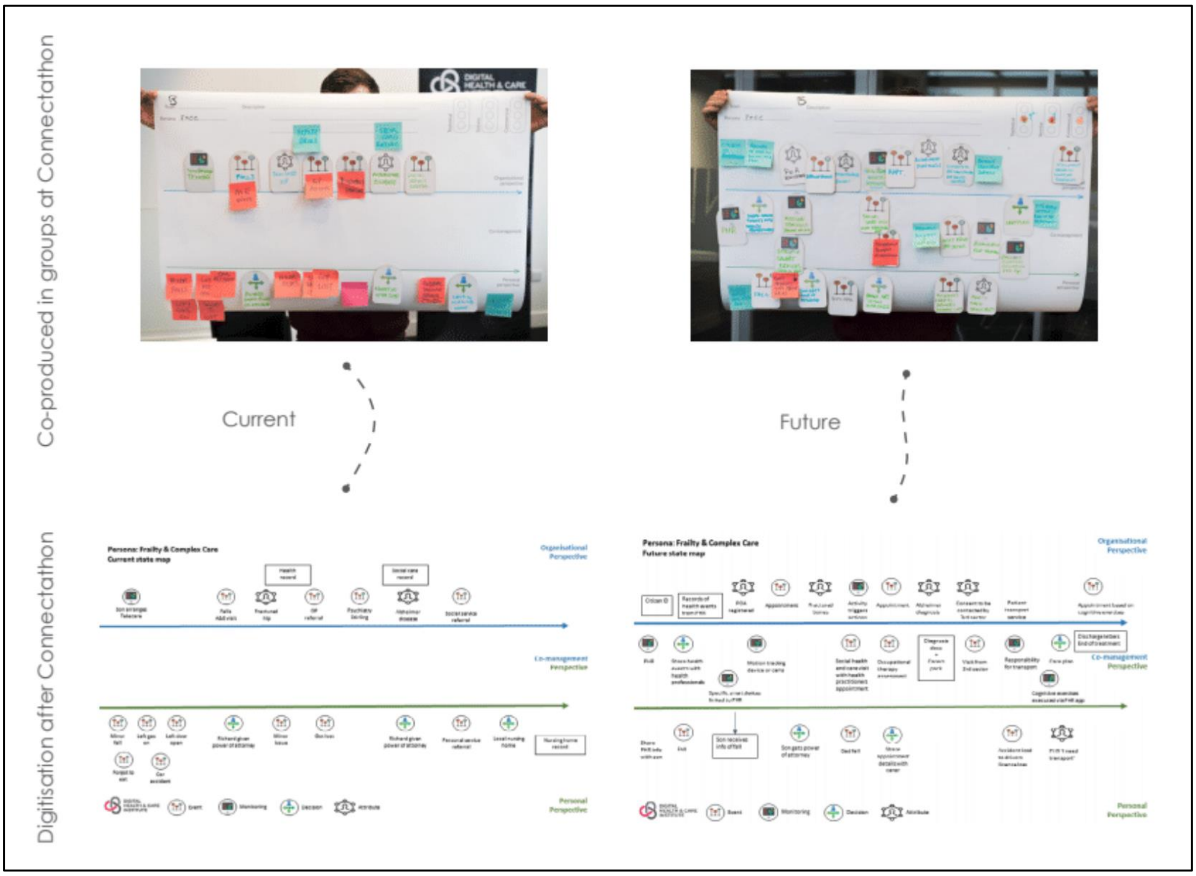
## 4.2. Horizon 1 Roadmap / Aims

The first stage of the simulation activity was to undertake some scenario development work with stakeholders. This involved investigating the unmet citizen needs arising from DHI co-design work (section 1.2) in the context of the learning and technical capabilities emerging from the previous project activity (section 3.1) and then selecting scenarios that would best demonstrate progress in the appropriate policy context (section 1.1).

### Connectathon Event

The common theme emerging from the previous work was that service design for integrated, co-managed health and care services was dependent on using the assets (skills, technologies, resources) from all the parties involved. The chief focus of the first engagement event - the DHI Connectathon - was to merge normally separate assets held by organisations and by individuals, creating new co-management methods in the middle. At this early stage the data sets were labelled as either statutory or consumer to reflect the fact that right now, person-held assets are usually managed via consumer digital services. The images below show some of the outputs from groups of service users and professionals spanning health and care, industry and academia.

*Figure 3: Connectathon Workshop Outputs*

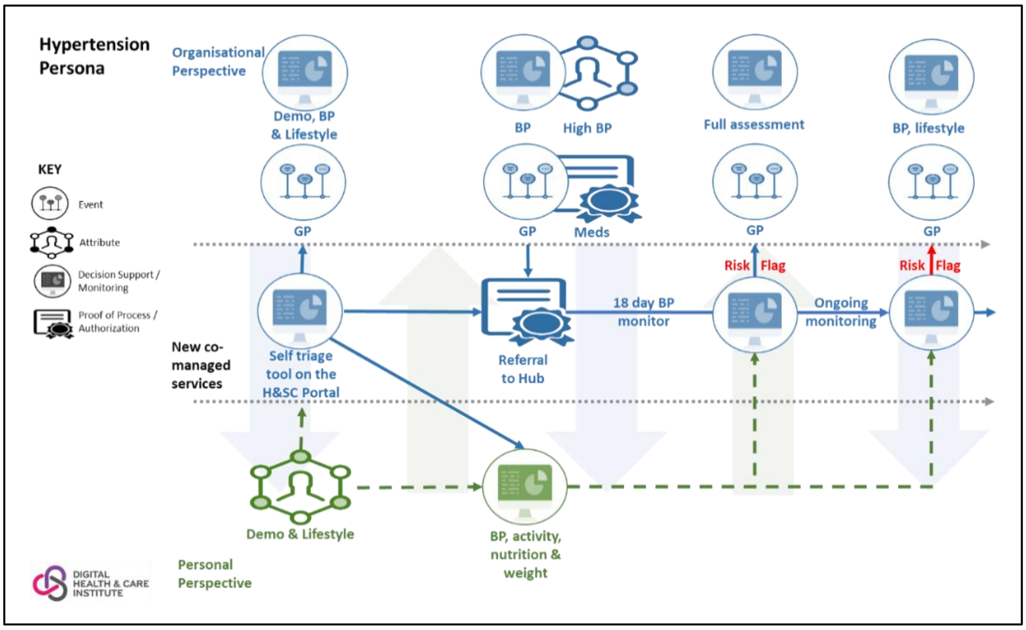


The overall emerging requirement was to provide data integration capabilities on both sides of this statutory-consumer divide and demonstrate some initial messaging between these two capabilities.

## Deeper Scenario & Persona Development

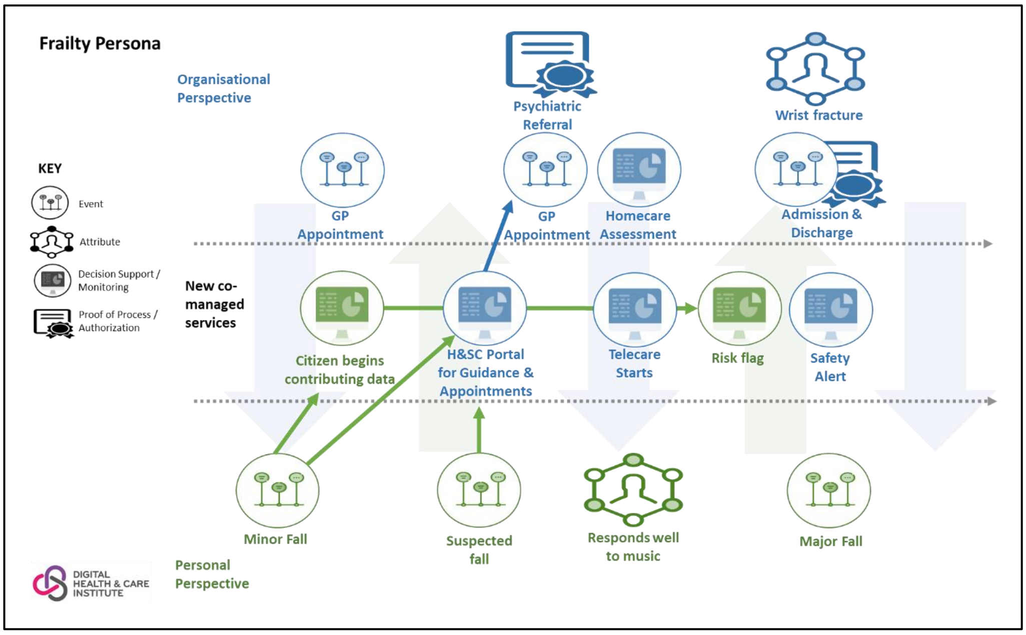
DHI took three of the Connectathon outputs forward for deeper development and simulation activity. Two of these, focused on hypertension and frailty, are the subject of this report, while the third – focused on cardiac rehabilitation, is being scoped for phase two simulation. In each case DHI engaged with groups of users, professionals and service providers to more fully flesh out potential future state service models to act as the foundation for technical simulation work.

*Figure 4: Hypertension Service Flow*



The key data transfers from the hypertension work were to transfer blood pressure readings, as well as contextual data e.g. family history, height, weight from consumer to statutory systems.

*Figure 5: Frailty Service Flow*

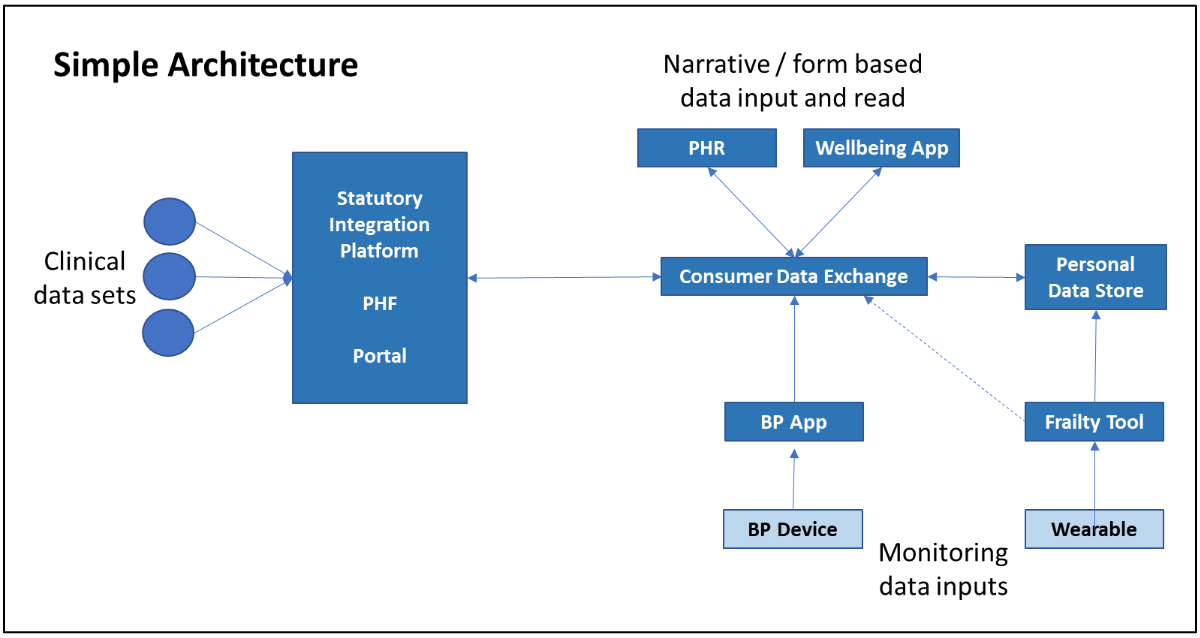


The key data transfers from the frailty work were to transfer a range of structured wellbeing data (e.g. mobility, sleep) between consumer systems, to extract structured diagnosis data from statutory to consumer systems and to pass documents between statutory and consumer systems (care summaries, appointment and referral letters).

## 4.3. High Level Reference Architecture

Based on the selected hypertension and frailty scenarios and building on the lessons drawn forward from co-design and previous technical project work, DHI proposed the following simple architecture for simulation to help merge the statutory and personal data sets to enable co-management methods.

*Figure 6: High Level Architecture*



On the left-hand side, a digital platform draws data from various statutory sources to be held in a 'tethered' Personal Health File (PHF). The tethered PHF is provisioned by the state and a portal allows the citizen to access, and to a limited extent edit, their clinical record. The platform also offers APIs to allow third parties to exchange data to and from services beyond the public sector digital boundary.

Some sort of certification process will guard the use of the APIs that cross the public-sector digital boundary. This will be a mix of technical and non-technical quality assurance to build confidence in both the quality of data coming in and the safety of sharing personal data out. The approach is still in development and so for now it is very difficult (in risk, not technical terms) to connect third party services into statutory platforms. DHI acted as a 'trust broker', held to a set of quality standards by the statutory integrators while simultaneously being able to move flexibly with industry partners.

Work proposed for this horizon would be focused on providing consumer driven / citizen-centred third party uses cases for the statutory digital platform APIs. While individual apps and devices could connect into the API, this horizon proposes to demonstrate how 'untethered' or consumer platform alternatives would add value to the 'tethered' work already underway.

These untethered capabilities – on the right of the diagram above - are differentiated by being activated and controlled by the citizen, offering a far greater degree of control, choice and personalisation, but with less governance, unknown quality and more risk. These untethered infrastructures would bring some shape and consistency to an otherwise uncontrollable consumer landscape. They offer the ability to store, combine, and visualise the citizen generated data, and to then combine this with the equivalent capability on the statutory side. This should allow for a blend of verified, trusted but infrequently collected clinical information and less controlled but frequent and important citizen generated data – e.g. preferences, needs, self-monitoring and outcomes. If services are to become truly co-managed, then there must be an understanding of how to trust the technologies and services that people choose to use in the open consumer market. This in part will occur through increasing consumer device compliance with the new Medical Device Regulations, but there is a need to understand the role unregulated technologies could and should play.

## 4.4. Implementing an Untethered Personal Data Store (PDS)

**Tethered Versus Untethered Personal Health Records**

NHS Digital recently offered a definition for Personal Health Record (PHR) systems that divided PHRs into two types:

| Type | Positioning | User Experience |
|---|---|---|
| **Tethered** | • provided to individuals by a health or care provider<br>• tightly connected to the system the provider uses to manage their organisation | • depends on the functionality available from the health or care provider<br>• might need the patient to access multiple PHRs to manage their care, if they're being treated by multiple providers<br>• offers limited control for what the patient can do with the data about them, as it's managed by the provider organisation |
| **Untethered** | • are standalone systems, provided by a health and care provider, or by an outside company<br>• give individuals control over the data they collate and store<br>• give individuals control over who they share that data with, including health and care providers | • is dependent on the functionality available from the PHR<br>• is not restricted by the functionality of the organisation's internal system, such as an electronic medical record |

When seen in the context of DHI's previous project work, market analysis and global best practice, there are two main issues with this approach:

1) **This definition reinforces the public sector health silo –** it focuses on health data and does not sufficiently allow for the 'whole of life' reality of a user's needs. Either the user must deal with multiple tethered PHR systems or the health record must be linked to many social care and pharmacy systems through large scale inter-organisational IT projects. There are a range of other public sector data silos e.g. benefits systems, that would be difficult to link, given

previous public concern around 'behind the scenes' linkage of their data in this way. There is little scope for third sector, housing, financial, consumer and other services at the edge of the public sector model being integrated. As a result, it is likely that the user will continue to experience their healthcare as a siloed activity that doesn't understand or respect their lived experience.

2) **The definition largely ignores the ethical and privacy issues in the 'untethered' market –** i.e. that most of the technology companies providing untethered PHRs will work to their own commercial goals. Many of these organisations are subject to different regulatory environments, particularly around use of personal data. In this model the user must pick between using a PHR provided by a government or by a commercial provider. In both cases there are concerns regarding control over data and its secondary uses. In both cases the user can be easily 'locked into' an ecosystem and so will not be able to gain the full value from their data.

### Tethered Versus Untethered General Records

DHI began its data sharing project work in 2015, with exploratory and co-design sessions. Emerging from this activity was the understanding of two different but complimentary models of data sharing that used the same language as the PHR model, but in the context of 'whole of life' data ecosystems:

- **Organisation-centric (tethered) –** To improve its service for a user, an organisation attempts to join up the various data held on that user. This helps the organisation's staff to optimise the service and reduces waste and duplication. It then gives the user a portal to view or, in some cases, edit their data. This improves communication and avoids effort for both the user and organisation. Organisations across a health and care value chain then begin to replicate this process to create more seamless services for the user based on better data sharing between organisations. In most cases the organisation, not the user, controls access to data.

- **Person-centred (untethered) –** the person is given the ability to hold their own data and acts as a point of integration for all participating services (health, care and other sectors). The citizen curates a 'single version of the truth' and through an active consent model, uses their data and verified attributes (e.g. clinically approved diagnosis) to activate services on their own terms, involving their informal carers or proxies where necessary and removing the need for extensive inter-organisation communication and direct data sharing with all the complexity that can involve. The data moves with the person and they can begin and end data sharing relationships at will.

This alternative view is that 'tethered' means that the user is dependent on the data sharing service provided by the organisation delivering their health, care or other services (which could include a commercial service) and 'untethered' means that you and your data sharing infrastructure stands separate from any one government or commercial interest.

Within this alternative view, there are strengths and weaknesses for both tethered and untethered models. Tethered data sharing is strong in that it doesn't require the user to be particularly interested or skilled – the organisation (government or commercial) takes responsibility for making everything work. A downside is that innovation is constrained by organisational risk management processes and the data is relatively narrow to the organisation's goals and usually infrequently collected or corrected. Untethered data sharing is strong by empowering the user to generate a broader data set at a higher frequency, and to share this data outside of the constraints involved in inter-organisational models, for example as health and social care services integrate. The downsides are that the provenance of the data is often harder to trace, and this approach would also give that user the power to disrupt the use of their data for public health, service improvement or commercial benefits.

There is continuous, on-going effort by public services to develop the tethered model, strengthening the ability of the organisation to participate in co-management with the user. DHI's co-design findings identify a gap where untethered infrastructures are needed to help a person gather their own digital assets to be able to participate in co-management with a range of organisations, but without undue influence or control by a government or commercial interest. This is particularly important in the context of the General Data Protection Regulations, in which 'tethered' models will need to be able to offer data control such as auditing access to records and portability for a significant portion of the co-managed record.

On this basis DHI procured a Personal Data Store (PDS) capability from Mydex CIC. This is a cloud based, user-controlled data repository that offers APIs to any third party wishing to connect (with the users consent). Part of the untethered infrastructure requirement is for the data to be held outside of an organisation's control – which is difficult when a consistent, scalable infrastructure is required. Mydex CIC is an asset locked community interest company that exists as a trust broker outside of government or commercial channels. It itself does not have access to the data held in the personal data store, it is neutral and operates the platform on a zero-knowledge basis.

This PDS was used during the work as an untethered anchor point to balance the normal assumption of a tethered system. In many cases in the next phases of work, the co-managed record was a mixture of tethered and untethered approaches, satisfying both the organisational need for control and stability and the person-centred / data privacy requirement of the user having a copy of their data to port and use on their own terms.

### What did we learn?

- Most people get the need for data privacy, ownership and control – especially as we move into an error of passive, ambient monitoring through Internet of Things technologies.
- Professionals regularly raise issues around the likelihood of people being able to manage their own personal data. This is in a large part informed by how difficult it is for professionals to manage this data in the current health and care model.
- There are many examples of the way people manage their own personal data or engage a trusted broker to do it for them, in the broader consumer markets. The key here is that people will curate their own data if doing so removes friction and improves their lived experience. In many cases this may be as simple as giving people the ability to auto complete forms or prove eligibility quickly. Anything that reduces friction, effort and saves time is seen as a major benefit for them and those they share information with.

## 4.5. Connecting a PDS to a Consumer Data Exchange

DHI's market analysis and knowledge exchange activities sought to understand global best practice in data sharing. The countries that had developed centralised data exchange platforms performed best in digital public services benchmarking. However, these exchange platforms are essentially 'tethered' records systems, and these countries are now reaching the limits of this approach and are seeking to understand how to mature their ecosystems to work in a more distributed manner, moving with markets and broader digital consumer services.

To build on this learning, and to capitalise on the 'untethered' personal data store (PDS), DHI undertook project and procurement activity to develop a 'consumer' data exchange – i.e. something that can allow integration of systems but not on a statutory service basis. This is not inherently a tethered or untethered infrastructure – this label would depend on the business model under which it is deployed. In DHI's use it is untethered in so far as DHI is using it outside of a health, care or commercial providers systems and objectives to give the user full control of their data. It focuses on focuses on providing a means for someone to connect many different consumer devices, sensors, and systems (e.g. Healthkit, Fitbit, etc.) together. The combination creates a hybrid model that merges the ability to connect a user's data from commercial apps (exchange platform) with the ability to secure personal control and portability of a copy of a persons' data (PDS).

This combination was identified not as a target architecture, but instead reflecting two emerging market offerings that may conflict or cooperate. DHI proposes to show exemplar infrastructure of both kinds working together to understand how the market might be stimulated in the near future.

After procuring a consumer data exchange from Storm ID, the project team undertook some sample integrations between the exchange and PDS. This was done with indicative sample data sets for contact details and care planning. The PDS is essentially a data store with APIs and offers a user interface 'as a last resort' – i.e. they want other services to handle the user experience. The data exchange platform team connected to the Mydex RESTful API and then created a web service that allowed the activation of a PDS through the data exchange user interface.

**What did we learn?**

- There is an inherent tension when getting a range of technology providers to integrate their digital platform products. In many cases they are competitors in normal market conditions. Almost by definition organisations acting in this space conceive of their platform as the centre of a data sharing ecosystem. This raises the question of whose API is used for the integration. In this case DHI made the call that the consumer data exchange should connect to the PDS API. it is likely in a future iteration of GDPR, that commercial providers will likely be required to connect to data portability services like a PDS to empower service users.
- The key learning is that the PDS will have to have the relevant data schema mapped across from any connecting data exchange to allow this model to work in the automated manner it would need to for seamless user experience. This is a reasonably significant up-front cost that may stall use of this model at scale and this should be considered in phase two simulation work.

## 4.6. Connecting a Consumer Data Exchange to a Consumer Data Store

Several consumer data stores exist in the market today. General examples include iCloud or Dropbox, and health specific ones include Apple Healthkit, Google Fit or Samsung Health. These are untethered PHRs as per the NHS Digital definition. However, from DHI's perspective they are still tethered data stores, in so far as they are controlled by commercial organisations, subject to varying data protection laws and all with a degree of commercial value gain by holding personal data. As a result, both individual users and national governments may have issue with sensitive personal data being stored in this way. Simultaneously, large numbers of consumers are happily trading the privacy and protection of this data in exchange for the convenience or access to cheap or free digital services.

Given the aim of supporting people to co-manage their own health and care public sector systems must learn how to interact with the ubiquitous technologies people have access to and are comfortable with. At the same time there are very large personal datasets that most public sector systems do not want unfettered integration with. In the proposed simulation model DHI positioned the consumer data exchange as a go-between that can integrate with various consumer data stores and draw the data out to allow the user portability and full control of the data outside of any health technology companies influence.

As an exemplar service, the data exchange project team built a connector app that can be downloaded onto an iPhone and connect to Apple Healthkit. It can then upload the data from Healthkit into the consumer data exchange and make it available via active consent to any other connecting party as the user sees fit. In this one connection the consumer data exchange has access to a large segment of the digital health consumer marketplace – offering users unparalleled choice, while also allowing them full agency over the data.

**What did we learn?**

- The Healthkit model required a separate iPhone app to extract the data i.e. there is no way to push data from Healthkit into another system. From a user experience perspective, this creates what may be an unnecessary step in the journey. At this stage it is a considered approach by Apple that ensures the data remains on your phone unless you allow a third party to extract it.
- Healthkit has its own issues trying to knit together so many different apps and systems on a consumer basis. For example, duplicate entries from multiple sources can cause confusion – for example both the phone and a wearable collecting step count and feeding a double entry back to the connected systems.
- When this is then extrapolated out to a diabetic handling six or seven different health apps, Healthkit as well as the consumer data exchange app – it can be quite intense to configure and troubleshoot the system correctly. What is missing here is a way of **orchestrating** the systems and helping the user to navigate between them easily. Normally this would be part of any given organisations service offer – but because these integrations cross so many different organisations and systems, there is no one responsible for this orchestration.
- Next phases of simulation work must expand out to other major smartphone operating systems such as Samsung Health and Google Android to address equality of access issues.

## 4.7. Connecting a Consumer Data Exchange to Statutory Integration Platform

In parallel to the initial DHI investigations of untethered data sharing infrastructures, NHS Greater Glasgow & Clyde (GG&C) was engaged by the Scottish Government to develop a proof of concept statutory integration platform and health and social care patient portal for Scotland. The technology platform, developed by NHS GG&C and Atos consisted of an integration hub, used the MyAccount scheme linked to the Community Health Index (CHI) for identity management and offered a suite of FHIR resources / APIs.

Initial engagement activities focused on DHI, NHS GG&C and the partnering businesses jointly exploring the FHIR resources and APIs for a range of test integrations. The first steps were to use the document FHIR resource to pass summaries from the integration platform connected to the GP document system (Docman) back and forth from the consumer data exchange.

After that, the group began to work with the observation resource to pass structured data (e.g. BP, diagnosis) back and forth between the two exchanges.

Further details of the two scenarios that were developed for full service integration follow in sections (3.8) and (3.9).

**What did we learn?**

- Working with a statutory integration platform significantly smoothed the process of simulating consumer system connections through the public sector firewall.
- However, it was difficult to move beyond the integration layer to develop new capabilities in concert with clinical endpoint systems (e.g. Trak, EMIS) without a clinically endorsed service model change to justify it.
- Linked to this was the issue of locating a ‘single version of the truth’ for many data items held across multiple siloed clinical endpoint systems. Even if NHS GG&C could do so from Glasgow based systems, then the same model may not work in other health boards using different systems, standards or definitions. For example, something as core as blood pressure and how hypertension was coded and captured varied across health boards. This limited the scalable potential of the digital services under development.
- From the outset of the project activity, there was uncertainty surrounding the MyAccount programme, and so it was unclear if this should be used as part of identity management. This led to the use of a range of solutions which created multiple layers of account creation and authentication.
- In summary – for future simulation activities, the scalability of any solution would be dependent on having a well-structured, single version of the truth for core clinical records, linked to a single identity management service.

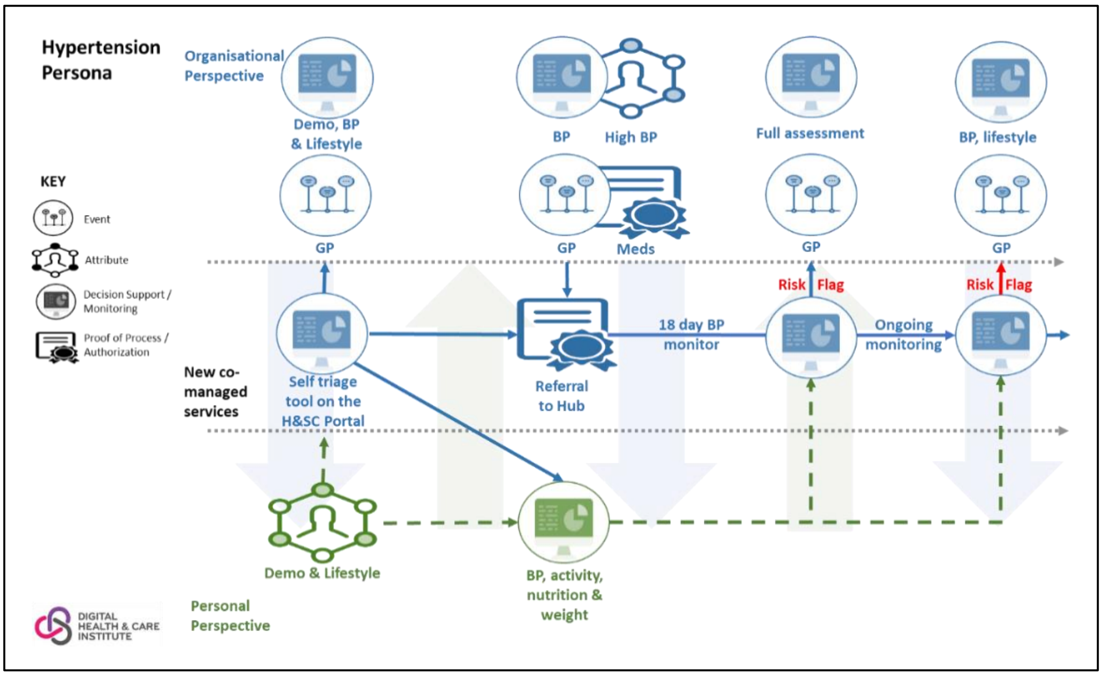
## 4.8. Simulating a Clinical Remote Monitoring Service - Hypertension

The first scenario selected for full simulation was for a hypertension management service. This was selected as a relatively simple initial exemplar focused on reducing routine appointments in primary care, detecting deterioration earlier. This service would collect BP device readings, adds lifestyle risk factors and monitoring data through consumer systems and submit this into statutory systems.

### Step 1 – High Level Service Mapping

Over several iterations, DHI engaged the project team and relevant experts, service providers and users to develop a preferred future state map, highlighting where the useful assets are held (by systems or people), and then developing co-managed service propositions (middle row).

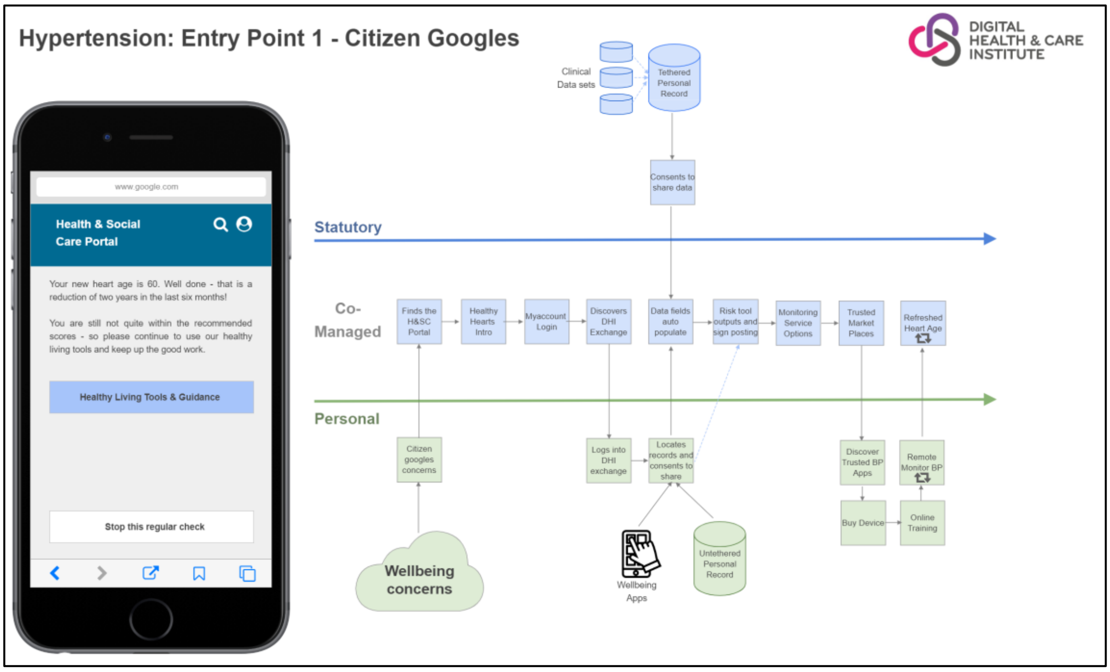
*Figure 7: Hypertension Service Flow*



### Step 2 – User Experience Mapping

A prototyping tool was used to model the user interface alongside a user journey map. This gave a more detailed idea of what data needed to be collected or transferred, at what time and in which context.

*Figure 8: Example User Experience Map*



Your new heart age is 60. Well done - that is a reduction of two years in the last six months!

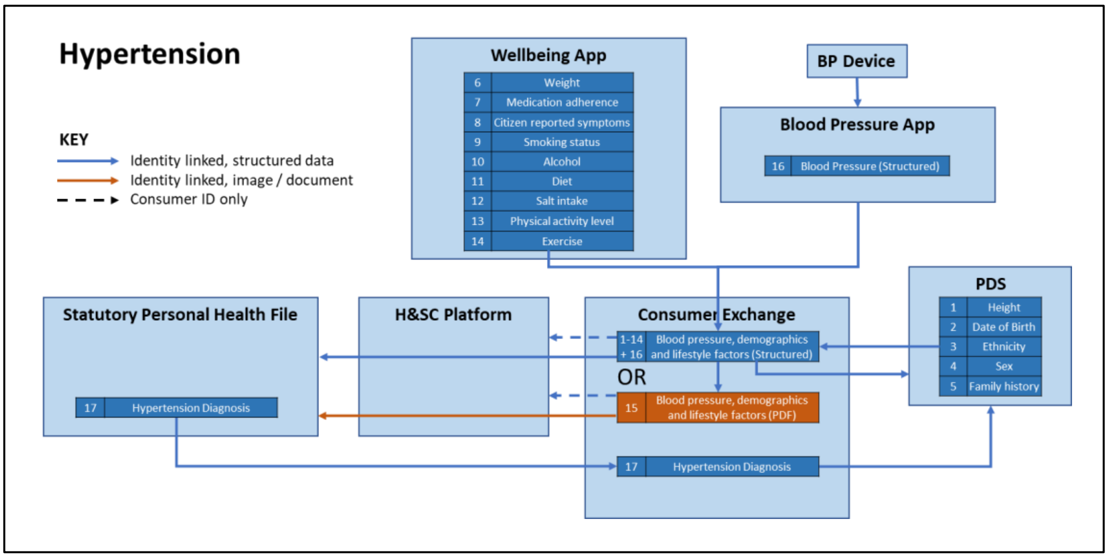
You are still not quite within the recommended scores - so please continue to use our healthy living tools and keep up the good work.

In this scenario, the team explored how a person self-activates through an online healthy heart tool, and then based on their risk, use their own blood pressure cuff and app to feed data into the tool. Ultimately, they were either able to continue to self-manage with consented ‘management by exception’ oversight from a remote monitoring clinical service, or they escalated to normal healthcare services, but with a bundle of decision support data pre-shared with the clinician prior to first contact.

## Step 3 – Data Integrations

The data sets were then mapped onto the reference architecture to help the project teams focus on the core integrations required to demonstrate a valid service. Note this means doing the minimum possible technical work to build confidence that this service can be delivered, while generating learnings in advance of a more complete implementation stage.

*Figure 9: Hypertension Data Model*



In this case focused data items were (6) structured weight, (16) structured blood pressure, and (15) PDF blood pressure report. These were then integrated between consumer and statutory systems using FHIR messaging standards.

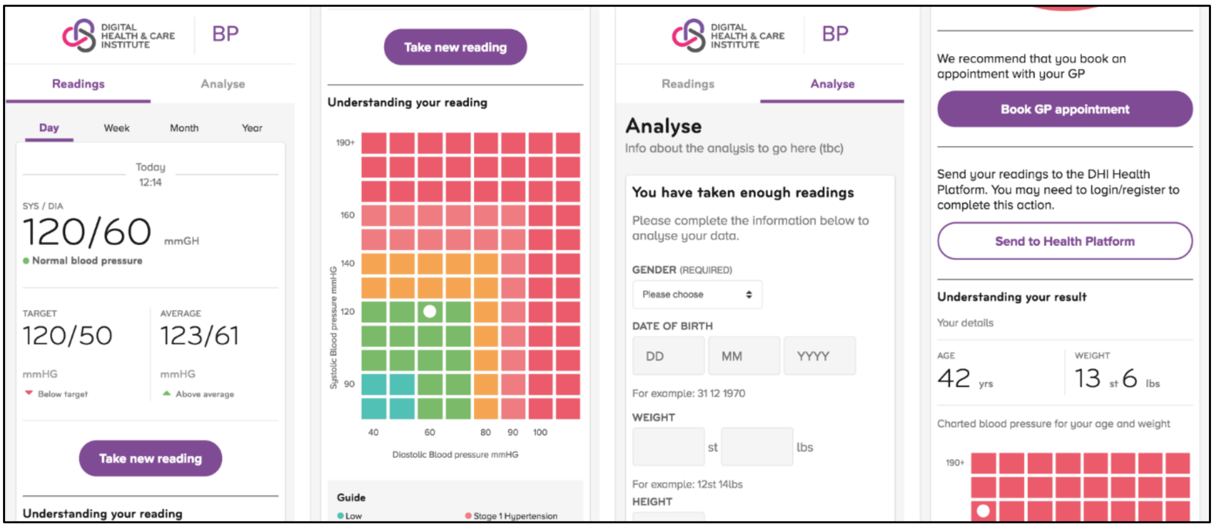
**Step 4 - Demonstration**

Once the test integrations were complete, the project team continued using the same iterative process to develop a user interface designed to demonstrate enough of the preferred future state service model, with enough of the core integrations to help build interest and confidence through DHI engagement activities (demonstrations in the DHI environment).

For hypertension, this was a service that allowed a user to connect a third-party blood pressure cuff and automatically transfer readings into an app on their phone via Bluetooth. It then gave them a self-management dashboard. A second tab allowed them to fill in a simple form for all the contextual data required to support a clinician's decision making. This service was then connected to the statutory integration platform to allow submission of structured data for weight, height and blood pressure entered via the FHIR API to show the integrations working at a practical level. This was all manual for the purpose of demonstration (to help the audience understand the consent and integration steps taken), but would be more seamless in a user-facing service with consent and data sharing arrangements remembered and fully automated.

Note that, after having integrated the consumer data exchange layer with Apple Healthkit, it is possible that any Healthkit compliant blood pressure app could be used, albeit without the ability to enforce a local clinical protocol, add the contextual data or to manage the ongoing data sharing consents via the same interface.

*Figure 10: Hypertension Demonstration Prototype*



Today
12:14

SYS / DIA
120/60 mmGH
● Normal blood pressure

TARGET
120/50
mmHG
Below target

AVERAGE
123/61
mmHG
Above average

**Analyse**

Info about the analysis to go here (tbc)

**You have taken enough readings**

Please complete the information below to analyse your data.

GENDER (REQUIRED)
Please choose

DATE OF BIRTH
DD MM YYYY
For example: 31 12 1970

WEIGHT
st lbs
For example: 12st 14lbs

HEIGHT

We recommend that you book an appointment with your GP

Send your readings to the DHI Health Platform. You may need to login/register to complete this action.

**Understanding your result**

Your details

AGE
42 yrs

WEIGHT
13 st 6 lbs

Charted blood pressure for your age and weight

**What did we learn?**

- How to pass structured data from a consumer system into a statutory system via FHIR APIs.
- How to gather the required consumer data together to enable a clinician to approach a hypertension diagnosis without the current heavy appointment load.
- How to make this more trustworthy than normal consumer offerings (i.e. using regulated devices and creating a user interface that follows the NICE guidelines / protocol for BP collection).
- That without a clear identity management solution for national systems it was difficult to offer a 'low to no' friction user experience.
- That it is possible to improve trust in an app by aligning with regulation and guidelines, but that in a system where the blood pressure reading may be used several times by several parties this may not be enough. There is a need to know how to prove the reading came from a regulated, calibrated device and a competent user automatically. That is to say that there needs to be a transparent, immutable transaction record alongside this data – allowing us to trust data instead of just devices - if this model is to power home-monitoring at scale.
- Apple Healthkit has inherent limitations as a part of the consumer integration offer. In this case, because there is no (commercially accessible) ways to differentiate the source of the original blood pressure reading, nor a way to consent to share from Healthkit to a clinical system, it would be difficult to develop a trusted system that fully takes advantage of the large range of blood pressure devices and apps that Healthkit already integrates into the Apple ecosystem.

## 4.9. Simulating an Informal Care Coordination Tool - Frailty

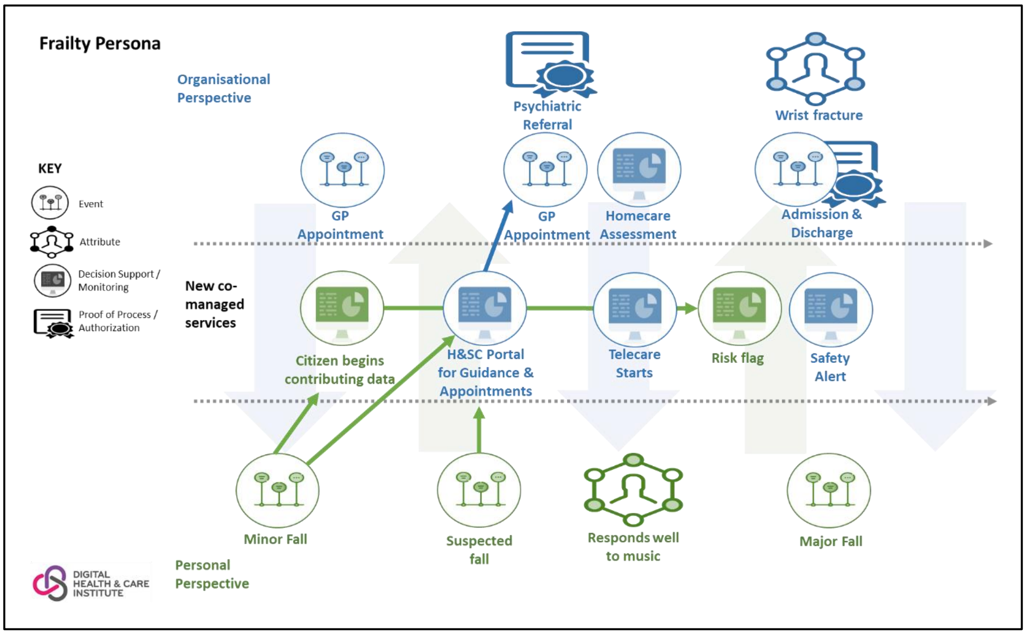
The second scenario was for a service to support integrated, co-managed care for a frail older person. This was a more complicated exercise to draw data from several statutory and consumer sources to support the frail person's informal care network to keep them well in the community.

### Step 1 – High Level Service Mapping

Over several iterations, DHI engaged the project team and relevant experts, service providers and users to develop a preferred future state map, highlighting where the useful assets are held (by systems or people), and then developing co-managed service propositions (middle row).

Due to the more complicated nature of this scenario, a persona for the frail person was created. This was modelled with clinicians to be a near complete simulated record with all the associated data and documents, recorded and encoded in line with Scottish clinical practice. This simulation digital persona was used throughout the exercise to test integrations and user experience.

*Figure 11: Frailty Service Flow*

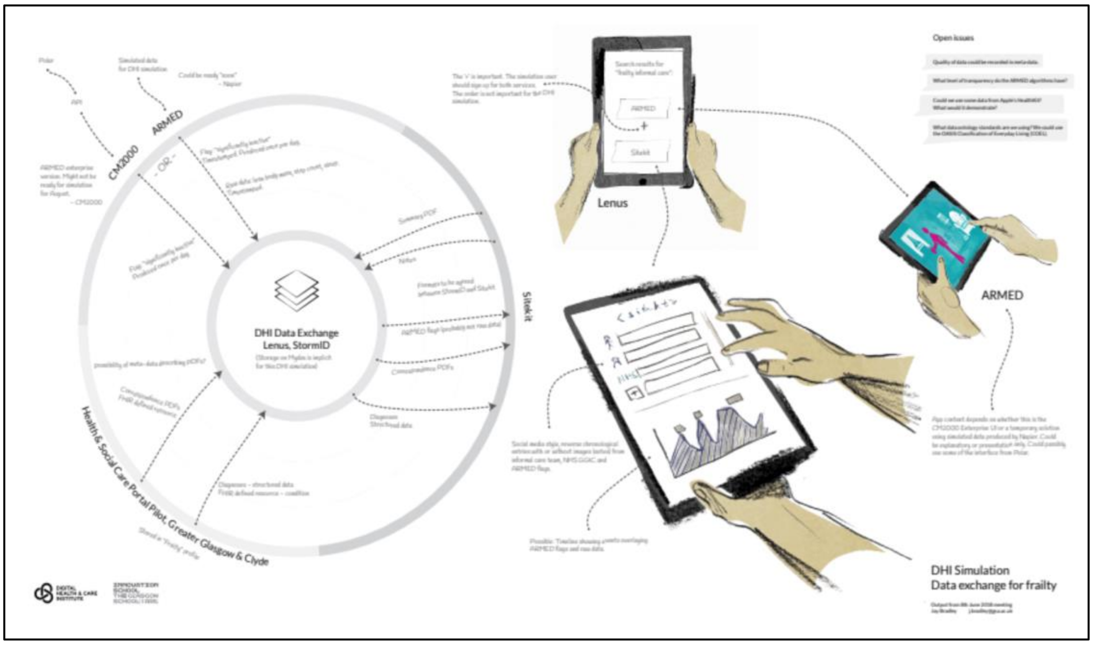


In this scenario, the focus was on how a person's digital assets – both statutory and consumer – can be brought together and shared as part of a dialogue-based tool with their informal circle of care. This could then be used to act preventatively and keep the person independent while making it easier for informal carers to coordinate care amongst the group.

## Step 2 – User Experience Mapping

A prototyping tool was used to model the user interface alongside a user journey map. This gave a more detailed idea of what data needed to be collected or transferred, at what time and in which context.

*Figure 12: Frailty User Experience Map*

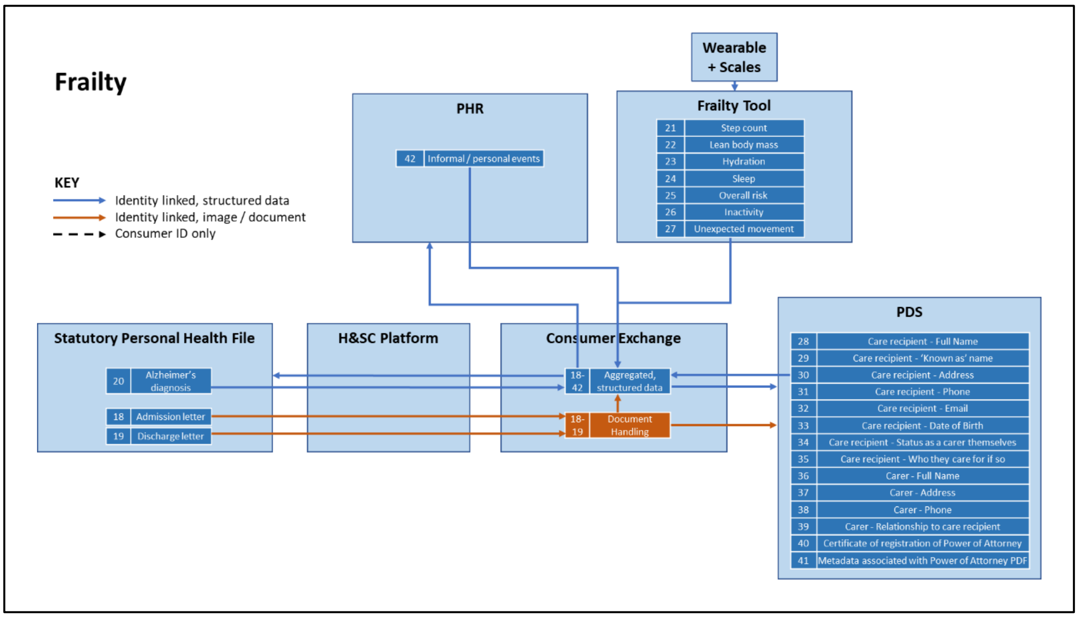


In this scenario, the user could add people into their circle of care app, which functioned like most group messenger social media tools. They could then draw data into the user interface – either wellbeing data from consumer services or clinical data from statutory services. These data items could then prompt prevention or care coordination action from the person and their carers.

### Step 3 – Data Integrations

The data sets were then mapped onto the reference architecture to help the project teams focus on the core integrations required to demonstrate a valid service. Note this means doing the minimum possible technical work to build confidence that this service can be delivered, while generating learnings in advance of a more complete implementation stage.

*Figure 13: Frailty Data Model*



In this case the project team focused on:

- statutory data sets - (20) structured diagnosis, (18-19) PDF clinical letters
- consumer data sets - (42) free text personal events, (26) risk flags for inactivity, (24) structured sleep data.

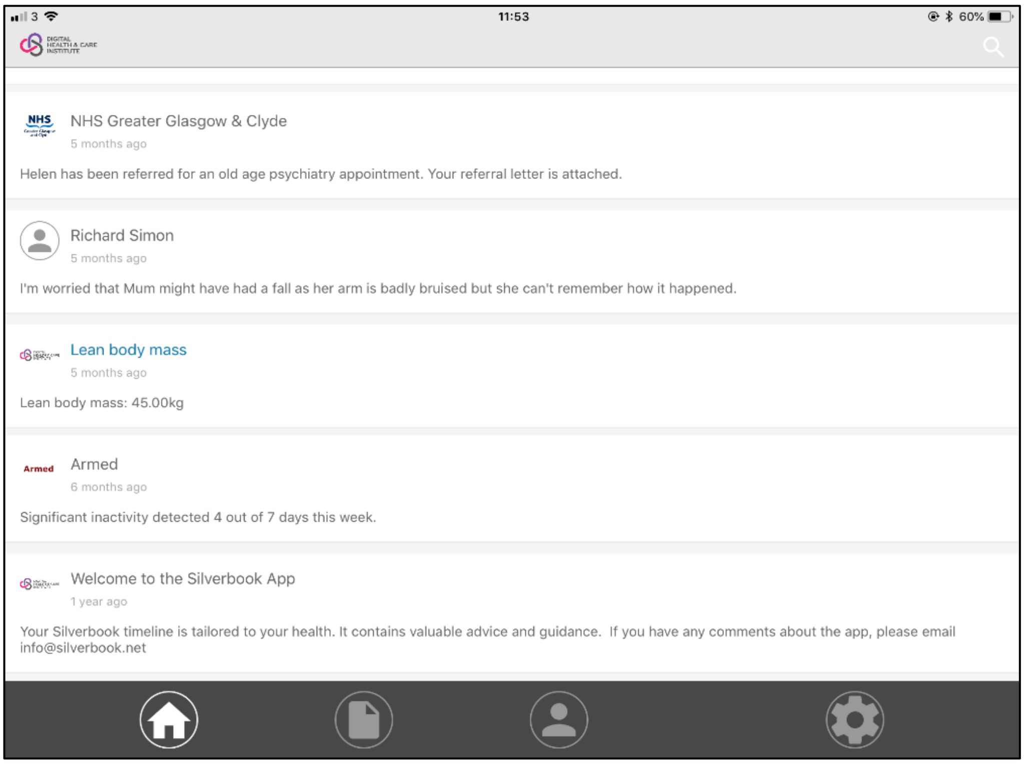
These were then integrated between consumer and statutory systems using FHIR messaging standards.

**Step 4 - Demonstration**

Once the test integrations were complete, the project team continued using the same iterative process to develop a user interface designed to demonstrate enough of the preferred future state service model, with enough of the core integrations to help build interest and confidence through DHI engagement activities (demonstrations in the DHI environment).

For frailty this involved the use of the frailty persona data alongside a user journey-based narrative, depicted within a frailty ‘circle of care’ messaging app (below) provided by Sitekit. The story featured an older person approaching a frail state, and then being empowered to work with their informal circle to take preventative action. This took the form of using a consumer wearable, smart scales and sleep monitor to help identify early deterioration and help the group focus on keeping the person active, strong and confident (provided by CM2000 and Edinburgh Napier University. It also allowed the person to draw their clinical assets into the same conversation – in this case referral details between clinicians and a diagnosis when appropriate. These acted as prompts for the carers to help arrange care, transport or be kept up to date with the user’s needs. Additional ‘mock up’ functionality was added to show falls and dementia guidance being signposted to the users automatically by the system (showing potential for a natural language processing innovation to support this).

*Figure 14: Frailty Demonstration Prototype (Screen 1)*



NHS Greater Glasgow & Clyde
5 months ago
Helen has been referred for an old age psychiatry appointment. Your referral letter is attached.

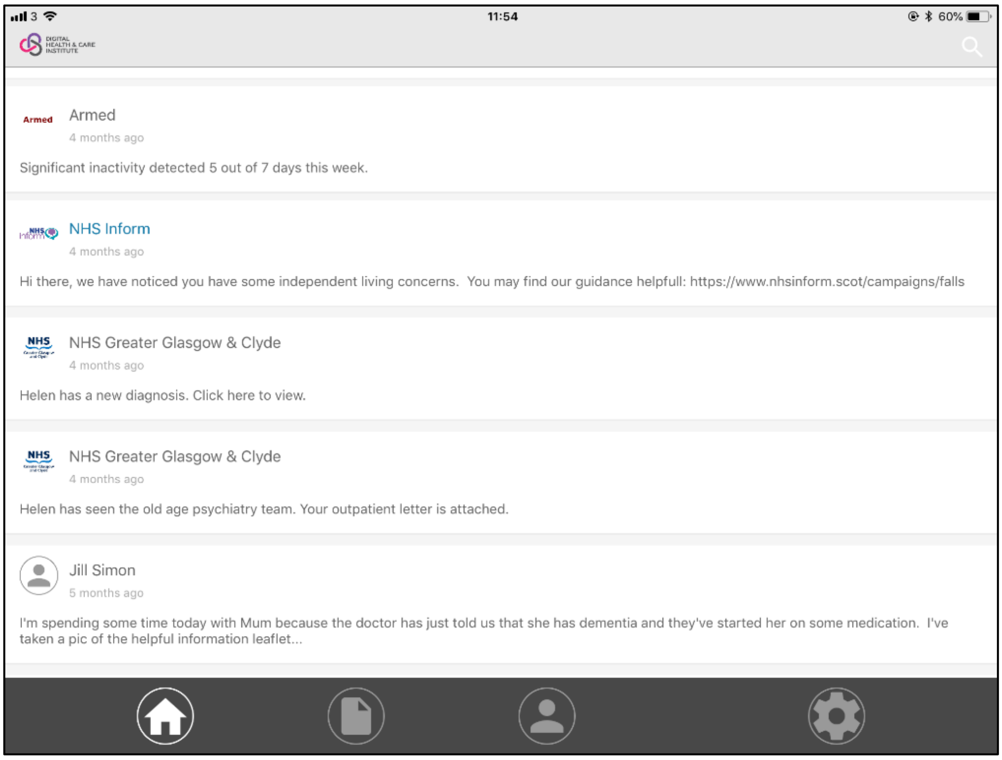
Richard Simon
5 months ago
I'm worried that Mum might have had a fall as her arm is badly bruised but she can't remember how it happened.

Lean body mass
5 months ago
Lean body mass: 45.00kg

Armed
6 months ago
Significant inactivity detected 4 out of 7 days this week.

Welcome to the Silverbook App
1 year ago
Your Silverbook timeline is tailored to your health. It contains valuable advice and guidance. If you have any comments about the app, please email info@silverbook.net

*Figure 15: Frailty Demonstration Prototype (Screen 2)*



Armed
4 months ago
Significant inactivity detected 5 out of 7 days this week.

NHS Inform
4 months ago
Hi there, we have noticed you have some independent living concerns. You may find our guidance helpfull: https://www.nhsinform.scot/campaigns/falls

NHS Greater Glasgow & Clyde
4 months ago
Helen has a new diagnosis. Click here to view.

NHS Greater Glasgow & Clyde
4 months ago
Helen has seen the old age psychiatry team. Your outpatient letter is attached.

Jill Simon
5 months ago
I'm spending some time today with Mum because the doctor has just told us that she has dementia and they've started her on some medication. I've taken a pic of the helpful information leaflet...

## What did we learn?

- How to gather structured data between consumer systems via FHIR APIs to empower service-users and their informal carers.
- How to flex the interface requirements for groups of people – learning from social media.
- A repeat of the issue of locating a 'single version of the truth' for many data items held across multiple siloed clinical endpoint systems – in this case a diagnosis of Alzheimer's.
- A diagnosis data item through a FHIR API is limited in so far as its authority as a fact is entirely derived from its source in the NHS clinical record. If a user wanted to actually be able to use that diagnosis to access other services, it would need to be accompanied by an 'attestation' from the diagnosing clinician – i.e. we need a verified attribute that would be trusted if directly submitted to the benefits systems, for example.
- There are issues around proxy and context sensitive permissions that were not addressed in this simulation – i.e. what happens when someone can't actively manage their own circle of care? What if you don't want your diagnosis made available to everyone in the circle?
- The changes to medical device regulations (coming into force in 2020) will have an impact on how far this kind of model could extend based on consumer technologies. Both the devices and sensors are not regulated devices, nor is the intermediary software that brings the data together. Efforts were made in this stage to simply represent the data cleanly from third party systems, without automation to help the user make sense of the data (and thereby mitigate the degree of regulation that apply). However, this increases the labour on the part of the user to gain value from the system. Further exploration of this tension will be required in Phase 2.

## 4.10. Project Close: Reflections

As part of the project close for the Phase 1b simulations, a lessons learned session was hosted. The method for capturing lessons was simple – each workshop participant was given some 'DHI currency' and was asked to annotate a fake bank note with something they valued in the project and put a number to it.

*Figure 16: Phase 1b Simulation Positive Project Value*

**Perceived Positive Value**

£500
Practical action while everyone else was talking

£100
Participation is strategic and vital as we have made our decision to put our eggs in the DHI basket

£100
Enjoyed working with Chal who we feel is well aligned in terms of view of healthcare transformation

£100
Successful transformation project between DHI and industry

£50
DHI has brought together disparate partners who possibly would not have gathered to work together

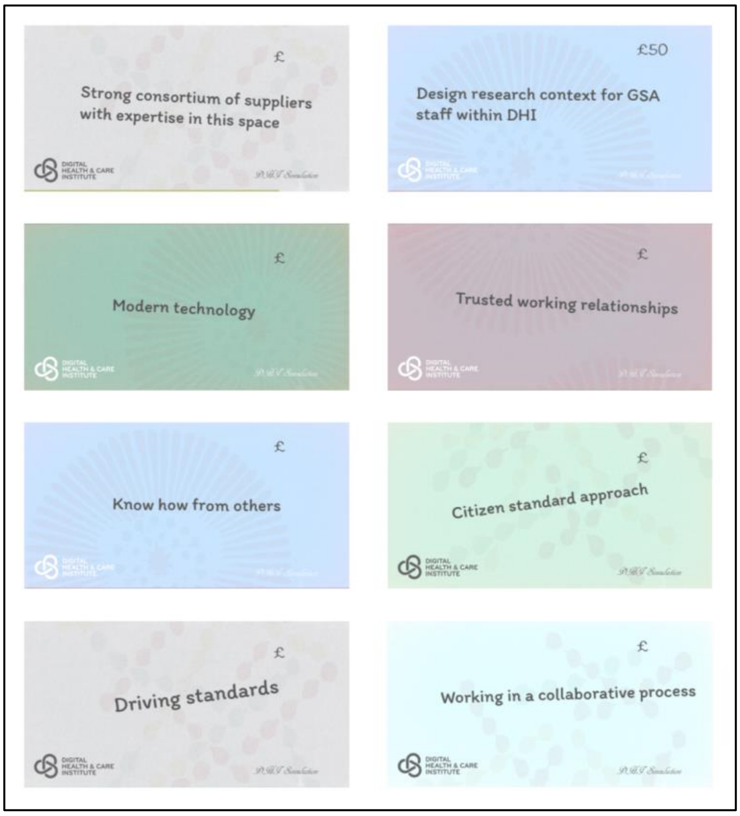
£50
Spin-off app that would otherwise not have been possible

£10
Excellent use-cases with significant core value to citizens of Scotland

£
Better understanding of NHS Greater Glasgow & Clyde integration challenges

£
Demonstrating the art of the possible

*Figure 17: Phase 1b Simulation Positive Project Value*



£

Strong consortium of suppliers with expertise in this space

£50

Design research context for GSA staff within DHI

£

Modern technology

£

Trusted working relationships

£

Know how from others

£

Citizen standard approach

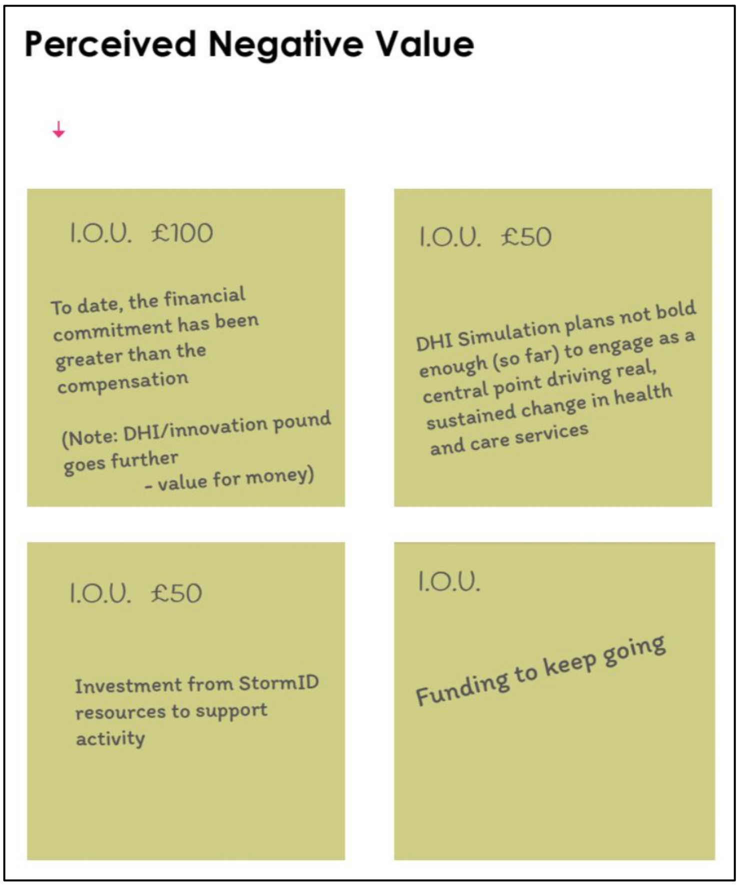
£

Driving standards

£

Working in a collaborative process

*Figure 18: Phase 1b Simulation Negative Project Value*



Perceived Negative Value

I.O.U. £100

To date, the financial commitment has been greater than the compensation

(Note: DHI/innovation pound goes further - value for money)

I.O.U. £50

DHI Simulation plans not bold enough (so far) to engage as a central point driving real, sustained change in health and care services

I.O.U. £50

Investment from StormID resources to support activity

I.O.U.

Funding to keep going

*Figure 19: Project Team Quotes*

"We had good developer to developer relationships across our partners."

"We were able to ignore some practicalities to make progress (such as authentication)."

"We have learned by doing practical work."

"We have 'followed the energy'."

"We needed multiple parties."

"The open APIs provided were necessary and will be in future to grow the list of contributing partners organically."

"We built a PLATFORM – and some sample services. Services run on a PLATFORM."

"We had a common objective and 'wore no badges'."

"We started small but have a big idea."

"In future we will need to set deadlines with slack for non-committed (non-fulltime or non-funded) partners to catch-up."

"We needed to make the distribution of running prototypes better. They were accessible for the DHI but needed to be accessible to all partners, so all partners could better evangelise their work."

"We should have had a formal change log administered by DHI."

"Building simulated services is worth 100 meetings."

"In the future we should produce live infrastructure."

"In the future we should produce more services on top of our open infrastructure."

"We produced service-oriented infrastructure. Infrastructure that allows new services to be built on it. Infrastructure supports service transformation."

"In future the DHI should push for industry to comply with its vision – stretch and push the boundaries of what is imaginable."

# 5. Demonstration & Stakeholder Feedback

## 5.1. The Horizon 1 Demonstration

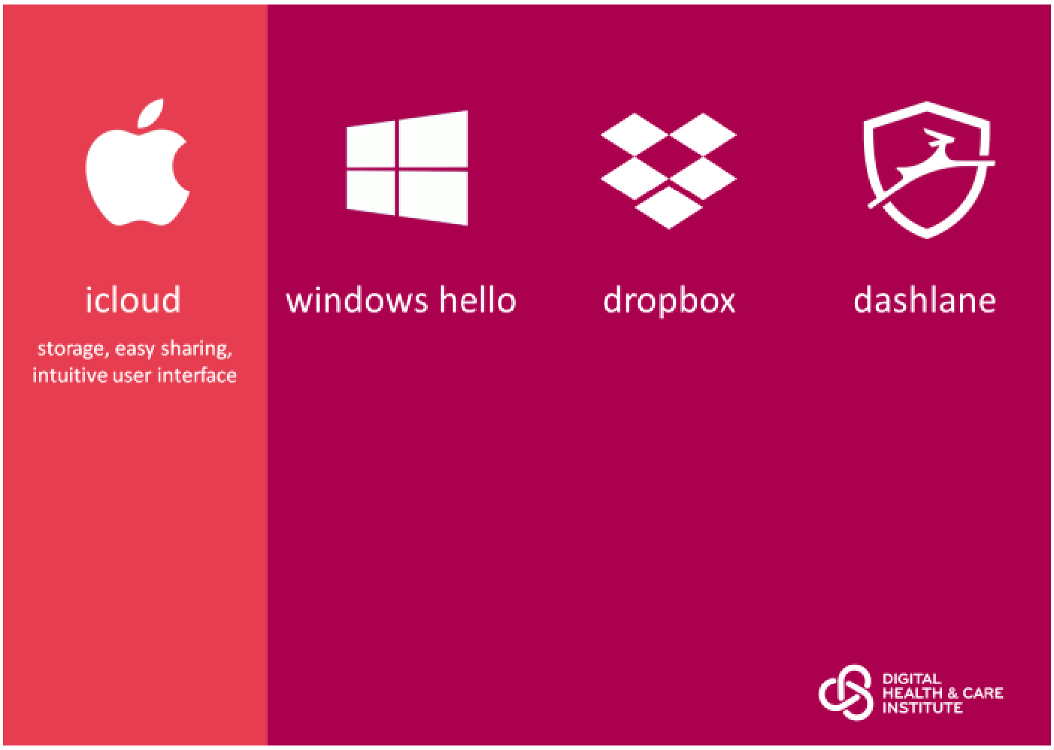
This paper has so far focused on the simulation part of the DSE, where DHI and partners undertook practical activity to integrate systems using person-centred, consent driven platform principles and capabilities. The ‘Demonstration’ part of the DSE refers to the environment’s broader functions to inform policy, engage stakeholders and help the ecosystem to manage change.

The two Horizon 1 simulations were embedded within an overarching narrative that drew on DHI’s broader co-design, academic, market engagement and analysis activities. This took the form of a two hour walk around tour of an immersive physical space, with groups of five to ten people, progressing through a story to help people understand and gain confidence in the change required to use digital capabilities in a truly person-centred way. The Horizon 1 tour will be available for the remainder of 2019-20, with the following summarising the eighth iteration of the demo content.

### Stage 1 – Reflecting on Broader Digital Consumer Trends

Irrespective of their background, visitors to the DSE all start the activities in the same way. They are asked to engage on a personal level, reflecting on their own practices and expectations as a digital consumer. This is an important step, as it stopped participants immediately shifting into their professional expectations of what is possible with technology in health and care service delivery and allowed them to be more demanding and receptive to the emergent digital possibilities.

*Figure 20: Demonstration Content for a Walk Through of Ubiquitous Digital Services*



icloud

storage, easy sharing, intuitive user interface

windows hello

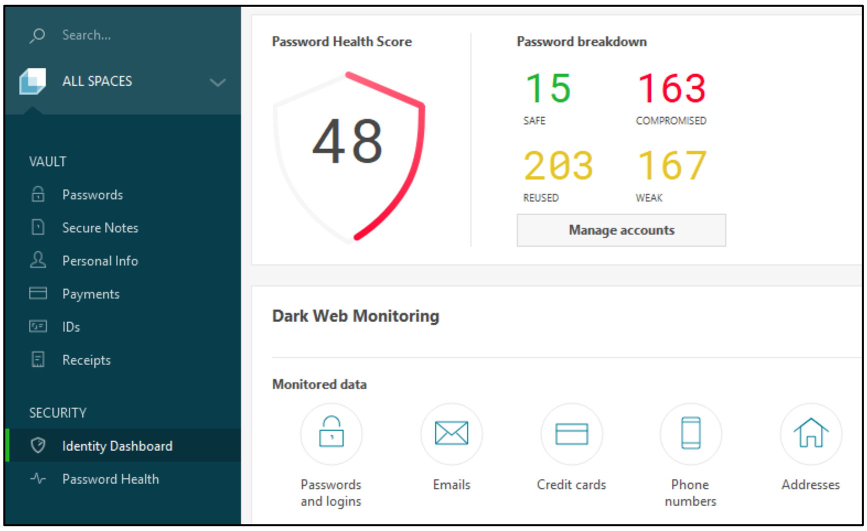
dropbox

dashlane

DIGITAL
HEALTH & CARE
INSTITUTE

The second half of this stage was a product demonstration of a password manager called Dashlane. This technology replicates the password management features common across web browsers, but in a multi-platform model.

*Figure 21: Product Demo – Dashlane Password Manager*



In essence, it allows you to curate your passwords, contact information, payment information and IDs in a way that allowed you to reuse the curated data to auto-login to websites, auto-fill in forms, or speed up online payments, all with a master password or fingerprint.

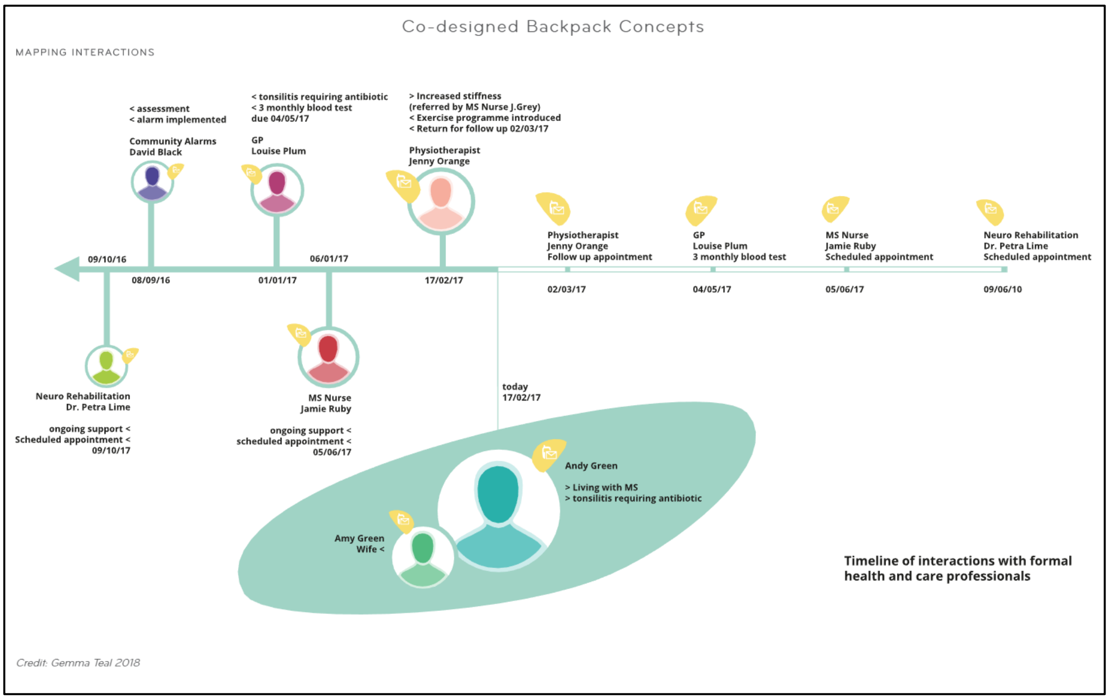
### What did we learn?

- The first demonstrations did not have this initial consumer behaviour stage. When the demo started with the concept of people actively curating their own data (a key co-design output from this phase – see stage two), the almost universal response from people delivering health and care services was that people either would not be capable of or have an interest in doing this.
- This conflicted with co-design work across a range of projects, which highlighted that people would want to do this, should the incentives and user experience be correct.
- This stage helped people take a different perspective. Reflecting on modern consumer services, most participants realised they were already managing their own data. This helped rephrase the question from "how can we get people to actively manage their own health data for their own good" to "by copying other digital consumer best practice, what friction and effort can we take away from people by getting them to curate their data once only, and then what is the health and care gain that results?" For example, this may be as simple as automating form completion for GP registration or hospital check in. Importantly the existing consumer methods would already account for a lot of the data in these kinds of forms.
- Once people accepted that empowering people to manage their own data was plausible, the conversation moved onto trust (security, privacy, ethics, etc.). Specifically, two questions arose that require further investigation:
    - Is it possible to delivery a service like Dashlane, but without a more trusted and governed provider?
    - Is it possible to delegate the administration of your personal data to some sort of trust broker that you choose but that organisations accept? Can you retain control without the administrative effort?

### Stage 2 – Translating into Health & Care

Building on the personal management of data reflections in the previous stage, the narrative translates the principles back into a health and care context. This section draws heavily on the Backpack project and its exploration of how a person with Multiple Sclerosis would use a Personal Data Store to co-manage their own care. The demonstration focuses on how they could 'tell their story once' to avoid a lot of the emotional labour of going through a benefits application every year or repeating their often-painful story to an endless stream of care professionals.

*Figure 22: Backpack (Personal Data Store) Demonstration Content – A Personally Held Care Timeline*



*Credit: Gemma Teal 2018*

The discussion progresses to how services could benefit from using the person as the point of integration for all the different care providers involved who otherwise can't see each other's records about the person – with the care timeline being of interest to everyone involved.

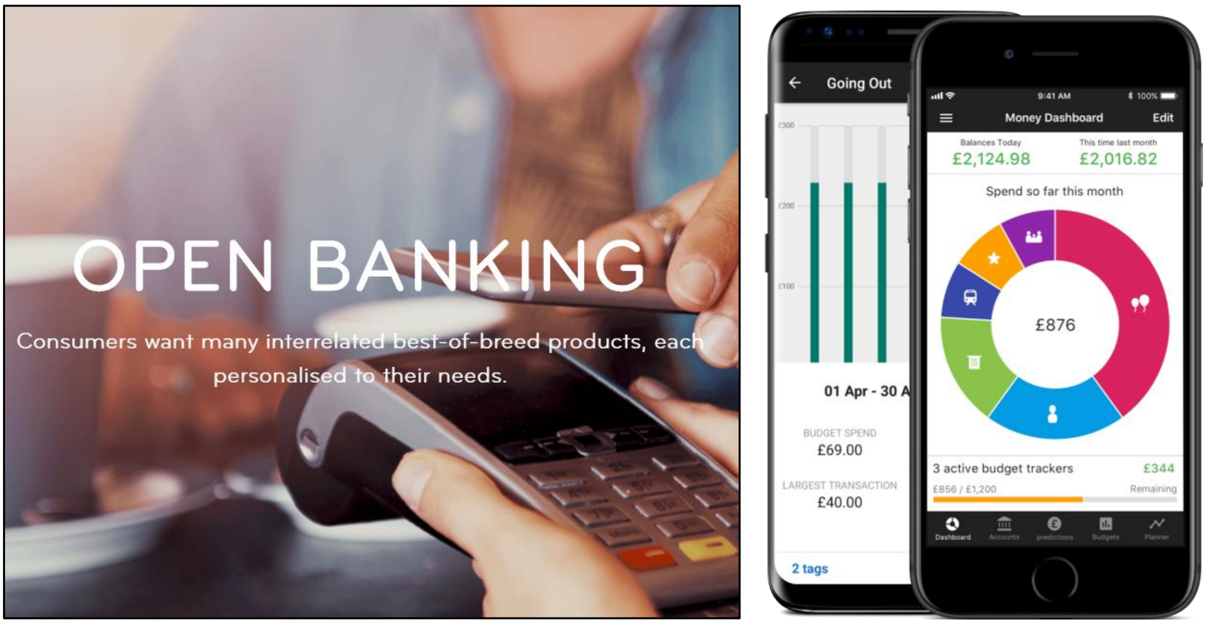
### What did we learn?

- Participants readily acknowledged that there were groups of people with long term conditions who have the right incentives to actively manage their assets in this way.
- Third and independent sector were particularly enthused about this approach. If the record follows and is controlled by the user, then organisations traditionally excluded from shared records due to their lack of information governance capability would benefit.
- Many people reflected that it was an enormous effort to integrate the many different organisational systems to try and achieve something near to a 'single version of the truth'. There has been little progress using the inter-organisational approach so far.
- Many saw this as the natural extension of the General Data Protection Regulation – and that soon this sort of thing may be a 'must have' rather than a 'nice to have'.

## Stage 3 – Reflecting on Open Platform Capabilities in Other Sectors

Having established the idea that people could actively manage their own data with the right incentives, user experience and brokerage, the narrative moves onto the sort of data sharing ecosystem needed to allow them use their data to activate services on their own terms.

*Figure 23: Open Banking Demonstration Content and Product Demo*



Financial services have been going through a phase of significant transformation – most notably for the consumer through the open banking regulations. These enforce the use of Open APIs so that third party develops can offer people alternative user experiences based on their banking data – i.e. stopping bank account providers from locking users into only using their products.

A product demonstration of Money Dashboard showcased the principle – showing an app that can gather your banking data from many different accounts, combine it and then use machine learning algorithms to auto-label expenditure – allowing the user to better budget across their finances.

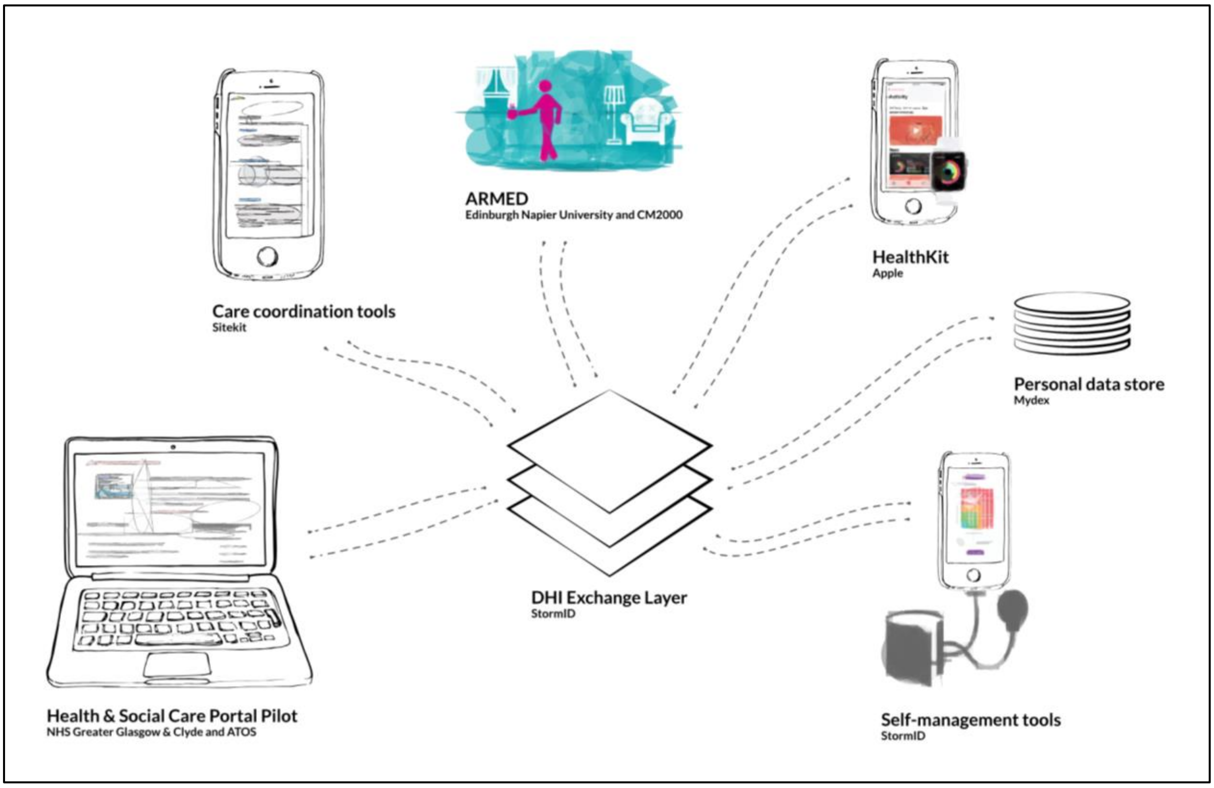
### What did we learn?

- In the average group of ten people, one person felt that this service made them vulnerable or exploitable. One person usually unreservedly said they wanted the product now, often downloading it before leaving the room. The other eight had a range of questions and started to sense make and evaluate the risk / benefit.
- Over the course of conversation around half of the undecided participants would consider this a useful service once they had understood that a) it was read only – you or the company could spend money through the demoed app, b) that there were a range of organisations you could pick from to do this and c) you could cease a relationship and withdraw your data at any time.
- This made clear to everyone that when engaging with digital services, the question is not a binary choice between privacy or sharing, or security versus insecurity. Instead people have a tolerance for how much data and privacy they are willing to trade in exchange for better service and for things that remove effort and friction from their lives. This tolerance significantly increases when they feel like the control the flow of data in an open platform ecosystem.

## Stage 4 – Translating into Health & Care

The last stage brings in the DHI simulation work and uses it to draw together the themes from the previous stages. It builds on both the idea of an ethical, governed place to hold your own personal data, and the use of open platform capabilities to allow you to control your digital relationships (both consumer and statutory) and use the data you collect to activate services on your own terms.

*Figure 24: Demonstration Content – High Level Visual of DHI Simulations*



This part of the demonstration showed how people can use their own digital assets to either co-manage with a public sector service (hypertension), or use public sector data, alongside consumer data, to empower their informal care circle to coordinate personalised and proactive care to help them stay independent in their own home (frailty).

### What did we learn?

- Participants generally reacted very positively at this stage. It was clear that seeing practical, technical work that implemented the principles in the context of person-centred care story helped to de-risk the proposition for many people.
- At this stage people did not need the whole service to be constructed – showing some exemplar integrations was enough to give people confidence.
- Many of people reflected on how well this kind of infrastructure could work with a Self-Directed Support / Personal Budgets approach.
- There was concern that as people connected more and more things into the ecosystem, that this could overwhelm users. This reinforced the need for some form of trust broker / virtual assistance / navigation / link worker types of service to help people get the most out of it.

## 5.2. Stakeholder Feedback

DHI has spent the last year giving the Horizon 1 demonstration to a range of stakeholders. Running from June 2018 the DHI has given over fifty demonstrations. Participants have included:

- Almost all territorial and special health boards, higher education institutions and national charities,
- Around fifty social care or smaller third sector organisations
- Scottish Government departments covering digital services, economy and education
- Several health trusts from across the UK, Public Health England and NHS Digital
- Over one hundred industry organisations, ranging from SMEs through to multi-national corporations
- Enterprise and international development agencies
- Delegations from a dozen countries

Section 4.1. summarised the key learnings emerging from stakeholder feedback that helped to shape the DHI demonstration over many iterations. Some additional overarching feedback included:

- The linkage across sectors and showing that DHI learns from previous work did a lot to build confidence in the concepts.
- The organic nature of the conversation allowed groups of participants to explore the topics in their own way – better than getting it spoken at you with a train tracked PowerPoint presentation.
- A significant number of participants wanted to see more things that are achieving adoption at scale today.
- People were most interested in discussing how the service and business model would change as a result of these capabilities. Examples of how these elements could evolve would add value.
- The content was still very healthcare focused. The frailty simulation work was more relevant from an integrated care perspective but was built and demonstrated through a healthcare lens.
- Linked to the above, the statutory integration was limited to the NHS. However, many participants also said that perhaps the ‘untethered’ infrastructure that integrates services via the person is should be the focus, rather than connecting into legacy social care systems for parity with healthcare.
- The simulations focused on active personal monitoring data (e.g. BP, activity, sleep), where more attention was needed on environmental data (e.g. air quality, temperature, motion). This would be particularly pertinent as telecare services move over to digital.
- The simulations focused on quantitative data, possibly at the expense of more holistic and qualitative approaches. For example, to get a more rounded picture, PROMS and PREMS data for pain or fatigue could be collected in parallel.
- Sharing data between systems is a good start, but for many participants working outside of public sector health and care, they were more interested in how to exchange ‘verified attributes’ (e.g. a digitally signed diagnosis from a doctor) to cut out lots of inter-organisational bureaucracy that slows down care delivery and burdens care givers.
- The demonstrations were really engaging, but more could have been done to give people advance notice of what they were going to participate in.

# 6. Conclusions & Next Stage Developments

## 6.1. Conclusions

DHI set out to demonstrate that is was possible to create a set of infrastructure that follows and is controlled by a person not and organisation, and that this could help to rebalance the power dynamic to help achieve the desired objective of co-managed, integrated, person centred services.

The existing simulations and the positive engagement to date stand as testament that this is indeed possible, but that there is still a perception among those delivering health and care services that people are not capable of managing their personal data in this way.

Our iterative demonstration and engagement work has sent a clear message that DHI should bring forward its Horizon 2 plans – to expand on the current work to handle distributed IOT estates to enable more environmental monitoring capabilities and social care use cases.

The creation of the National Digital Health & Care Platform by NES Digital Service also sends a clear signal that DHI's next simulation activities should consider how best to work with existing and emerging healthcare data interoperability standards such as FHIR HL7v3, SNOMED and OpenEHR to make sure these untethered and consumer capabilities can integrate with statutory systems in the future. DHI welcomes this platform as a statutory 'anchor' point for its work, given that the platform is aiming to solve two of the issue DHI encountered in this last phase – around a clear 'single version of the truth' for core medical data and a single identity management proposition to help smooth the user journey.

Moving forward it is clear that while the technologies can be developed and can use open platform approaches to integrate, this does not account for what an organisation managing technology on behalf of a user would normally do. That is, that there are orchestration requirements that still need to be met as a user interacts with a range of digital services. This raises the question – how would a range of service orchestrators work on top of a distributed, open platform architecture?

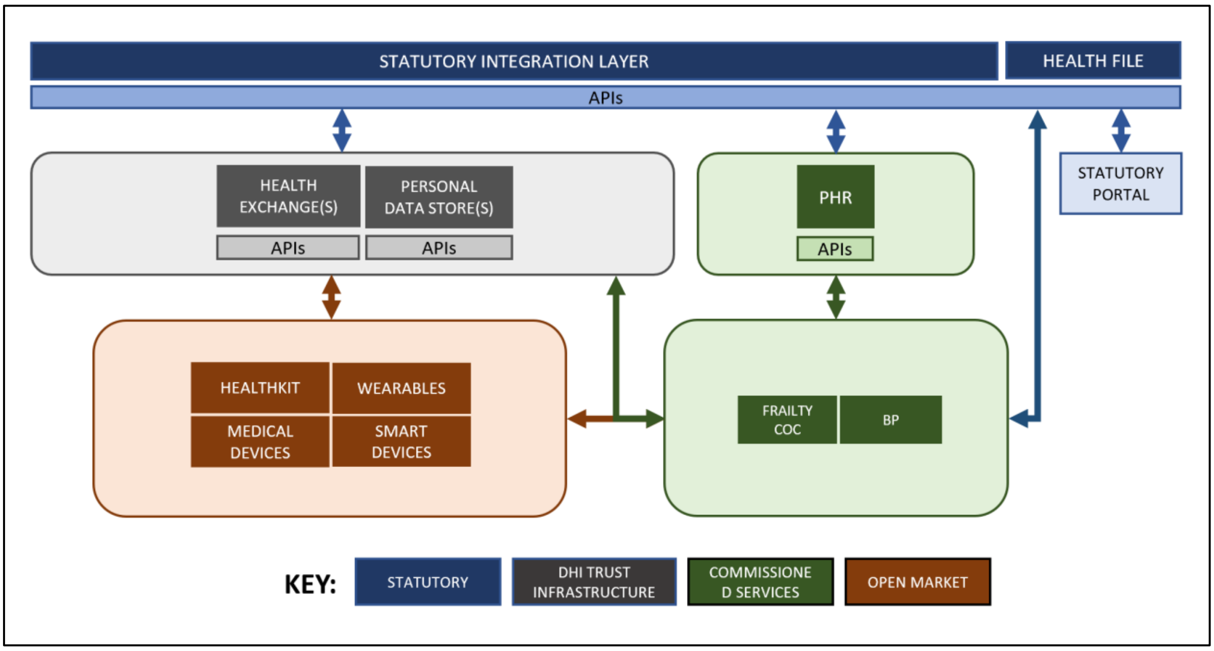
Further, there is a clear need for some sort of trust broker organisation to help people manage their own data across many ecosystems when they may not have the interest or capability to do so directly themselves. The insight emerging from Phase 1 was that people want to 'control, but not administrate, their data'. DHI has, in effect acted in this trust broker capacity for these simulations and can continue to do so in the short term – but in the longer-term dedicated organisations may need to emerge to help the ecosystem support person-centred co-management of care and the data it depends on. DHI Horizon 3 activities look to distributed trust architecture developments that may support the transparent, immutable record of transactions needed to allow this brokerage with minimal administration.

## 6.2. Next Steps

DHI will seek to undertake its Phase 2 simulation work from September 2019. Requirements for an extended set of consumer / untethered digital infrastructure are being set with reference to the lessons found in this report, with the intention to release a PIN Notice in June 2019 and undertake procurement activity in September 2019.

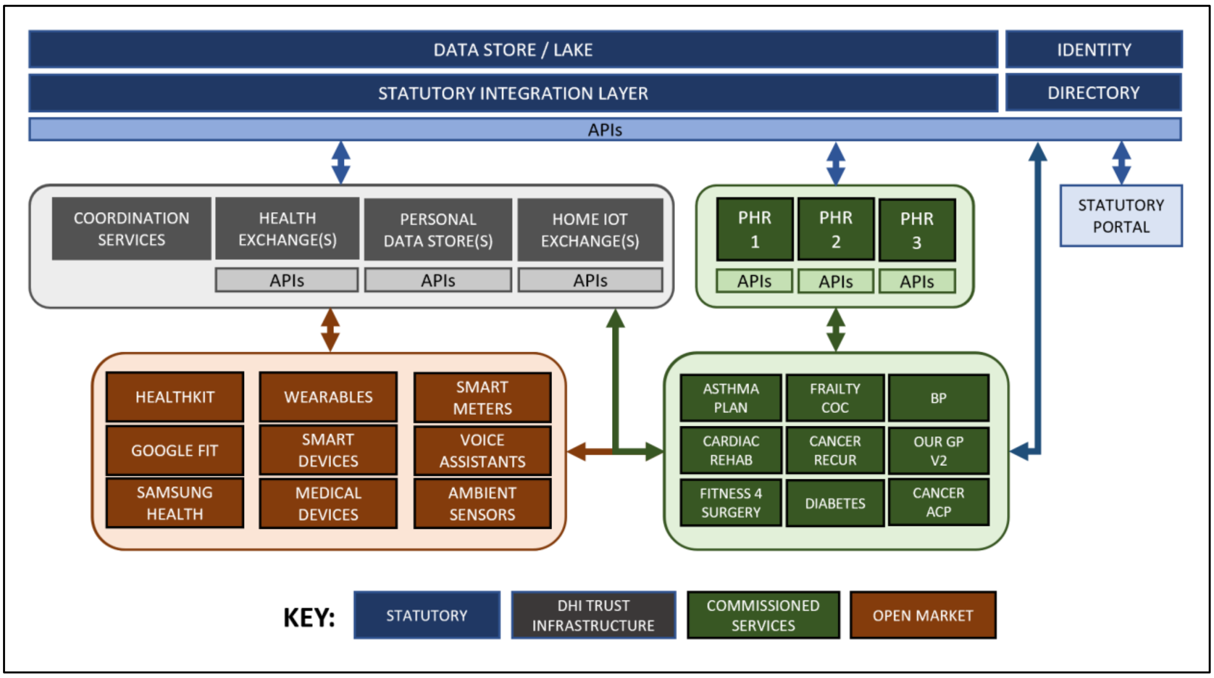
To summarise, this report documents the research and development behind a set of products, platforms and services connected as per Figure 25 below.

*Figure 25: Phase 1b High Level Architecture*



DHI's proposed Phase 2 architecture (Figure 26) builds on this, but now seeking to address the lessons learned and the gaps and opportunities uncovered in Phase 1. More detailed descriptions can be found below, and examples of commissioned services found in **Appendix 1**.

*Figure 26: Proposed Phase 2 High Level Architecture*



As a reminder, the infrastructure depicted in Figure 26 and listed below are designed to be an indicative set of capabilities reflecting current market capabilities. This is not a target or reference architecture for public service delivery, nor will DHI be running such a service. DHI instead is engaging the market as it is to understand how these otherwise siloed capabilities might work together and how this can be done in a person-centred way. Through ongoing co-design work DHI will understand common capabilities for trust and will engage the market to provide these for digital innovators so they can work on service development and transformed user experiences, with DHI smoothing the route to integration, resourcing and adoption.

### Existing Statutory and Consumer Capabilities

With reference to Figure 26, these are capabilities that will exist outside of any DHI procurement or development activity:

#### Statutory Services (Blue)

- An OpenEHR Clinical Data Lake within a digital platform offering a range of statutory integration services is being provided by NES Digital.
- DHI will engage the market for OpenEHR specialist input and work with NES Digital to access a test environment of their platform for simulation purposes.

#### Open Market (Orange)

- **Consumer Health Ecosystems -** There are a range of consumer digital health ecosystems evolving, including Apple Healthkit, Samsung Health and Google Fit.
- **Health Devices** – a mixture of consumer wellbeing devices e.g. wearables, smart scales and medical devices (regulated) e.g. Blood Pressure Cuffs and Blood Glucose Meters.
- **General Devices** – other consumer devices that may provide data around activities of daily living (e.g. smart meters, home sensors), or provide new methods of communication or support (e.g. virtual assistants).

### DHI Phase 2 Procurements & Developments

With reference to Figure 26, these are the infrastructures, apps and services DHI will procure and develop in Phase 2:

#### DHI Trust Architecture (Grey)

- **Health Data Exchange -** Building on Phase 1b health data exchange activity, DHI will procure an equivalent capability with a focus on extending into more major consumer health data integrators (android, apple, Samsung and major consumer digital health brands). Continued focus on allowing a citizen to combine a mixture of statutory and consumer data and assets. There will be a revised approach to statutory integration based on both FHIR and OpenEHR standards and methods. This infrastructure will allow DHI to support health and care organisations to redesign their self and co-management activities to better reflect the kinds of digital service people are already using.
- **Personal Data Store -** Building on Phase 1b Personal Data Store activity, DHI will procure an equivalent capability with a focus on extending the technical schema to cover the bulk of data types transacted by other data exchange platforms. The capability will be

integrated with health and IOT data exchanges and be available to third parties for use in R&D activity. A connector may be built for the NES Digital Platform if appropriate.
This infrastructure will allow DHI to provide third sector, independents, consumer services and project teams with a place to store data that is fully GDPR compliant a not controlled by either public or private sector systems. This is a necessary component for user privacy and control over large quantities of passive, ambient data collected via some home monitoring solutions. During the next phase, subject to securing additional funding, DHI will use the infrastructure to house 'verified attributes' e.g. a digitally signed diagnosis token, to allow a user to prove risk or eligibility and use these to activate services on their own terms.

- **Home IOT Exchange -** This is a new infrastructure required for working with the industrial scale Internet of Things Technologies and networks that will emerge to support the next generation of digital telecare. Where the National Digital Platform and the consumer health exchanges focus on well structured, actively managed health data sets and processes, this infrastructure is instead designed to secure and process large quantities of ambiently collected sensor data created by homes and environments. It will have security features and edge computing capabilities that extend through local hardware up to cloud services – allowing an integrated approach to security for both data and analytics – maximising privacy while still making the data tradeable and actionable across networks. This infrastructure will allow DHI and its partners to draw in environmental data cheaply and securely at scale.
- **Coordination Services -** This is an online marketplace that is connected to a users' data and makes recommendations for quality assured apps based on their needs. It continuously scans mobile app stores and curates the services available on consumer marketplaces to support quality assured discovery. This procurement is for initial concept development and some limited technical proof of concept work.

### DHI & Partner Commissioned Services (Green)

- **Personal Health Records (PHRs) -** This is another category of service that DHI had some experience of in Phase 1b, with the intention of expanding this capability in Phase 2. Where procurements 1-4 cover generic, horizontal infrastructures that may exist across many ecosystems, this procurement focuses on more specialised, feature rich products. These are labelled PHRs in industry parlance, though when the data hosting and sharing infrastructure exists outside of these products, they could be thought of more as person-held care communication, coordination and planning tools. DHI proposes to engage up to three different providers of these services to capture a wide range of capabilities. Some will focus on informal 'circle of care' discussion and coordination, while others will broker patient-clinician interactions or deliver clinics virtually. In all cases, they help care givers and receivers to communicate and use data to co-manage care better.
  These products will allow DHI to maximise the use of the horizontal platform capabilities (both statutory and consumer), by helping users make sense of otherwise unmanageable datasets and processes. These will be focused on individual use cases but procured as general platform capabilities that can be repurposed across different condition and care services.
- **Individual Apps & Services** – A range of smaller procurements and developments for focused service redesign activities. See **Appendix 1** for example scenarios that are indicative of the types of services DHI will start to work on.

## Appendix 1: Example Scenarios for Phase 2 Simulation

The following example are indicative of the type of digital services DHI will explore in the next phase, supported by the untethered data sharing and Personal Health Record (PHR) technologies:

- **Scenario 1: Fitness for surgery -** An app to assess readiness for surgery and then submit a self-referral form for an exercise programme if the user is not ready. This needs to draw data from a Clinical Data Repository to complete the form.
- **Scenario 2: Diabetes -** An asynchronous clinic service that allows citizen generated data to feed into both an aggregated dashboard for themselves, and into a Clinical Data Repository. There should be some concept prototype work around how this interacts with education services / platforms.
- **Scenario 3: Cancer Anticipatory Care Plan (ACP) -** An app that draws in activity, sleep, diet and PROMS / PREMS data (e.g. around pain or fatigue) and uses some simple logic to automate actions when thresholds are met. This needs to compliment other ACP technologies – e.g. respect form on the National Digital Platform or the HIS ACP app.
- **Scenario 4: OurGP -** An app that allows a user to keep their contact details, needs, preferences and goals up to date, and for this to automatically feed into GP systems directly or via a Clinical Data Repository.
- **Scenario 5: Asthma Care Plan –** A service that uses data from a person's broader environment, activities and wellbeing, as well as the core asthma data (peak flow, inhaler use). This would allow an asthma care action plan to be digitised and then for data flow through it, activating components of the plan to support self-management or to signpost, refer or grant eligibility to the user. This would allow asynchronous clinics to be developed that would not require a fixed appointment – rather mix automated analysis and messaging with oversight time from remote clinical supervisors and robust escalation routes as appropriate.
- **Scenario 6: Mental Health –** Focused on self-management involving some symptom, medication and PROMS / PREMS functionality.
- **Scenario 7: Cardiac Rehab -** The future state involves the user leaving hospital having been on-boarded to a digital cardiac rehab service. They can consent to share their wellbeing and vital signs data remotely. This allows trend analysis by the clinical team, who can proactively engage with people who are not rehabilitating well. The rehab can be given remotely, with the person-generated activity data feeding back on effort and capability changes.
- **Scenario 8: Dynamic Digital Passport –** A user can form their own image based digital record (e.g. PAMIS) that can be integrated with health and care records systems – allowing care teams to adjust service delivery in advance or a least be aware of the service-users circumstances and preferences – not always relying on an activated carer having the capacity to share the passport manually. It would also migrate to a highly configurable and dynamic digital system that would allow for the highly variable nature of the materials and interface for each persons' bespoke solution.
- **Scenario 9: Frailty -** Continued exploration of the use of consumer tools to offer a variety of user experiences for independent living. Some will use wearables or ambient home sensors to help the reassure a care circle that the person is in their normal routine. Other's may prioritise physical activity and diet tracking to help with strength building or social connections and peer support to reduce isolation.
- **Scenario 10: Pharmacy Based Hypertension Management -** A service in which a user can prove their own risk and use this to qualify for consumer-friendly technology that they can use to proactively submit readings and other data to the GP. This would mean that the first appointment is higher quality and diagnosis possible in a faster and cheaper manner. It opens the possibility that advanced analytics techniques could be used to triage those at moderate risk for referral directly into preventative measures run by pharmacy or third sector.