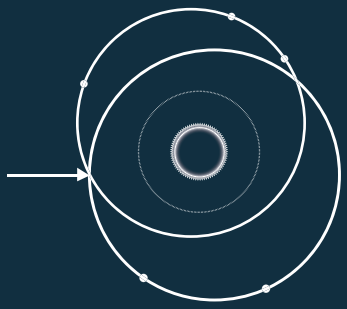

A Person-Centred Vision of Care for People Living with Multiple Long-Term Conditions

for

The Modern Outpatient Programme

Gemma Teal
The Innovation School
The Glasgow School of Art

March 2018

INNOVATION SCHOOL THE GLASGOW SCHOOL OF ART

DIGITAL HEALTH & CARE INSTITUTE

Final Report →

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INNOVATION SCHOOL THE GLASGOW SCHOOL OF ART

DIGITAL HEALTH & CARE INSTITUTE

The Modern Outpatient Programme / Digital Health and Care Institute
Led by The Glasgow School of Art (GSA)

A Person-Centred Vision of Care for People Living with Multiple Long-Term Conditions

The project employed a participatory design approach to develop a person-centred vision for the future of Outpatient services. Through interviews with people living with multiple long-term conditions, pop-up public engagement and co-design workshops with NHS staff, rich insights were generated about how people would like to be supported to self manage, and new models of person-centred care were designed.

Participants: 27 +

General Public in 2 x hospitals

Methods:
- Pop-up engagement
- In-depth interview
- Experience mapping
- Co-design workshop

Seven Interviews
+ **Three** Exp.Labs
+ **Two** Pop-ups
+ **One** Internal Lab

Locations:
- Glasgow (WEST)
- Edinburgh (EAST)
- Forres (NORTH)
- Dr Gray's hospital
- Raigmore hospital

2017-2018

18 Hours Experience Lab time

7 Hours Interview time

8 Hours Pop-up public engagement time

6 Hours Internal Lab time

Team:

- Gemma Teal
- Cate Green
- Angela Tulloch
- Dr. Tara French
- Dr. Jay Bradley
- Jeroen Blom
- Daniela Quacinella
- Ciarán Morrison

multimorbidity

person-centred

future vision

Outputs:

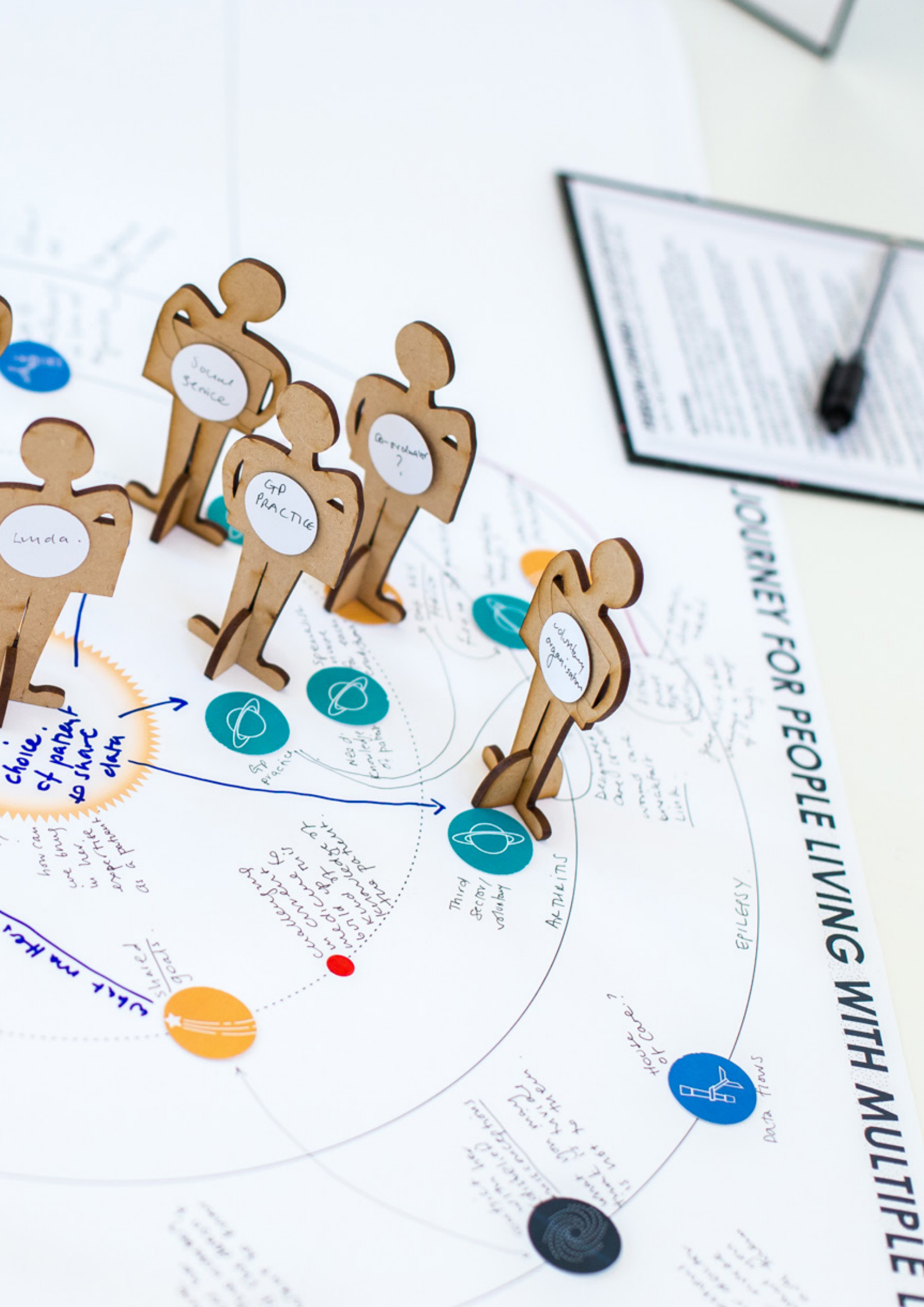
x2 x2 x6

- 2 Reports
- 2 Videos
- 6 Visualisations

Tools & Artefacts:

x33

- Interview mapping tool x 4
- Real Job descriptions x 16
- Person-centred job description
- Current care mapping tool x 6
- Person-centred care mapping tool x 6


JOURNEY FOR PEOPLE LIVING WITH MULTIPLE
Social Service
GP PRACTICE
Co-ordinator ?
Lunda.
choice of patient to share data
GP practice
Third Sector/ voluntary
ARTHRITIS
EPILEPSY
House of Care ?
Data flows
shared goals

Executive Summary

This document provides a description of work undertaken by the Digital Health and Care Institute (DHI), led by design researchers at The Glasgow School of Art to support The Modern Outpatient Programme. The project was undertaken between August 2017 and February 2018, with the purpose of informing the ongoing and future work of The Modern Outpatient Programme. The report is accompanied by a short film illustrating the co-design process, including feedback from NHS staff participants. Digital versions of the various co-design tools used within the workshops are provided as an appendix following requests from participants who wish to use the tools with their colleagues. The report and appendices will be made available to all NHS staff via the Knowledge Network (www.knowledge.scot.nhs.uk).

The Scottish Government has commissioned the DHI to support health and care service transformation, specifically in relation to a number of identified themes. The first of these themes relates broadly to high volume, routine care, and more specifically the transformation of outpatient care, which is the role of The Modern Outpatient Programme led by Pauline Fyfe. The Modern Outpatient will deliver care closer to the patient's home, providing more person-centred care, utilising new and emerging technologies, while maximising the role of clinicians across primary, secondary and community based services.

In consultation with the Programme Director - Outpatient Services, a focus area was identified as: *individuals who present with multiple long-term conditions who currently require regular interaction with outpatient services*. This represents a high priority area which lends itself to a participatory design approach. The DHI Design Group at The Glasgow School of Art devised a programme of research, with the aim of developing a person-centred vision for the future of outpatient care

for people living with multiple long-term conditions.

Through a participatory design process including public engagement, interviews with people living with multiple long-term conditions, and co-design workshops with NHS staff, rich insights were generated about how people would like to be supported to self manage, and ideas for new models of care centred on the needs and aspirations of people living with long-term conditions were developed.

The findings are visually presented, with insights about the current challenge mapped along a representation of the journey of care for people living with multiple long-term conditions. A person-centred vision for future care is described, in terms of the aspirations and ideas of people living with multiple long-term conditions and NHS staff. These aspirations and ideas are mapped against current policy, illustrating how they relate and connect to other work underway in Scotland.

Finally, a roadmap is presented which proposes a development process for this new vision of person-centred care, and shows how this process could connect and integrate with existing innovation projects.

Research activities with people living with multiple long-term conditions and the general public received ethical approval from the GSA Research Ethics Committee. The workshops with NHS staff was reviewed and approved by the GSA Ethics Advisor.

The Innovation School

The Design for Health and Wellbeing Group within the Innovation School at The Glasgow School of Art has developed a design capability to innovate systems, pathways and experiences of care. We do this through three main activities: visualisation, strategic road-mapping and co-design.

The visual language of design enables communication and understanding of the current complex health and social care landscape. The visual exploration of a shared problem space generates an understandable system-level map which generates insights and immediate actions for improvement. With our partners and participants, we also create a map or vision of the preferable future that shows how things would be if the issues that have been identified were solved. Using this preferable future map as the agreed strategic direction, projects can be defined which translate the insights and ideas into tangible outputs, working with stakeholders to co-design and prototype solutions dynamically.

Researchers use current and emerging design research methods to engage with our partners and participants, who are encouraged to share their own experiences and ideas. Real-life practice is often replicated to allow new technology, services, processes and behaviour to be trialled rapidly.

The Design for Health and Wellbeing Group within the Innovation School is a central element in the Digital Health & Care Institute (DHI), a Scottish Innovation Centre funded by the Scottish Funding Council, in partnership with Scottish Enterprise and Highlands and Islands Enterprise.

The Digital Health & Care Institute

The Glasgow School of Art is a founding partner in the Digital Health & Care Institute, which is a partnership between NHS 24, Scottish Enterprise and Highlands and Islands Enterprise.

The DHI Innovation Centre creates an open community where industry can collaborate effectively with academia, health, care and social partners on innovation opportunities that will create societal and economic benefits in Scotland. The DHI will co-create sustainable economic growth through new products, services and systems. These solutions will generate high value health and social care solutions to the benefit of the people of Scotland and further afield.

Project Team

Core Team:	
Gemma Teal	Research Fellow, The Glasgow School of Art
Cate Green	Production Manager, The Glasgow School of Art
Supported by:	
Elizabeth Brooks	Internal Responsible Owner, The Glasgow School of Art
Jeroen Blom	Research Fellow, The Glasgow School of Art
Angela Tulloch	Innovation Designer, The Glasgow School of Art
Dr. Tara French	Research Fellow, The Glasgow School of Art
Dr. Jay Bradley	Research Fellow, The Glasgow School of Art
Dr. Leigh Anne Hepburn	Research Fellow, The Glasgow School of Art
Sneha Raman	Innovation Designer, The Glasgow School of Art
Daniela Quacinella	Innovation Designer, The Glasgow School of Art
Ute Schauberger	Innovation Designer, The Glasgow School of Art
Louise Mathers	Photographer and Videographer, No Middle Name
Paul Campbell	Photographer and Videographer
Policy review:	Research and Knowledge Management
Ciarán Morrison	Officer, Strathclyde University

Acknowledgements

We would like to thank all of our interview participants for giving up their valuable time and for generously sharing their stories to inspire service redesign.

We would also like to thank Andrew Strong and colleagues from The Health and Social Care Alliance (The ALLIANCE) for supporting recruitment of interview participants, and for members of The Modern Outpatient Programme team for supporting recruitment of NHS staff for co-design workshops.

Finally, many thanks to managers at Raigmore Hospital and Dr. Gray's Hospital for permitting and facilitating our pop-up engagement sessions in their busy outpatients foyers, and to all the citizens and staff who engaged with us to share their views.

CONTEXT

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Why focus on multiple long-term conditions?

The increasing prevalence of long-term conditions is the main challenge facing health systems worldwide [1]. In Scotland, it is estimated that 47 per cent of the adult population have at least one long term condition and the number of people who live with multiple and complex conditions is growing [2]. The simultaneous presence of multiple conditions is more of a rule than an exception [3]. The National Institute for Health and Care Excellence (NICE) define multiple long-term conditions (or multimorbidity) as: "the presence of 2 or more long-term health conditions, which can include:

- defined physical and mental health conditions such as diabetes or schizophrenia
- ongoing conditions such as learning disability
- symptom complexes such as frailty or chronic pain
- sensory impairment such as sight or hearing loss
- alcohol and substance misuse." [4, page 5]

The health system has been designed around single-conditions with silos of specialists in secondary care. While this structure may advance expertise in clinical care, it has been challenged as inefficient and burdensome for a population with 23% of patients living with multiple long-term conditions as of 2007 [6]. This raises key questions in relation to what structure a system centred around the person living with multiple long-term conditions would take and how it could change the experience of care.

How are clinical and policy guidelines responding to these challenges?

The majority of clinical guidelines provide individual disease recommendations requiring clinicians and citizens to read a separate document for every different condition the person may have [6]. In addition, following multiple guidelines may result in over-treatment and over-complex medication regimes (ibid). Guthrie et al. highlight the need for electronic formats that cross reference guidelines based on demographic and clinical information, starting with patterns of comorbidity, for example cross referencing guidelines for depression and pain as common comorbidities of many other conditions (ibid). NICE have subsequently published dedicated guidelines for an approach to care that takes into account multimorbidity, using measures of disease, treatment burden, frailty, and patient preferences and priorities to work with the person to develop an individualised management plan and review prescribed medicines [4].

The policy agenda in Scotland calls for a move to care that is person-centred rather than condition focused, and an increase in health and care delivered in community settings [7]. A number of key publications have highlighted the need to change the way health systems are configured to reflect multiple long-term conditions in a number of key publications [7, 8], and it is a feature of the new GP contract [9]. A key ambition of these changes is the goal of stronger integration between health and social care, as well as with independent and third sector providers [7]. This reflects a realisation that challenges in living well with a long-term condition are often not solved by clinical intervention, leading to "the medicalisation of common life experiences" [8] and the evidence that collaboration across organisational boundaries can transform outcomes in a complex system [10].

How is the NHS responding to these challenges?

In order to achieve these ambitions, NHS Scotland champion a number of innovative service redesign projects and new approaches to working collaboratively within the health service and with people living with long-term conditions [8, 11]. House of Care, Teach Back, Key Information Summary, Anticipatory Care Planning and the development of patient focused booking with open access all aim to support these new ways of working, and new technologies and systems such as video conferencing clinics (using Attend Anywhere) and home health monitoring all offer a means

of tailoring care and moving towards a community based model.

Across the UK, a review of medical training highlighted the need for more doctors who are capable of providing general care in broad specialities in response to the increase in people living with multiple long-term conditions [12]. Further changes to the work force to meet this need include extending the roles of nurses and allied health professionals in supporting people living with long-term conditions.

References

1. *World Health Organization. Global status report on noncommunicable diseases 2010. Geneva: World Health Organization. 2011.*
2. *Scottish Government. The Scottish Health Survey. 2016.*
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4. *National Institute for Health and Care Excellence. Multimorbidity: clinical assessment and management. 2016.*
5. *Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet. 2012 Jul 7;380(9836):37-43.*
6. *Guthrie B, Payne K, Alderson P, McMurdo ME, Mercer SW. Adapting clinical guidelines to take account of multimorbidity. BMJ: British Medical Journal (Online). 2012 Oct 4;345.*
7. *Scottish Government. A National Clinical Strategy For Scotland. 2016.*
8. *Scottish Government. Chief Medical Officer for Scotland Annual Report 2014/15 Realistic Medicine. 2016.*
9. *Scottish Government. The 2018 General Medical Services Contract in Scotland. 2017.*
10. *10. Burns H. Targets and Indicators in Health and Social Care in Scotland: A Review. 2017.*
11. *Scottish Government. The Modern Outpatient: A collaborative Approach 2017-2020. 2017.*
12. *Greenaway D. Securing the future of excellent patient care. 2013.*

PROJECT AIMS

The aim of the project was to develop a person-centred vision for the future of outpatient care for people living with multiple long-term conditions. The objectives were:

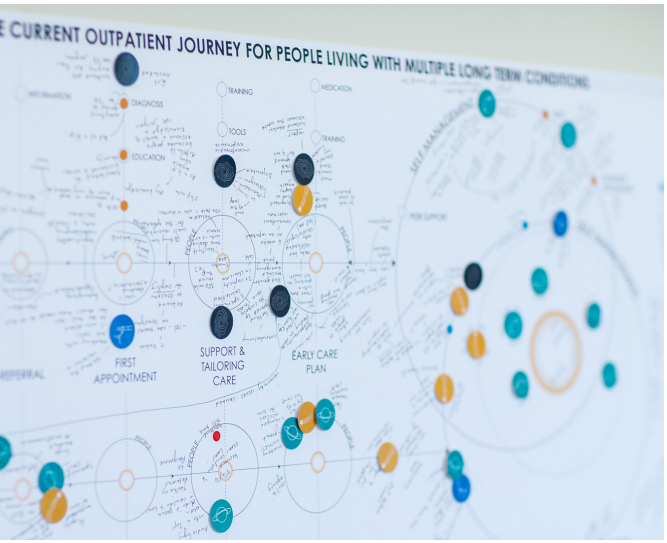
1. To understand the current challenge, specifically:
   a) The challenges of living with multiple long-term conditions and the kinds of support people value;
   b) The challenges of health professionals in supporting people living with multiple long-term conditions within the current health and care system;
   c) The challenges of innovating in outpatient care.
2. To generate ideas for new ways of working to support people living with multiple long-term conditions:
   a) To understand how people living with multiple long-term conditions would like to be supported in the future;
   b) To support NHS staff to co-design new person-centred models of care to meet the needs and aspirations of people living with multiple long-term conditions.
3. To distill the insights and ideas generated into a roadmap for the development of person-centred models of care, supported by new digital tools.

DESIGN RESEARCH ACTIVITY

Mapping interviews
Four in-depth interviews were conducted with individuals living with multiple long-term conditions. These interviews used a bespoke tool designed to structure and record the person's health story, sharing their current experiences of self management and accessing support in the context of their personal life and background, reflecting on their past experiences of diagnosis and looking ahead to future aspirations for their wellbeing and care. Experiences of living with conditions such as diabetes, angina, depression, epilepsy, Crohn's disease and arthritis were explored in the interviews, with participants from four different regions of Scotland. The interview tools were used as inspiration for subsequent workshops (see workshop description for detail).

Three further interviews were conducted with a consultant cardiologist, a programme manager for long-term conditions and a member of the Modern Outpatient team. In addition, the design researcher observed a focus group session with staff from cardiology services across Scotland. These activities aimed to understand the current challenges in innovating outpatient services.

Pop-up Engagement
Two pop-up public engagement events took place in the outpatient reception areas of Raigmore hospital in Inverness and Dr Gray's hospital in Elgin. These sessions aimed to start a conversation with the public about what they value about outpatient



services and gather ideas to improve their experience. The pop-up materials included sketches of design concepts that built on insights from DHI phase one research, alongside the provocation 'What if…? Share your ideas for improving outpatient care'. Design concepts for the pop-up were generated during an internal workshop, which involved the entire Design Group responding to a series of briefs focused on reimagining the outpatient waiting room. Conversations with the public were recorded on panels as sketches and on post-its, which were used as inspiration materials in subsequent workshops.

Co-Design Workshops

Three full-day workshops with NHS staff took place in Glasgow (25th October 2017), Forres (1st November 2017) and Edinburgh (7th November 2017). These sessions brought together consultants, GPs, nurses, allied health professionals, telehealth experts, strategic and clinical leads, and service and programme managers from six NHS regions, to consider the current experience of services for people living with multiple long-term conditions. The morning activities were designed to map the current patient experience, highlighting positive moments and aspects of care that could be improved. In the afternoon session we shared the stories of the people we interviewed, using the interview tools as real personas*, whom the participants were asked to place at the centre, redesigning services around their needs and aspirations. Insights relating to aspirations for future care across the four interview maps were distilled into a 'person-centred job description', which formed the challenge (or design brief) for this activity. The three workshops resulted in six sets of current and future state maps of outpatient care for people living with multiple long-term conditions, which include a wealth of insight, and new ideas for transforming care.

Policy Review

In parallel with the Design Group activities, the DHI Research and Knowledge Management Team have undertaken a collation, review and summation of key documents relating to outpatient services in Scotland. Ten key documents were identified and summarised, with key themes identified. A connecting thread of these documents was the drive towards 'person-centred care'; the use of this term has been reviewed across the documents to consider commonalities and differences in how this term is defined, what it means in practice for people living with long-term conditions and health and care professionals, and how it can be measured. This review is presented in an accompanying report, *"Defining Person-Centred Care"*. The key points from this review have been translated into a visual summary of person-centred care (Figure 2).

** "A persona consolidates archetypal descriptions of user behaviour patterns into representative profiles, to humanise design focus, test scenarios, and aid design communication." Cooper, Alan. The inmates are running the asylum: why high-tech products drive us crazy and how to restore the sanity. Indianapolis, IN: Sams-Pearson Education, 2004.*

FINDINGS

Introduction

Firstly we present a visual representation of a policy review of person-centred care undertaken by the DHI Research and Knowledge Management Team, considering definitions, intended impacts and measures of person-centred care. This provides a visual overview of current thinking about person-centred care at policy level, providing a baseline on which we layer our findings in relation to aspirations for care and new ideas to show where they fit to current ambitions. The policy review is provided in an accompanying report. The findings of the Design Group are then structured into:

- The Current State;
- Aspirations for Care;
- The Future State;
- The Roadmap.

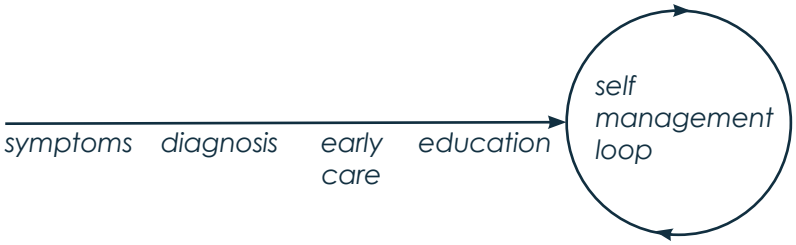
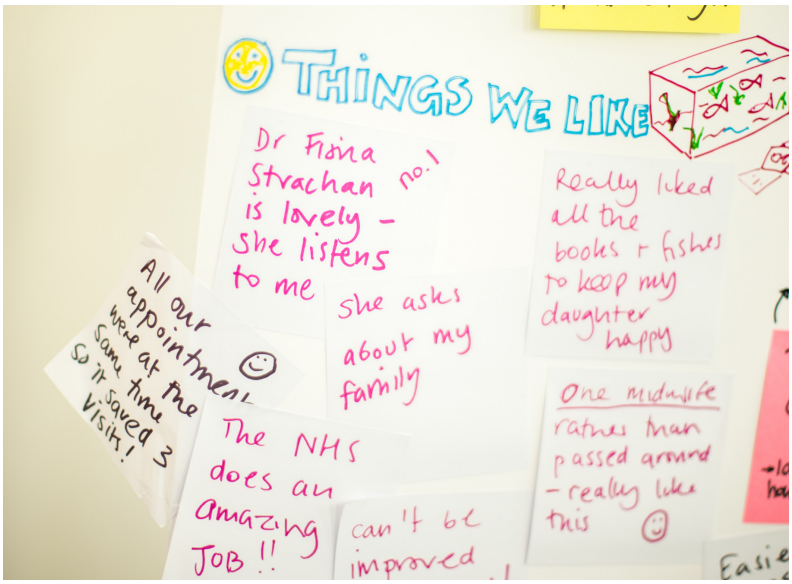


Figure 1: Trajectory through diagnosis and education to self management (G. Teal 2018)

The insights about the current challenge and the ideas for the future are mapped onto a simple representation of the trajectory of a person living with a long-term condition (Figure 1) the straight line representing their path from first symptoms through diagnosis, clinical management and education; a circle representing their ongoing experience of self management.

Finally, the roadmap presents a description of the development process for these new ideas through a series of project proposals. Many of these new ways of working rely on improved access to person-centred information and communication, and complementary links are drawn to the DHI Backpack Person-Owned Data Store project (see Page 15). Two visuals are presented to demonstrate how the proposed projects integrate, and to communicate the suggested development process.



INTRO TO THE MAPS

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THE CURRENT STATE

FIGURE 3 (page 18): The perspective of people living with multiple long-term conditions

This map shows the insights from the perspective of people living with multiple long-term conditions, mapped onto a simple representation of the trajectory of care (Figure 1). Two journeys are overlaid to show insights that relate to the impact of multiple conditions.

A key insight provided by this map is that the majority of challenges raised can relate to people living with one complex long-term condition. This is supported by previous work at the DHI which has explored the challenges of accessing health and care while living with Multiple Sclerosis. The challenge is not so much about the number of conditions, but the complexity of the condition and the number of different health and care professionals they may need to interact with over time. This suggests that the focus on improving resources for people living with multiple long-term conditions could be of benefit to the wider population living with one condition.

A key transition point in the journey is when the person understands that the goal of the clinician is to support them to live well with the condition, rather than to find a cure. This realisation can take time, as information about their condition and self management 'sink in' and they are empowered to take control of their own care. The findings of the interviews suggest that this point signified a positive turning point in the journey, often brought about by the support of a key person or group, who may be a clinician, a third sector organisation or a peer support group.

FIGURE 4 (page 20): The perspective of NHS staff

This map shows the insights from the perspective of NHS staff supporting people living with multiple long-term conditions, mapped along the same trajectory towards self management.

A number of insights were identified in relation to clinical pathways, shown along the dotted line hovering above the journey to self management. The difference between 'fuzzy' and 'well-defined' pathways were illustrated by the examples of a person experiencing a heart attack and developing arthritis. The impact of a 'fuzzy' pathway on both the person and on the care teams supporting them was in significantly increasing the time taken to transition to self management and uncertainty which leads to anxiety for the person and inefficiencies in the system. The findings of engagement with consultants revealed that people rarely conform to a clinical pathway and that the consultant's role is in tailoring the care to the person, however this can lead to challenges in working as part of a multidisciplinary team as the person may then receive conflicting advice.

As in the previous map, the transition to self management prompted discussion. NHS staff acknowledged a reluctance to 'let go' of their patients, due to concern that the person would feel abandoned or due to mistrust in other parts of the system to meet the person's needs.

As secondary care is organised by specialism, NHS staff reflected that collaborative working to support their patients across multiple conditions is challenging. Staff also acknowledged the expertise of third sector organisations in supporting self management and in having conversations centred around the person rather than the condition, however challenges in sharing information and connecting people to services outside the NHS were seen as a barrier. Added to this, variation in the availability of third sector services across different regions and instability in funding were barriers to collaboration with the third sector.

Challenges in innovating services

When seeking to improve and innovate outpatient care, a number of additional challenges were identified. While there is significant evidence that waiting times are a pragmatic indicator of better outcomes [10], they can be seen as a barrier to collaboration and innovation. For some clinicians, taking innovative steps to reduce waiting times such as discharging patients for whom return appointments are of little value or investing time in triaging referrals could lead to vital staff being redirected to other services effectively reversing any improvement to their service.

Service managers experienced a lack of engagement and reluctance to try ideas that had worked elsewhere in the system. Barriers centred around the belief that ideas from other regions or specialisms would not be directly transferable due to regional differences. When seeking to develop new technologies to support innovation in outpatient care, challenges were identified in engaging with industry using open innovation models, as these competitions tended to prioritise the market potential of innovations over their ability to solve the problem they were tasked with addressing. De-risking and integrating new technologies within legacy systems prior to implementation was also seen as a challenge to service innovation.

ASPIRATIONS FOR CARE

Aspirations for care identified from interviews with people living with multiple long-term conditions were translated into a person-centred job description (page 22), highlighting the activities, expertise and skills people were seeking from their health and care professionals.

FIGURE 5 (page 24): Aspirations For Care Mapped On To The Policy Visualisation

Co-design activities were reviewed to identify the aspirations NHS staff had for the services they deliver, both in terms of ways of working but also the resources and systems they needed to support them to create person-centred care.

The aspirations of both citizens and NHS staff have been mapped onto the policy visualisation to show how they build and link to existing policies.

Added together, these form a set of aims or service principles to work towards in redesigning care around the person.

THE FUTURE STATE MAPS

FIGURE 6 (page 26): Mapping ideas across the outpatient journey

This map presents the new ideas generated through co-design activities plotted along the trajectory of care. Existing service development and innovations highlighted by participants were also included in this map.

The overarching goal of increasing the value of appointments but decreasing the frequency was shared among people living with multiple long-term conditions, NHS staff and policy makers. To this end, many of the ideas relate to improving the quality of interactions with health professionals through resources and ways of working that centre the conversation on the goals of the person. Ideas that supported clinicians to reduce the number of appointments included ways of ensuring the person can access support following discharge, by giving them permission and tools to engage when needed. In addition to the smart outpatient booking and triage system being developed by The Modern Outpatient Programme, this included an idea for a self management tool called 'what to do when', which would help people to understand their condition, know their personal symptoms and triggers; and know what to do to manage symptoms and when (and who) to contact if additional support is required.

Many of the ideas are dependent on the use of a person-owned data store (Backpack*) to overcome difficulties in sharing information among the multidisciplinary team and with third sector organisations to enable partnership working. A person-owned data store would allow the person to choose to share their information with people and organisations they trust, overcoming restrictions on data sharing outside of the NHS. This includes the use of the Backpack to establish and share person-centred outcomes that can be used to evaluate care at every interaction.

In response to the challenges identified with 'fuzzy' pathways and the anxiety caused by uncertainty in the early stages of the journey, ideas were proposed for new ways of representing pathways for both the person and the primary care teams. Innovation of pathways may also be an opportunity to embed links to the third sector, and better integrate new technologies.

FIGURE 7 (page 28): Ideas and aspirations for person-centred care in relation to current policy

Again, the ideas were layered onto the policy visualisation alongside aspirations for care to reveal the connections (Figure 7).

** The 'Backpack' project was undertaken as part of DHI Phase 1, with partners Mydex CIC, NHS Gramian, University of the Highlands and Islands, Moray Council and led by The Glasgow School of Art. Please contact the authors of this report for further information or visit: https://www.futurehealthandwellbeing.org/backpack*

POLICY VISUALISATION

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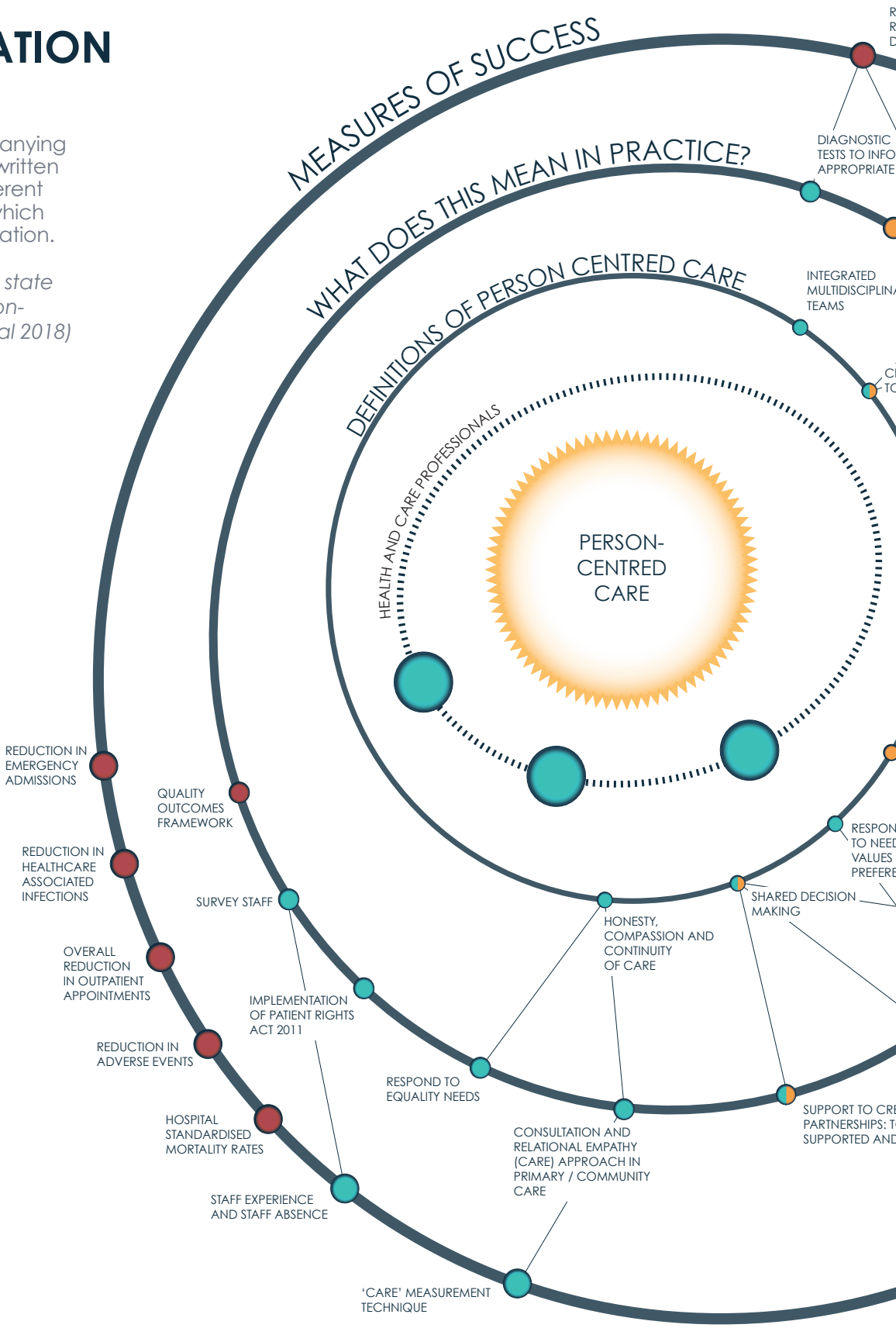
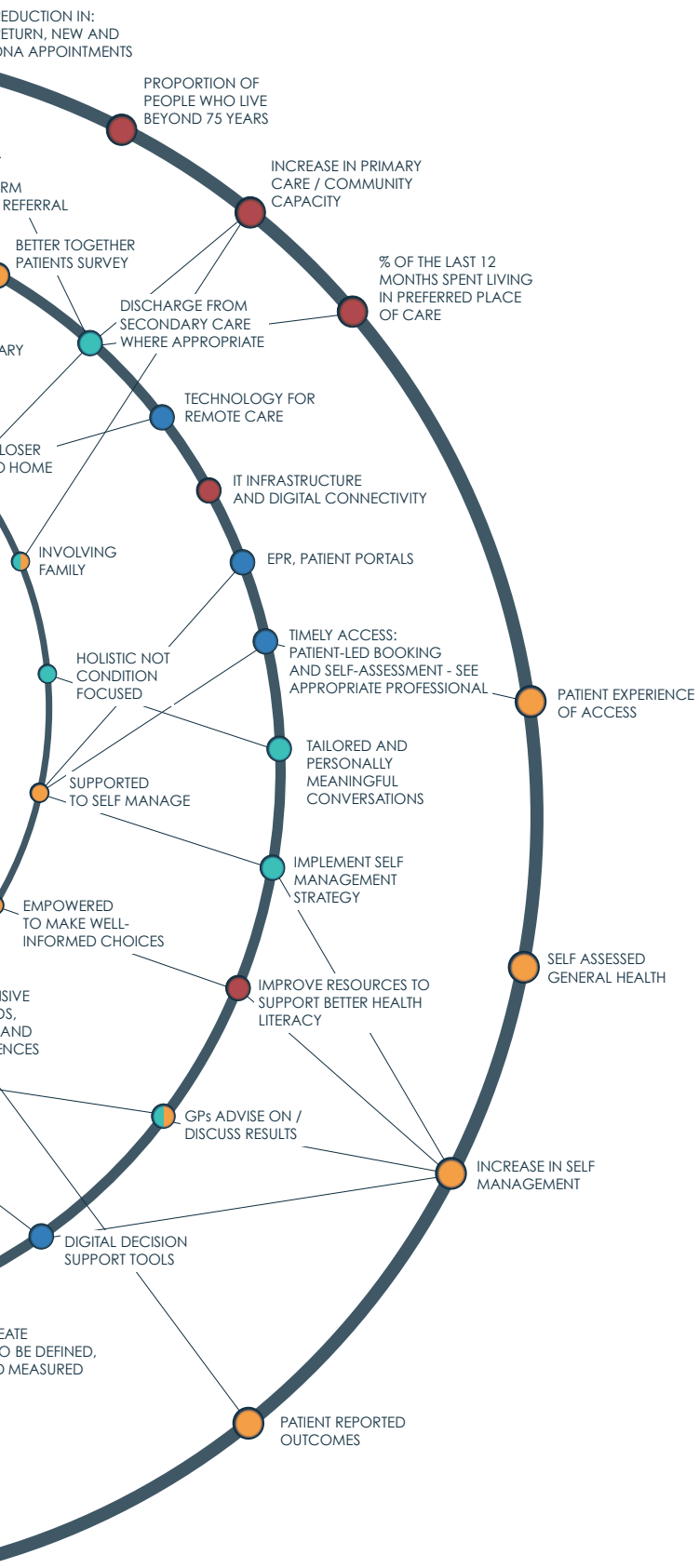
Please see accompanying Policy Review for a written summary of the different policy documents which informed this visualisation.

Figure 2. The current state policy map for person-centred care (G. Teal 2018)





Scottish Government policy documents reviewed for this visualisation:

- The Modern Outpatient: A collaborative Approach 2017-2020. 2017.
- The Healthcare Quality Strategy for NHS Scotland. 2010.
- A National Clinical Strategy For Scotland. 2016.
- Chief Medical Officer for Scotland Annual Report 2014/15 Realistic Medicine. 2016.
- Chief Medical Officer for Scotland Annual Report 2015/16 Realising Realistic Medicine. 2017.
- NHS Scotland eHealth Strategy 2014-17. 2015.

PERSON LIVING WITH LONG-TERM CONDITIONS

HEALTH AND CARE PROFESSIONALS

SYSTEM

NEW DIGITAL TOOLS

THE CURRENT STATE

FROM THE PERSPECTIVE OF:

PEOPLE LIVING WITH MULTIPLE LONG-TERM CONDITIONS

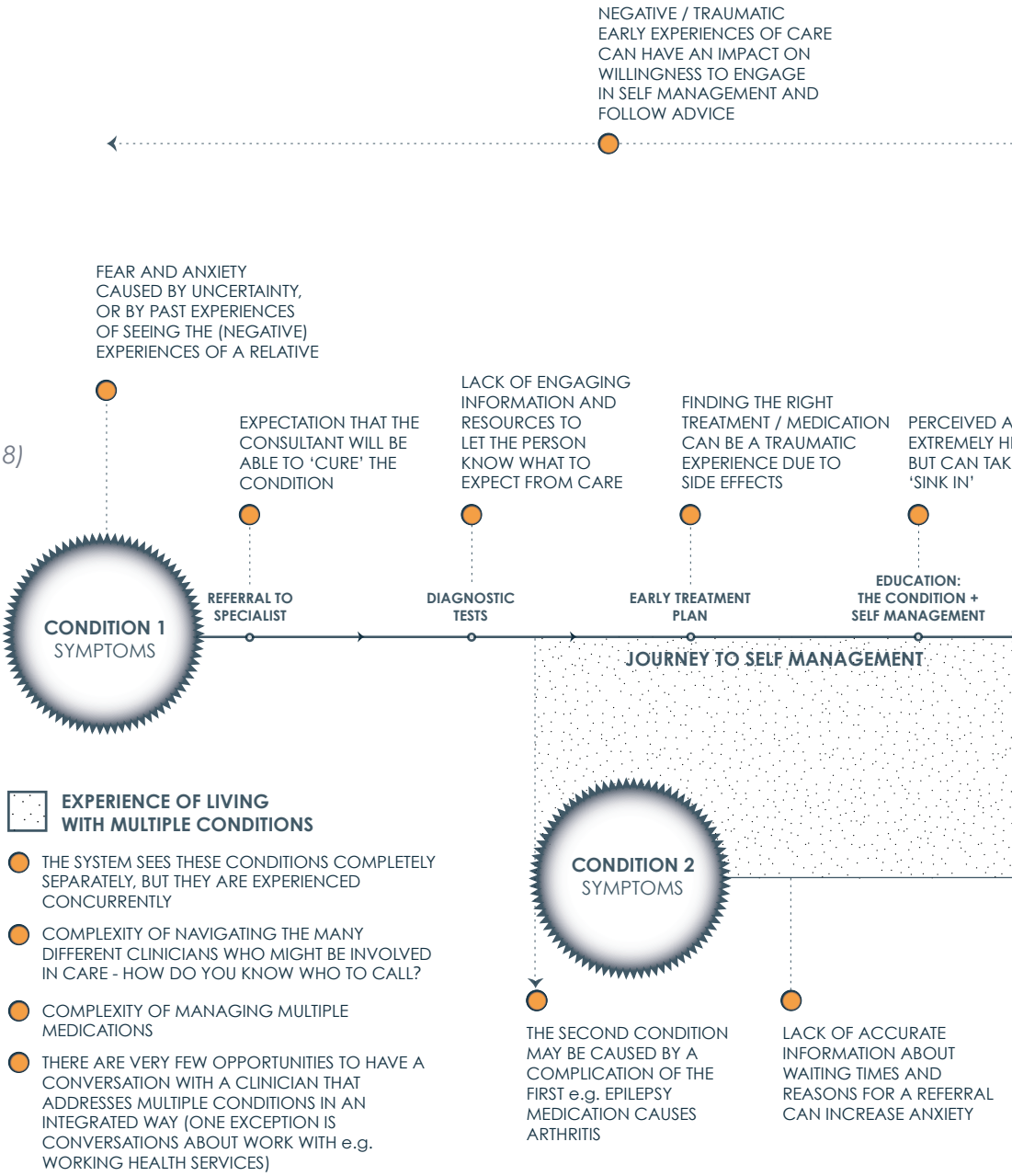
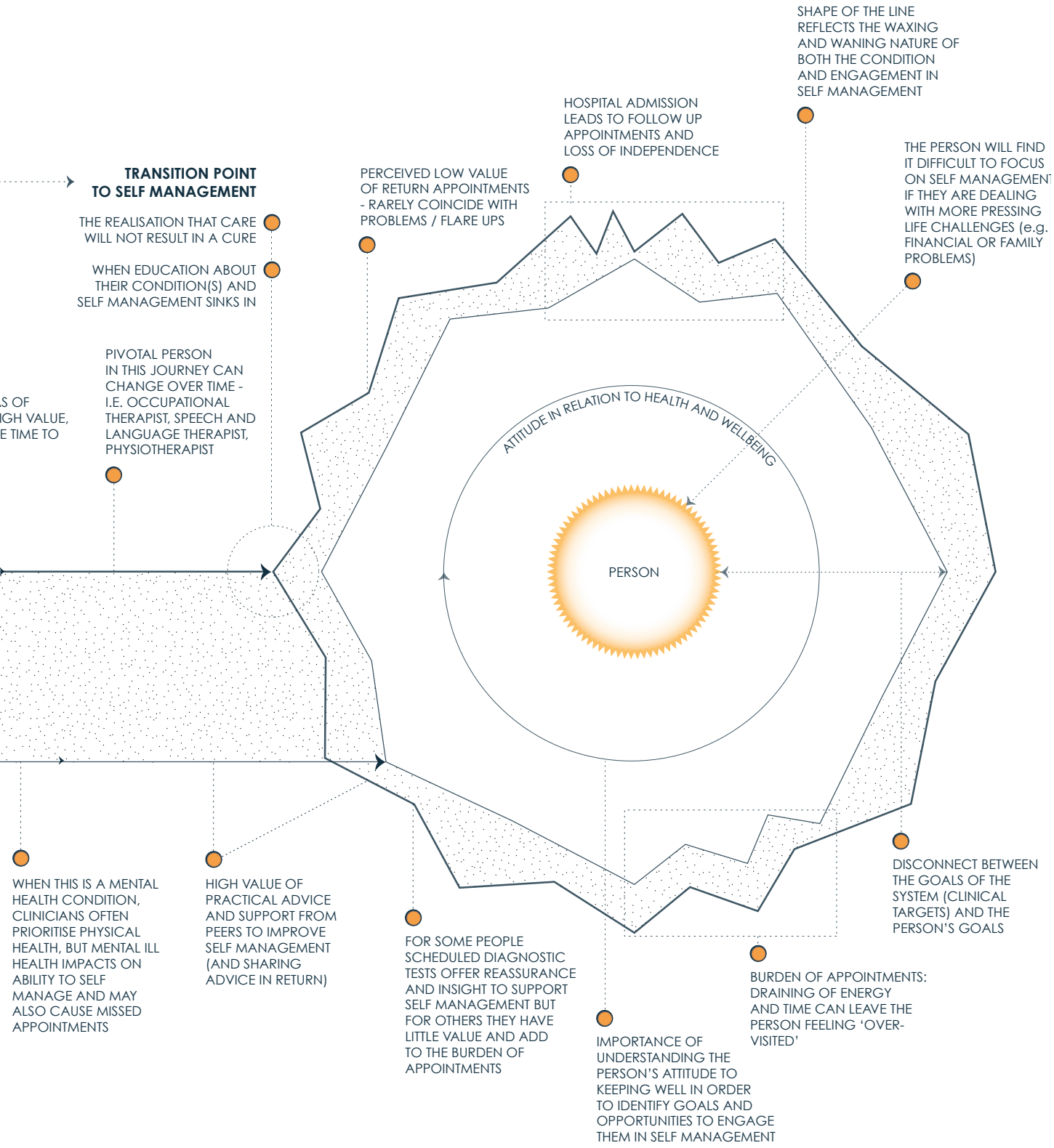


Figure 3: The outpatient journey for people living with multiple long-term conditions: the person's perspective (G. Teal 2018)


SHAPE OF THE LINE REFLECTS THE WAXING AND WANING NATURE OF BOTH THE CONDITION AND ENGAGEMENT IN SELF MANAGEMENT
HOSPITAL ADMISSION LEADS TO FOLLOW UP APPOINTMENTS AND LOSS OF INDEPENDENCE
THE PERSON WILL FIND IT DIFFICULT TO FOCUS ON SELF MANAGEMENT IF THEY ARE DEALING WITH MORE PRESSING LIFE CHALLENGES (e.g. FINANCIAL OR FAMILY PROBLEMS)
TRANSITION POINT TO SELF MANAGEMENT
PERCEIVED LOW VALUE OF RETURN APPOINTMENTS - RARELY COINCIDE WITH PROBLEMS / FLARE UPS
THE REALISATION THAT CARE WILL NOT RESULT IN A CURE
WHEN EDUCATION ABOUT THEIR CONDITION(S) AND SELF MANAGEMENT SINKS IN
PIVOTAL PERSON IN THIS JOURNEY CAN CHANGE OVER TIME - I.E. OCCUPATIONAL THERAPIST, SPEECH AND LANGUAGE THERAPIST, PHYSIOTHERAPIST
ATTITUDE IN RELATION TO HEALTH AND WELLBEING
PERSON
WHEN THIS IS A MENTAL HEALTH CONDITION, CLINICIANS OFTEN PRIORITISE PHYSICAL HEALTH, BUT MENTAL ILL HEALTH IMPACTS ON ABILITY TO SELF MANAGE AND MAY ALSO CAUSE MISSED APPOINTMENTS
HIGH VALUE OF PRACTICAL ADVICE AND SUPPORT FROM PEERS TO IMPROVE SELF MANAGEMENT (AND SHARING ADVICE IN RETURN)
FOR SOME PEOPLE SCHEDULED DIAGNOSTIC TESTS OFFER REASSURANCE AND INSIGHT TO SUPPORT SELF MANAGEMENT BUT FOR OTHERS THEY HAVE LITTLE VALUE AND ADD TO THE BURDEN OF APPOINTMENTS
IMPORTANCE OF UNDERSTANDING THE PERSON'S ATTITUDE TO KEEPING WELL IN ORDER TO IDENTIFY GOALS AND OPPORTUNITIES TO ENGAGE THEM IN SELF MANAGEMENT
BURDEN OF APPOINTMENTS: DRAINING OF ENERGY AND TIME CAN LEAVE THE PERSON FEELING 'OVER-VISITED'
DISCONNECT BETWEEN THE GOALS OF THE SYSTEM (CLINICAL TARGETS) AND THE PERSON'S GOALS

THE CURRENT STATE

FROM THE PERSPECTIVE OF:

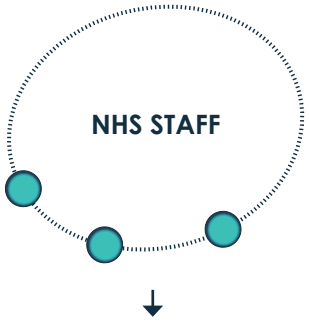


Figure 4: The outpatient journey for people living with multiple long-term conditions: the NHS staff perspective (G. Teal 2018)

SOME PATHWAYS REQUIRE THE GP TO ATTEMPT TO TREAT IN PRIMARY CARE PRIOR TO REFERRAL - IF WAITING LISTS ARE LONG THEY MAY DECIDE TO REFER TO AVOID A LONG WAIT

ENSURING AN APPOPRIATE REFERRAL RELIES ON THE GP ASKING THE RIGHT QUESTIONS TO IDENTIFY THE CORRECT PATHWAY

SOME PATHWAYS SEND PATIENTS 'STRAIGHT TO TEST' PRIOR TO THEIR APPOINTMENT TO REDUCE DELAYS IN DIAGNOSIS

CLEARLY-DEFINED PATHWAYS (e.g. HEART FAILURE) SUPPORT THE MDT TO WORK COLLABORATIVELY, EFFICIENTLY AND SAFELY

CONSULT… THEIR EXP… ADAPT TH… FOR THEIR… WHICH LE… VARIATIO… THE HEAL…

CLINICAL PATHWAYS

CONVERSELY 'FUZZY' PATHWAYS MAKE IT HARDER FOR THE MDT AND GP TO ENSURE CARE IS DELIVERED BY THE MOST APPROPRIATE PERSON

MEASURING THE PERFORMANCE OF A SERVICE BY ADHERENCE TO WAITING TIME TARGETS DISINSENTIVES INNOVATION TO REDUCE WAITING TIMES AS RESOURCE WILL BE REALLOCATED TO SERVICES WHICH ARE STRUGGLING

LONG WAITING LISTS FOR DIAGNOSTIC TESTS

MISUSE OF DIAGNOSTICS INCREASES DEMAND AS CLINICIANS CAN BE RISK AVERSE (e.g. REPEAT TESTS)

IN SOME … SECTOR … HAVE MO… SELF MAN… EDUCATIO…

CONDITION 1 SYMPTOMS

REFERRAL TO SPECIALIST → **DIAGNOSTIC TESTS** → **EARLY TREATMENT PLAN** → **EDUCATION: THE CONDITION + SELF MANAGEMENT**

JOURNEY TO SELF MANAGEMENT

CONDITION 2 SYMPTOMS

= CHALLENGES RAISED BY NHS STAFF

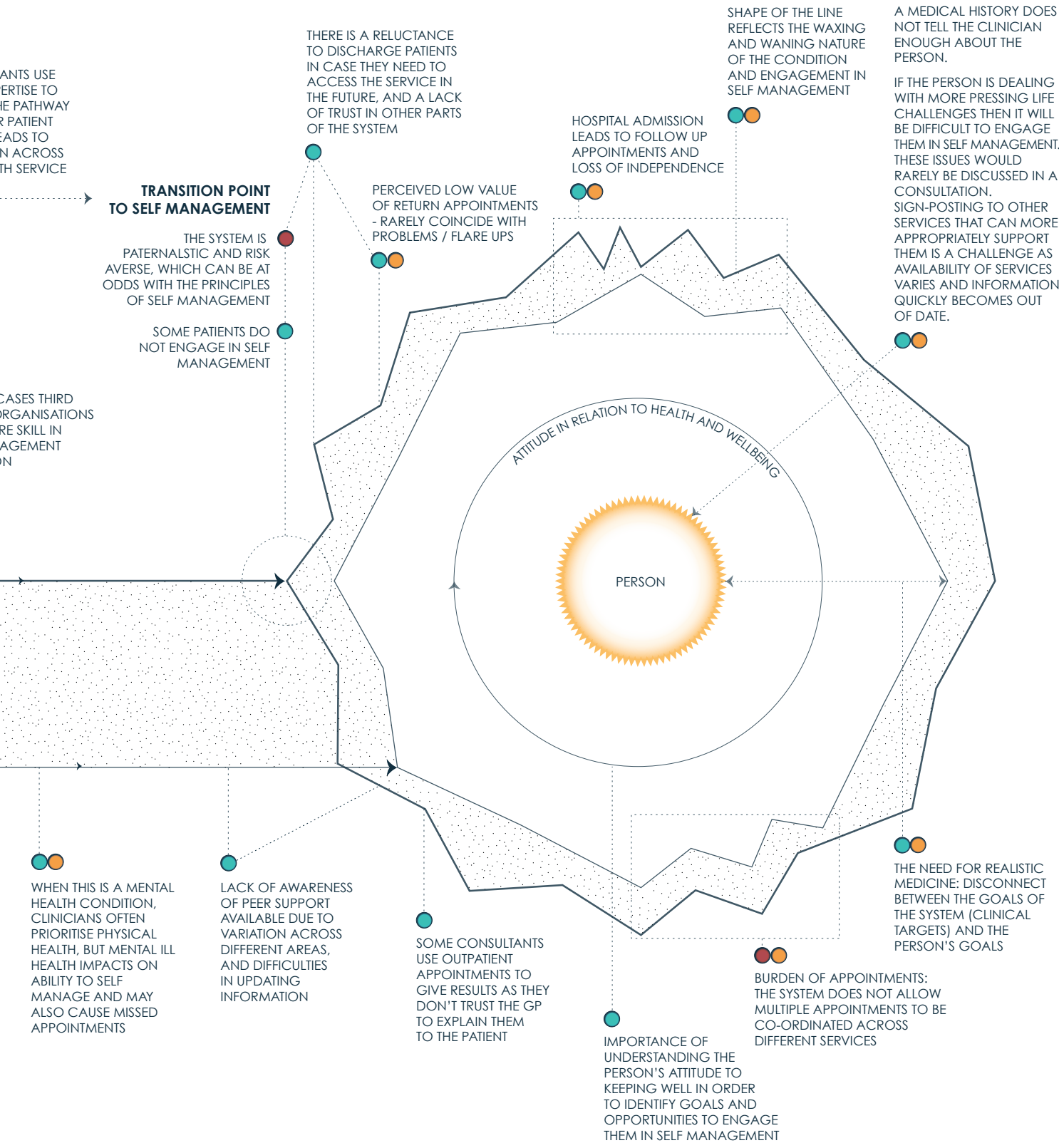
= ALSO IDENTIFIED BY PEOPLE LIVING WITH LTC

= SYSTEM LEVEL CHALLENGES

CHALLENGES OF SUPPORTING PEOPLE LIVING WITH MULTIPLE CONDITIONS:

- THE SYSTEM SEES THESE CONDITIONS COMPLETELY SEPARATELY, BUT THEY ARE EXPERIENCED CONCURRENTLY
- THE SYSTEM IS DESIGNED TO WORK IN SILOS OF CLINICAL SPECIALISMS, MAKING COLLABORATIVE WORKING A CHALLENGE
- THERE IS LITTLE GUIDANCE TO SUPPORT CLINICIANS IN MANAGING MULTIPLE CLINICAL GUIDELINES CONCURRENTLY, IN PARTICULAR WHEN THEY CONFLICT, OR WHEN MEDICATIONS ARE CONTRA-INDICATED
- THERE ARE VERY FEW OPPORTUNITIES TO HAVE A CONVERSATION WITH A PATIENT THAT ADDRESSES MULTIPLE CONDITIONS IN AN INTEGRATED WAY (ONE EXCEPTION IS CONVERSATIONS ABOUT WORK WITH e.g. WORKING HEALTH SERVICES). THIRD SECTOR ORGANISATIONS MAY HAVE MORE EXPERTISE IN THESE CONVERSATIONS, HOWEVER THE SYSTEM RESTRICTS PARTNERSHIP WITH THIRD SECTOR ORGANISATIONS BY PROHIBITING INFORMATION SHARING

LACK OF ACCURATE INFORMATION ABOUT WAITING TIMES MAKES IT DIFFICULT TO MANAGE PATIENT'S EXPECTATIONS TO REDUCE ANXIETY


ANTS USE
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RGANISATIONS
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AGEMENT
ON
TRANSITION POINT
TO SELF MANAGEMENT
THERE IS A RELUCTANCE TO DISCHARGE PATIENTS IN CASE THEY NEED TO ACCESS THE SERVICE IN THE FUTURE, AND A LACK OF TRUST IN OTHER PARTS OF THE SYSTEM
THE SYSTEM IS PATERNALSTIC AND RISK AVERSE, WHICH CAN BE AT ODDS WITH THE PRINCIPLES OF SELF MANAGEMENT
SOME PATIENTS DO NOT ENGAGE IN SELF MANAGEMENT
PERCEIVED LOW VALUE OF RETURN APPOINTMENTS - RARELY COINCIDE WITH PROBLEMS / FLARE UPS
HOSPITAL ADMISSION LEADS TO FOLLOW UP APPOINTMENTS AND LOSS OF INDEPENDENCE
SHAPE OF THE LINE REFLECTS THE WAXING AND WANING NATURE OF THE CONDITION AND ENGAGEMENT IN SELF MANAGEMENT
A MEDICAL HISTORY DOES NOT TELL THE CLINICIAN ENOUGH ABOUT THE PERSON.
IF THE PERSON IS DEALING WITH MORE PRESSING LIFE CHALLENGES THEN IT WILL BE DIFFICULT TO ENGAGE THEM IN SELF MANAGEMENT. THESE ISSUES WOULD RARELY BE DISCUSSED IN A CONSULTATION. SIGN-POSTING TO OTHER SERVICES THAT CAN MORE APPROPRIATELY SUPPORT THEM IS A CHALLENGE AS AVAILABILITY OF SERVICES VARIES AND INFORMATION QUICKLY BECOMES OUT OF DATE.
ATTITUDE IN RELATION TO HEALTH AND WELLBEING
PERSON
WHEN THIS IS A MENTAL HEALTH CONDITION, CLINICIANS OFTEN PRIORITISE PHYSICAL HEALTH, BUT MENTAL ILL HEALTH IMPACTS ON ABILITY TO SELF MANAGE AND MAY ALSO CAUSE MISSED APPOINTMENTS
LACK OF AWARENESS OF PEER SUPPORT AVAILABLE DUE TO VARIATION ACROSS DIFFERENT AREAS, AND DIFFICULTIES IN UPDATING INFORMATION
SOME CONSULTANTS USE OUTPATIENT APPOINTMENTS TO GIVE RESULTS AS THEY DON'T TRUST THE GP TO EXPLAIN THEM TO THE PATIENT
IMPORTANCE OF UNDERSTANDING THE PERSON'S ATTITUDE TO KEEPING WELL IN ORDER TO IDENTIFY GOALS AND OPPORTUNITIES TO ENGAGE THEM IN SELF MANAGEMENT
BURDEN OF APPOINTMENTS: THE SYSTEM DOES NOT ALLOW MULTIPLE APPOINTMENTS TO BE CO-ORDINATED ACROSS DIFFERENT SERVICES
THE NEED FOR REALISTIC MEDICINE: DISCONNECT BETWEEN THE GOALS OF THE SYSTEM (CLINICAL TARGETS) AND THE PERSON'S GOALS

PERSON-CENTRED JOB DESCRIPTION

HOW THE PERSON WOULD LIKE TO BE CARED FOR...

Activities:

- Build a collaborative relationship with people living with long term conditions to empower them to do the things they want to do, so that they are able to feel productive and useful, and live a fulfilling life;
- Provide high quality education following diagnosis to support people to understand their condition and the steps they can take to live well;
- Help people to think about the future, and make plans for their care and wellbeing;
- Encourage contact as needed, ensuring access is quick and easy to build trust that they will get in touch if they need support rather than on a scheduled basis;
- Discuss information about choices and results to empower the person to make informed decisions about their care;
- Help people to learn to identify their personal symptoms and triggers early, to enable them to get support before a relapse or issue gets more serious;
- Support people to connect with other useful organisations and people living with the same condition.

Skills and expertise required:

- A passion for caring for people;
- Highly developed listening skills;
- An ability to empathise and put the person's wishes and aspirations at the centre;
- Openness and transparency.

Goals:

- Interactions that are of high value to people living with long-term conditions (insightful, supportive and informative);
- The people you care for are empowered and largely autonomous, getting in touch when they need your support.

PERSON-CENTRED JOB DESCRIPTION
HOW THE PERSON WOULD LIKE TO BE CARED FOR...
ACTIVITIES
> Build a collaborative relationship with people living with long term conditions to empower them to do the things they want to do, so that they are able to feel productive and useful, and live a fulfilling life
> Provide high quality education following diagnosis to support people to understand their condition and the steps they can take to live well
> Help people to think about the future, and make plans for their care and wellbeing
> Encourage contact as needed, ensuring access is quick and easy to ensure trust that they will get in touch if they need support rather than on a scheduled basis
> Discuss information about choices and results to empower the person to make informed decisions about their care
> Help people to learn to identify their personal symptoms and triggers early, to enable them to get support before a relapse or issue gets more serious
> Support people to connect with organisations and other people living with the same condition
SKILLS AND EXPERTISE REQUIRED
> A passion for caring for people
> Highly developed listening skills
> An ability to empathise and put the person's wishes and aspirations at the centre
> Openness and transparency
GOALS
> Interactions that are of high value to people living with long term conditions (insightful, supportive and informative)
> The people you care for are empowered and largely autonomous, getting in touch when they need your support

CPN
mental
health

ASPIRATIONS FOR CARE

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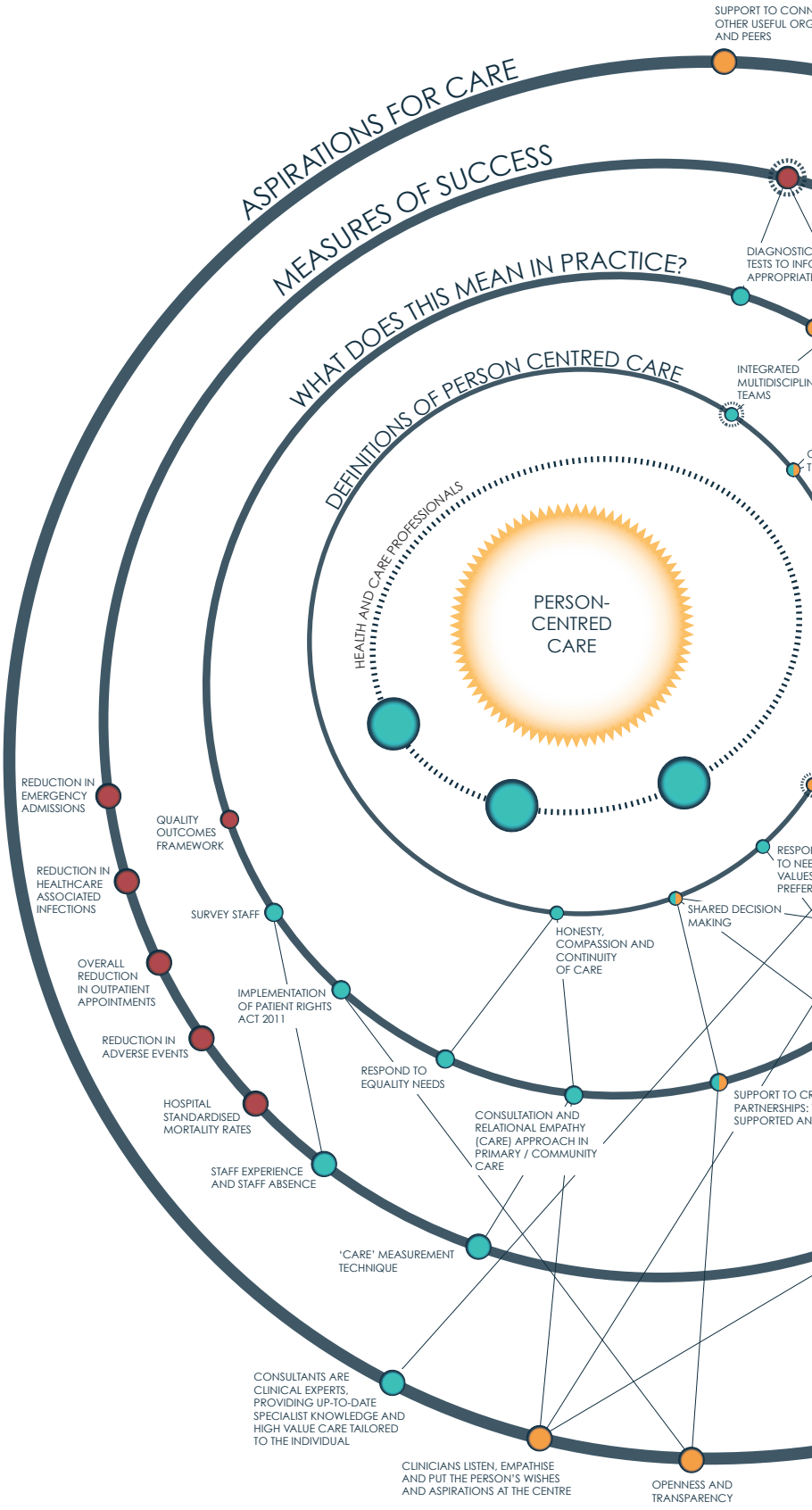
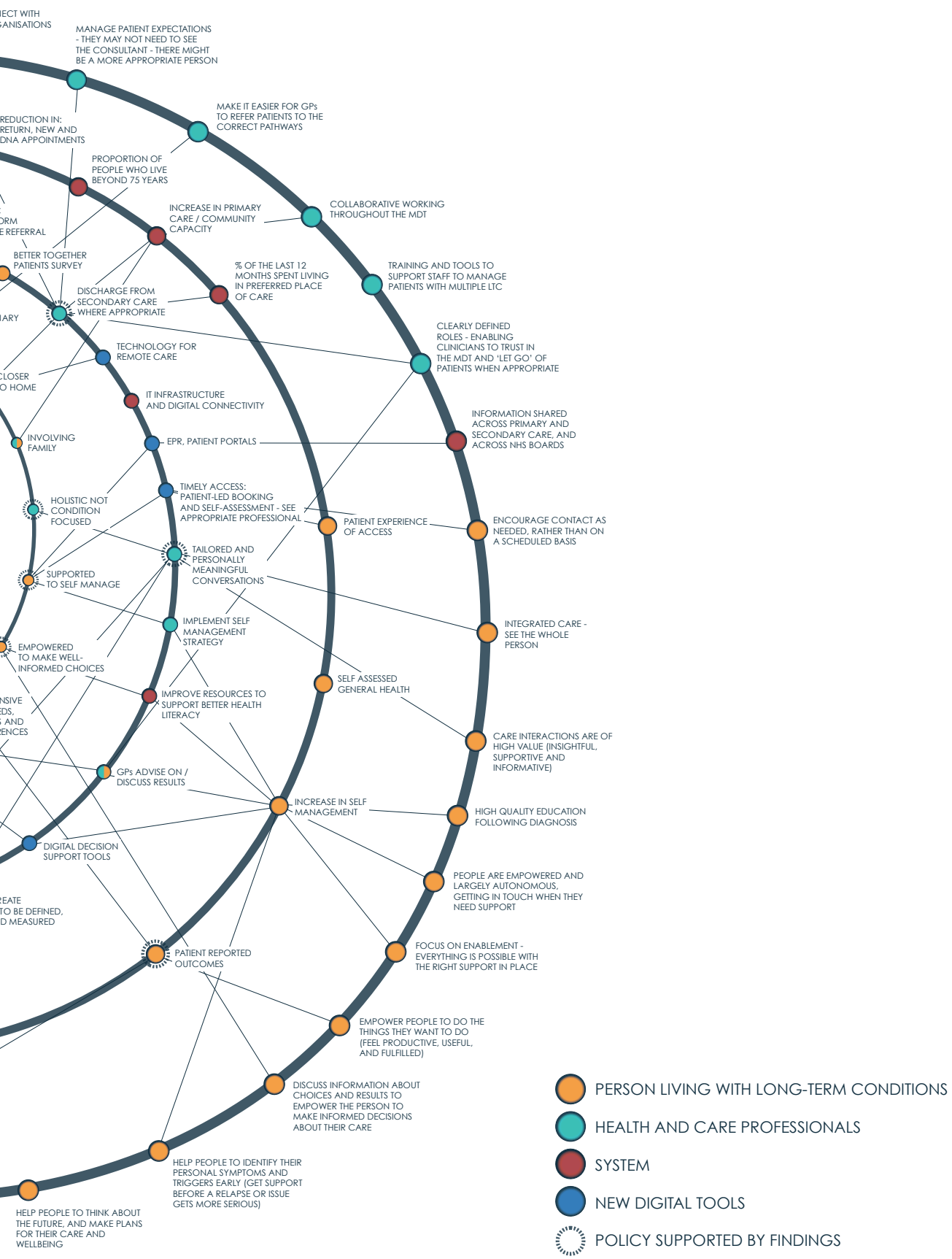
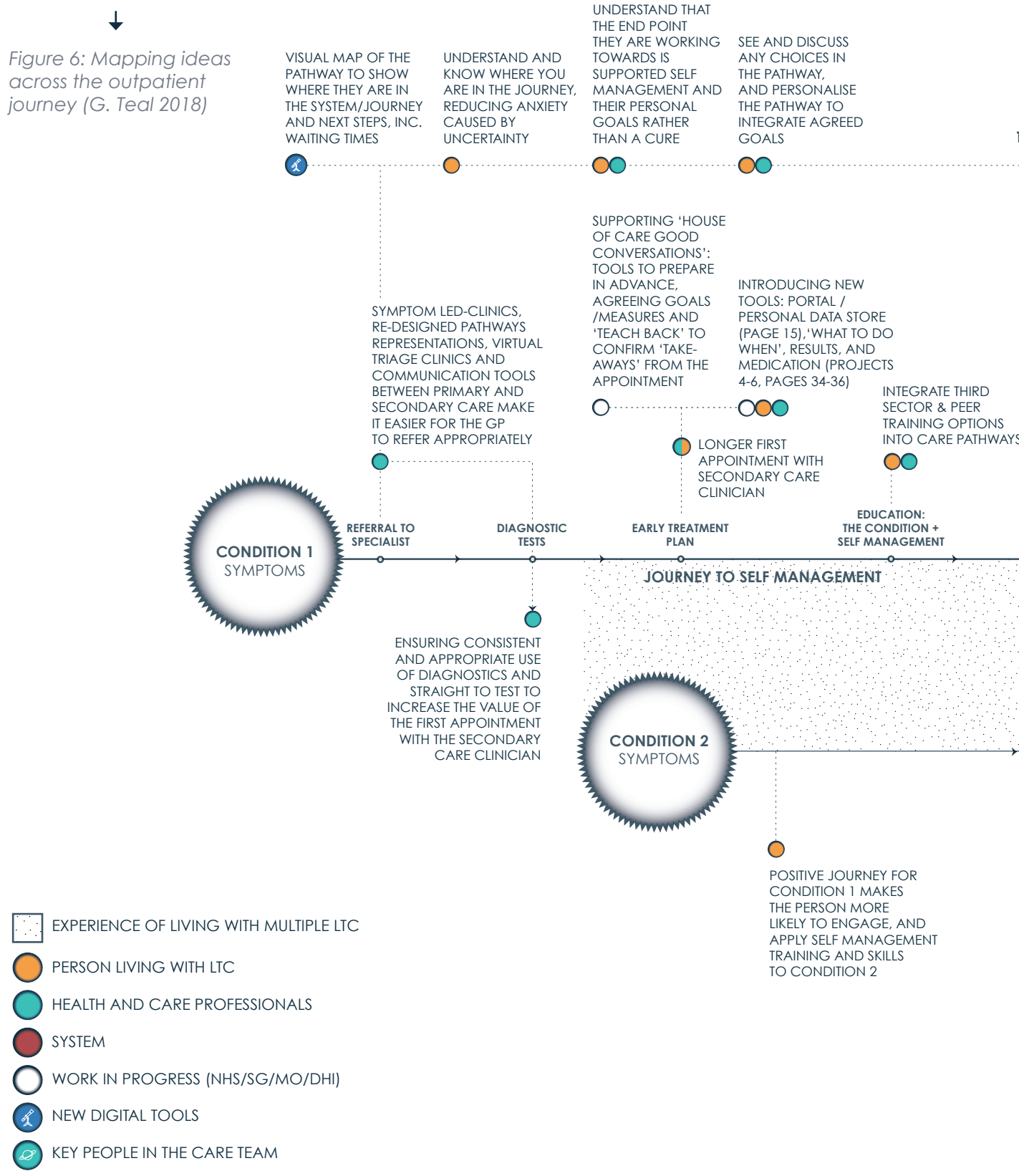
Figure 5: Aspirations for person-centred care in relation to current policy (G. Teal 2018)

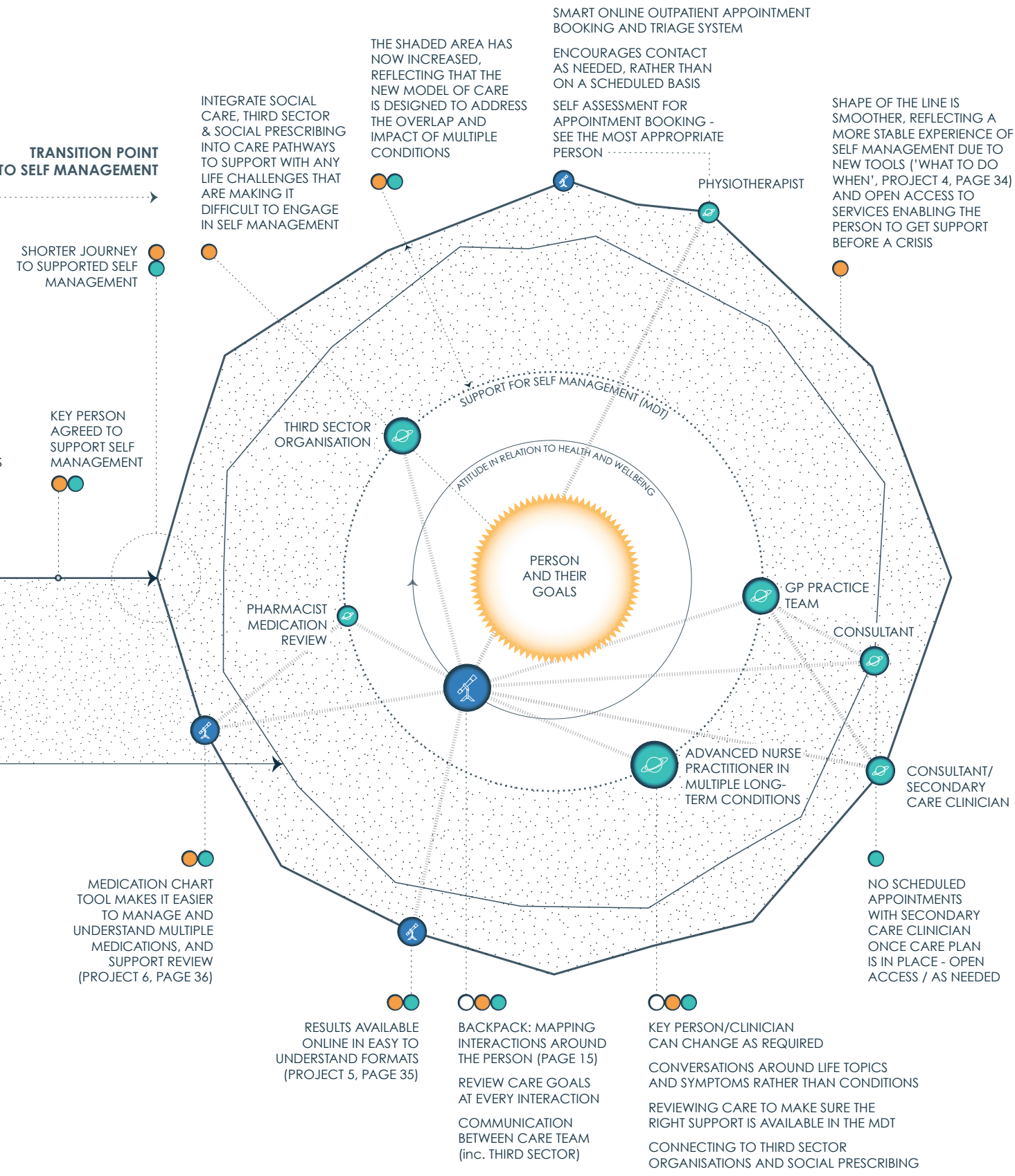



MANAGE PATIENT EXPECTATIONS - THEY MAY NOT NEED TO SEE THE CONSULTANT - THERE MIGHT BE A MORE APPROPRIATE PERSON
MAKE IT EASIER FOR GPs TO REFER PATIENTS TO THE CORRECT PATHWAYS
PROPORTION OF PEOPLE WHO LIVE BEYOND 75 YEARS
COLLABORATIVE WORKING THROUGHOUT THE MDT
INCREASE IN PRIMARY CARE / COMMUNITY CAPACITY
BETTER TOGETHER PATIENTS SURVEY
% OF THE LAST 12 MONTHS SPENT LIVING IN PREFERRED PLACE OF CARE
TRAINING AND TOOLS TO SUPPORT STAFF TO MANAGE PATIENTS WITH MULTIPLE LTC
DISCHARGE FROM SECONDARY CARE WHERE APPROPRIATE
CLEARLY DEFINED ROLES - ENABLING CLINICIANS TO TRUST IN THE MDT AND 'LET GO' OF PATIENTS WHEN APPROPRIATE
TECHNOLOGY FOR REMOTE CARE
IT INFRASTRUCTURE AND DIGITAL CONNECTIVITY
INFORMATION SHARED ACROSS PRIMARY AND SECONDARY CARE, AND ACROSS NHS BOARDS
INVOLVING FAMILY
EPR, PATIENT PORTALS
TIMELY ACCESS: PATIENT-LED BOOKING AND SELF-ASSESSMENT - SEE APPROPRIATE PROFESSIONAL
HOLISTIC NOT CONDITION FOCUSED
PATIENT EXPERIENCE OF ACCESS
ENCOURAGE CONTACT AS NEEDED, RATHER THAN ON A SCHEDULED BASIS
TAILORED AND PERSONALLY MEANINGFUL CONVERSATIONS
SUPPORTED TO SELF MANAGE
IMPLEMENT SELF MANAGEMENT STRATEGY
INTEGRATED CARE - SEE THE WHOLE PERSON
EMPOWERED TO MAKE WELL-INFORMED CHOICES
SELF ASSESSED GENERAL HEALTH
IMPROVE RESOURCES TO SUPPORT BETTER HEALTH LITERACY
CARE INTERACTIONS ARE OF HIGH VALUE (INSIGHTFUL, SUPPORTIVE AND INFORMATIVE)
GPs ADVISE ON / DISCUSS RESULTS
INCREASE IN SELF MANAGEMENT
HIGH QUALITY EDUCATION FOLLOWING DIAGNOSIS
DIGITAL DECISION SUPPORT TOOLS
PEOPLE ARE EMPOWERED AND LARGELY AUTONOMOUS, GETTING IN TOUCH WHEN THEY NEED SUPPORT
PATIENT REPORTED OUTCOMES
FOCUS ON ENABLEMENT - EVERYTHING IS POSSIBLE WITH THE RIGHT SUPPORT IN PLACE
EMPOWER PEOPLE TO DO THE THINGS THEY WANT TO DO (FEEL PRODUCTIVE, USEFUL, AND FULFILLED)
DISCUSS INFORMATION ABOUT CHOICES AND RESULTS TO EMPOWER THE PERSON TO MAKE INFORMED DECISIONS ABOUT THEIR CARE
HELP PEOPLE TO IDENTIFY THEIR PERSONAL SYMPTOMS AND TRIGGERS EARLY (GET SUPPORT BEFORE A RELAPSE OR ISSUE GETS MORE SERIOUS)
HELP PEOPLE TO THINK ABOUT THE FUTURE, AND MAKE PLANS FOR THEIR CARE AND WELLBEING
PERSON LIVING WITH LONG-TERM CONDITIONS
HEALTH AND CARE PROFESSIONALS
SYSTEM
NEW DIGITAL TOOLS
POLICY SUPPORTED BY FINDINGS

THE FUTURE STATE

Figure 6: Mapping ideas across the outpatient journey (G. Teal 2018)




TRANSITION POINT TO SELF MANAGEMENT
SHORTER JOURNEY TO SUPPORTED SELF MANAGEMENT
KEY PERSON AGREED TO SUPPORT SELF MANAGEMENT
INTEGRATE SOCIAL CARE, THIRD SECTOR & SOCIAL PRESCRIBING INTO CARE PATHWAYS TO SUPPORT WITH ANY LIFE CHALLENGES THAT ARE MAKING IT DIFFICULT TO ENGAGE IN SELF MANAGEMENT
THE SHADED AREA HAS NOW INCREASED, REFLECTING THAT THE NEW MODEL OF CARE IS DESIGNED TO ADDRESS THE OVERLAP AND IMPACT OF MULTIPLE CONDITIONS
SMART ONLINE OUTPATIENT APPOINTMENT BOOKING AND TRIAGE SYSTEM
ENCOURAGES CONTACT AS NEEDED, RATHER THAN ON A SCHEDULED BASIS
SELF ASSESSMENT FOR APPOINTMENT BOOKING - SEE THE MOST APPROPRIATE PERSON
PHYSIOTHERAPIST
SHAPE OF THE LINE IS SMOOTHER, REFLECTING A MORE STABLE EXPERIENCE OF SELF MANAGEMENT DUE TO NEW TOOLS ('WHAT TO DO WHEN', PROJECT 4, PAGE 34) AND OPEN ACCESS TO SERVICES ENABLING THE PERSON TO GET SUPPORT BEFORE A CRISIS
SUPPORT FOR SELF MANAGEMENT (MDT)
THIRD SECTOR ORGANISATION
ATTITUDE IN RELATION TO HEALTH AND WELLBEING
PERSON AND THEIR GOALS
PHARMACIST MEDICATION REVIEW
GP PRACTICE TEAM
CONSULTANT
ADVANCED NURSE PRACTITIONER IN MULTIPLE LONG-TERM CONDITIONS
CONSULTANT/ SECONDARY CARE CLINICIAN
MEDICATION CHART TOOL MAKES IT EASIER TO MANAGE AND UNDERSTAND MULTIPLE MEDICATIONS, AND SUPPORT REVIEW (PROJECT 6, PAGE 36)
RESULTS AVAILABLE ONLINE IN EASY TO UNDERSTAND FORMATS (PROJECT 5, PAGE 35)
BACKPACK: MAPPING INTERACTIONS AROUND THE PERSON (PAGE 15)
REVIEW CARE GOALS AT EVERY INTERACTION
COMMUNICATION BETWEEN CARE TEAM (inc. THIRD SECTOR)
KEY PERSON/CLINICIAN CAN CHANGE AS REQUIRED
CONVERSATIONS AROUND LIFE TOPICS AND SYMPTOMS RATHER THAN CONDITIONS
REVIEWING CARE TO MAKE SURE THE RIGHT SUPPORT IS AVAILABLE IN THE MDT
CONNECTING TO THIRD SECTOR ORGANISATIONS AND SOCIAL PRESCRIBING
NO SCHEDULED APPOINTMENTS WITH SECONDARY CARE CLINICIAN ONCE CARE PLAN IS IN PLACE - OPEN ACCESS / AS NEEDED

THE FUTURE STATE

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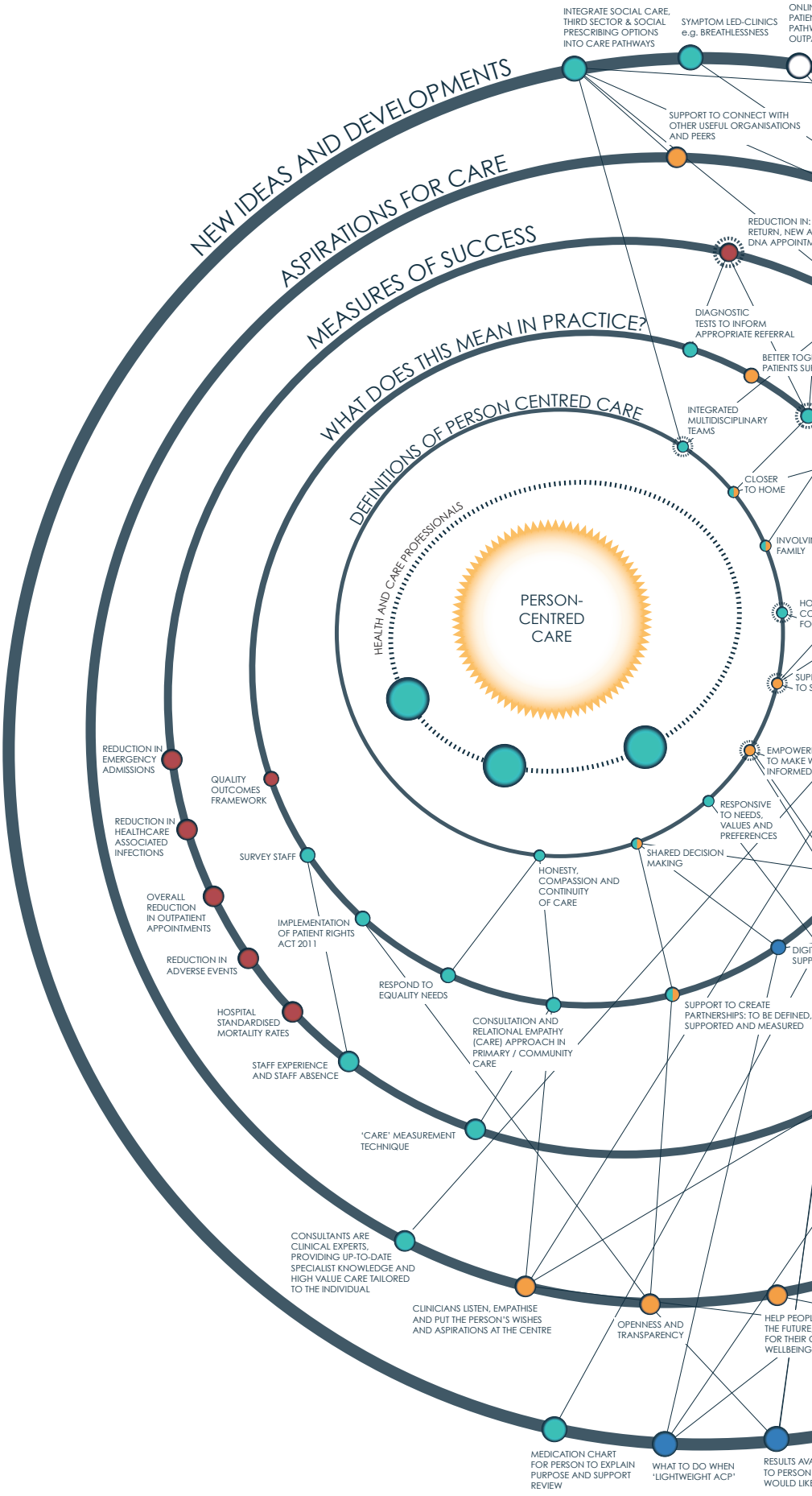
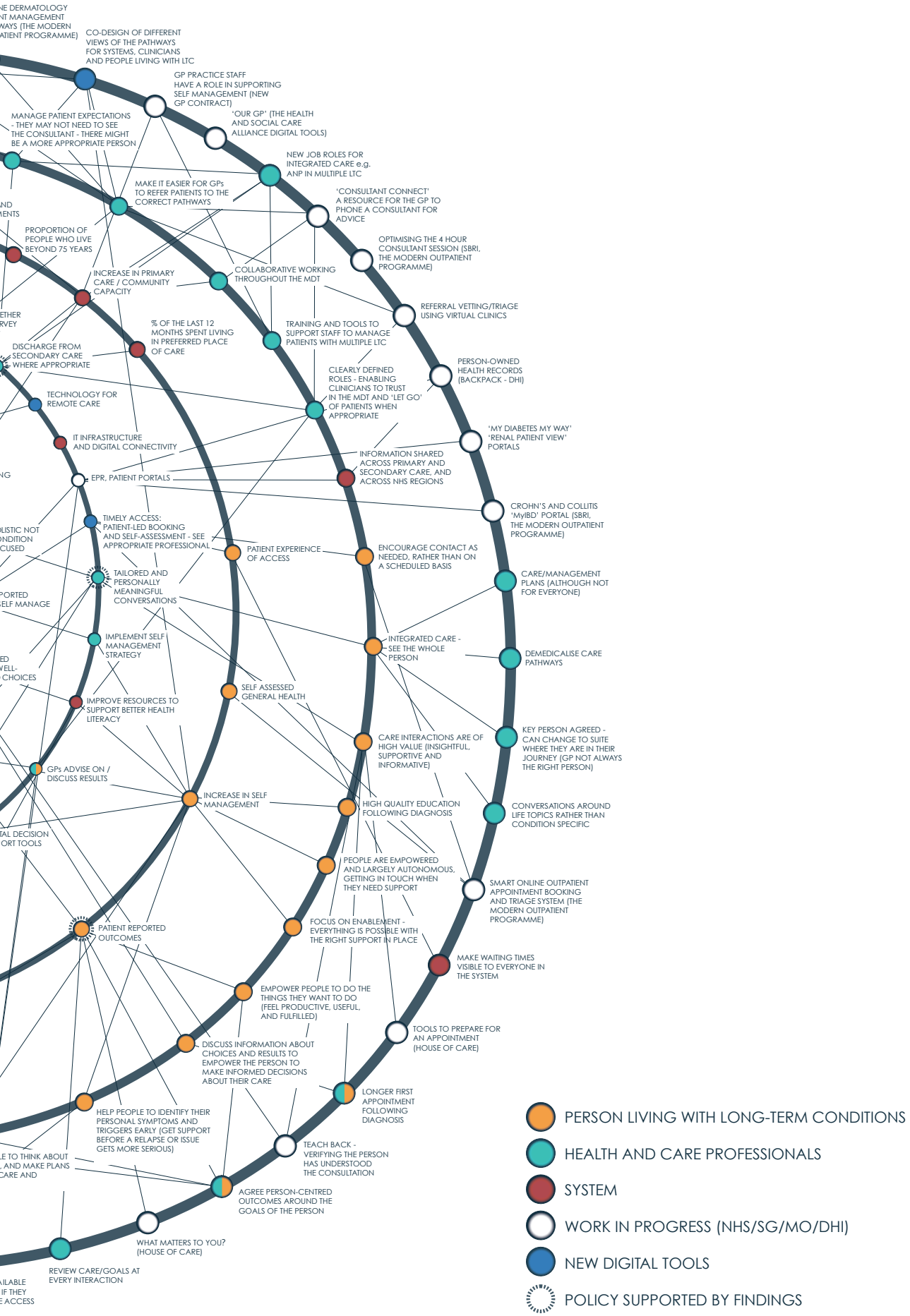
Figure 7: Ideas and aspirations for person-centred care in relation to current policy (G. Teal 2018)




CO-DESIGN OF DIFFERENT VIEWS OF THE PATHWAYS FOR SYSTEMS, CLINICIANS AND PEOPLE LIVING WITH LTC
GP PRACTICE STAFF HAVE A ROLE IN SUPPORTING SELF MANAGEMENT (NEW GP CONTRACT)
'OUR GP' (THE HEALTH AND SOCIAL CARE ALLIANCE DIGITAL TOOLS)
MANAGE PATIENT EXPECTATIONS - THEY MAY NOT NEED TO SEE THE CONSULTANT - THERE MIGHT BE A MORE APPROPRIATE PERSON
NEW JOB ROLES FOR INTEGRATED CARE e.g. ANP IN MULTIPLE LTC
MAKE IT EASIER FOR GPs TO REFER PATIENTS TO THE CORRECT PATHWAYS
'CONSULTANT CONNECT' A RESOURCE FOR THE GP TO PHONE A CONSULTANT FOR ADVICE
PROPORTION OF PEOPLE WHO LIVE BEYOND 75 YEARS
OPTIMISING THE 4 HOUR CONSULTANT SESSION (SBRI, THE MODERN OUTPATIENT PROGRAMME)
INCREASE IN PRIMARY CARE / COMMUNITY CAPACITY
COLLABORATIVE WORKING THROUGHOUT THE MDT
REFERRAL VETTING/TRIAGE USING VIRTUAL CLINICS
% OF THE LAST 12 MONTHS SPENT LIVING IN PREFERRED PLACE OF CARE
TRAINING AND TOOLS TO SUPPORT STAFF TO MANAGE PATIENTS WITH MULTIPLE LTC
DISCHARGE FROM SECONDARY CARE WHERE APPROPRIATE
PERSON-OWNED HEALTH RECORDS (BACKPACK - DHI)
CLEARLY DEFINED ROLES - ENABLING CLINICIANS TO TRUST IN THE MDT AND 'LET GO' OF PATIENTS WHEN APPROPRIATE
TECHNOLOGY FOR REMOTE CARE
'MY DIABETES MY WAY' 'RENAL PATIENT VIEW' PORTALS
IT INFRASTRUCTURE AND DIGITAL CONNECTIVITY
INFORMATION SHARED ACROSS PRIMARY AND SECONDARY CARE, AND ACROSS NHS REGIONS
EPR, PATIENT PORTALS
CROHN'S AND COLLITIS 'MyIBD' PORTAL (SBRI, THE MODERN OUTPATIENT PROGRAMME)
TIMELY ACCESS: PATIENT-LED BOOKING AND SELF-ASSESSMENT - SEE APPROPRIATE PROFESSIONAL
PATIENT EXPERIENCE OF ACCESS
ENCOURAGE CONTACT AS NEEDED, RATHER THAN ON A SCHEDULED BASIS
TAILORED AND PERSONALLY MEANINGFUL CONVERSATIONS
CARE/MANAGEMENT PLANS (ALTHOUGH NOT FOR EVERYONE)
IMPLEMENT SELF MANAGEMENT STRATEGY
INTEGRATED CARE - SEE THE WHOLE PERSON
DEMEDICALISE CARE PATHWAYS
SELF ASSESSED GENERAL HEALTH
IMPROVE RESOURCES TO SUPPORT BETTER HEALTH LITERACY
CARE INTERACTIONS ARE OF HIGH VALUE (INSIGHTFUL, SUPPORTIVE AND INFORMATIVE)
KEY PERSON AGREED - CAN CHANGE TO SUITE WHERE THEY ARE IN THEIR JOURNEY (GP NOT ALWAYS THE RIGHT PERSON)
GPs ADVISE ON / DISCUSS RESULTS
INCREASE IN SELF MANAGEMENT
HIGH QUALITY EDUCATION FOLLOWING DIAGNOSIS
CONVERSATIONS AROUND LIFE TOPICS RATHER THAN CONDITION SPECIFIC
PEOPLE ARE EMPOWERED AND LARGELY AUTONOMOUS, GETTING IN TOUCH WHEN THEY NEED SUPPORT
SMART ONLINE OUTPATIENT APPOINTMENT BOOKING AND TRIAGE SYSTEM (THE MODERN OUTPATIENT PROGRAMME)
PATIENT REPORTED OUTCOMES
FOCUS ON ENABLEMENT - EVERYTHING IS POSSIBLE WITH THE RIGHT SUPPORT IN PLACE
MAKE WAITING TIMES VISIBLE TO EVERYONE IN THE SYSTEM
EMPOWER PEOPLE TO DO THE THINGS THEY WANT TO DO (FEEL PRODUCTIVE, USEFUL, AND FULFILLED)
TOOLS TO PREPARE FOR AN APPOINTMENT (HOUSE OF CARE)
DISCUSS INFORMATION ABOUT CHOICES AND RESULTS TO EMPOWER THE PERSON TO MAKE INFORMED DECISIONS ABOUT THEIR CARE
LONGER FIRST APPOINTMENT FOLLOWING DIAGNOSIS
HELP PEOPLE TO IDENTIFY THEIR PERSONAL SYMPTOMS AND TRIGGERS EARLY (GET SUPPORT BEFORE A RELAPSE OR ISSUE GETS MORE SERIOUS)
TEACH BACK - VERIFYING THE PERSON HAS UNDERSTOOD THE CONSULTATION
AGREE PERSON-CENTRED OUTCOMES AROUND THE GOALS OF THE PERSON
WHAT MATTERS TO YOU? (HOUSE OF CARE)
REVIEW CARE/GOALS AT EVERY INTERACTION
PERSON LIVING WITH LONG-TERM CONDITIONS
HEALTH AND CARE PROFESSIONALS
SYSTEM
WORK IN PROGRESS (NHS/SG/MO/DHI)
NEW DIGITAL TOOLS
POLICY SUPPORTED BY FINDINGS

THE ROADMAP

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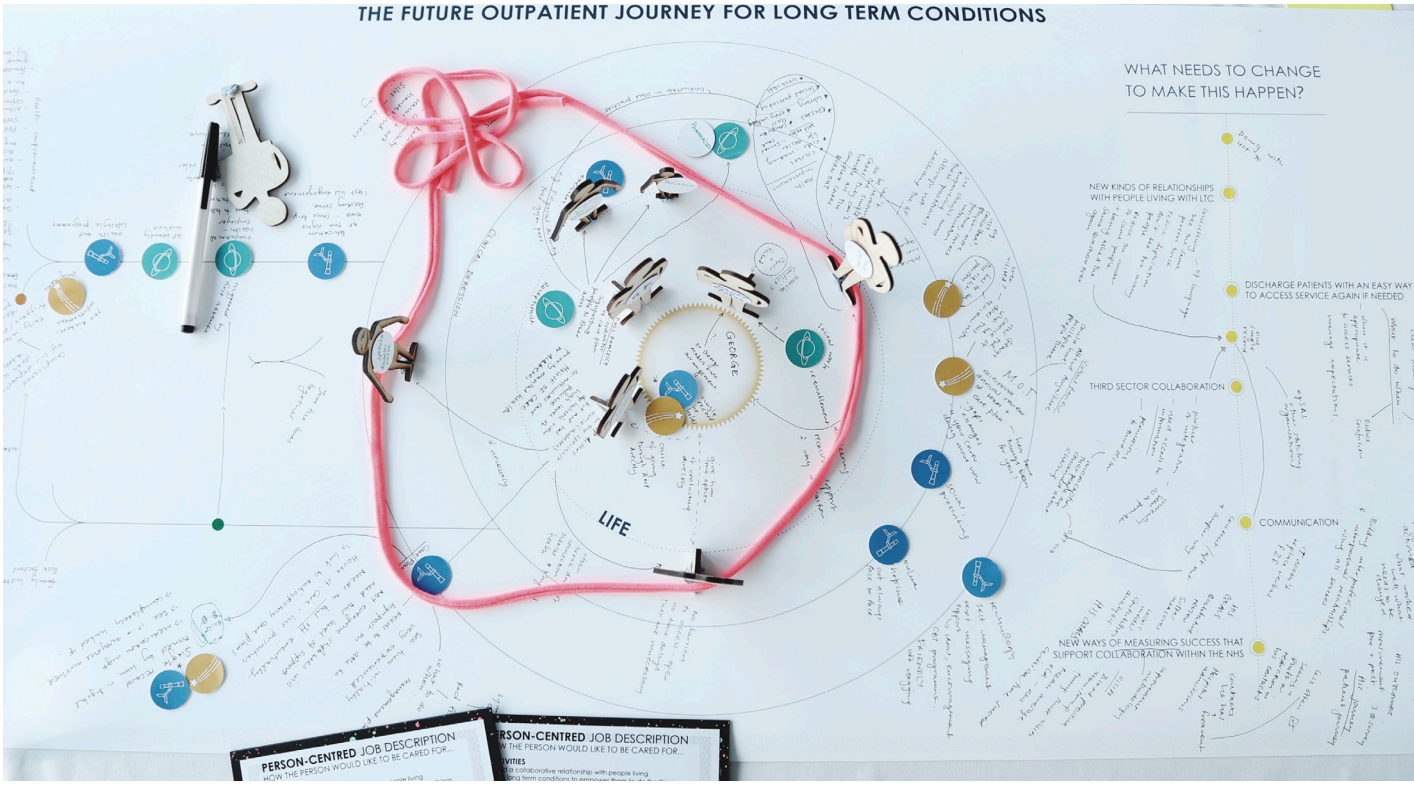
The roadmap presents a description of the development process for these new ideas through a series of project proposals. Many of these new ways of working rely on improved access to person-centred information and communication, and complementary links are drawn to the DHI Backpack Person-Owned Data Store project, currently at the proof of concept stage of development. A table is presented to communicate the suggested development process (Figure 8).

The proposed projects all employ a participatory design approach to develop new technologies and ways of working with the people who will deliver and receive services. Given the challenges highlighted in innovating across different regions and specialisms, a participatory design approach is important to ensure a broad mix of NHS staff and citizens are meaningfully involved to ensure services and resources meet the identified needs and are accepted.

The value of design in the context of health and social care innovation lies in the strengths of design practice in visualisation, strategic roadmapping and co-design. The visual language of design gives form to complexity in a way that creates shared understanding by creatively engaging people in co-design towards identifying preferable responses to health and care challenges. The visual exploration of a shared problem space generates insights that can be translated into tangible opportunities and actions for change. Taking forward this preferable future vision for person-centred care, design provides strategic and creative direction to support transformation by dynamically prototyping solutions through iterative co-design. In this way, design can meaningfully enable the reconfiguration of services, pathways, and systems, responding to the needs and aspirations of all stakeholders involved and capitalise on new insights to transform care experiences.



PROJECT 1

Person-centred pathways innovation

Exploring:

- How can clinical pathways be best represented to inform patients and GPs to help them to navigate the complexities of the system? How does this vary for citizens, primary and secondary care staff?
- How can new pathways integrate social care, third sector, social prescribing and peer support alongside clinical care?
- How can these new representations of pathways enable shared decision making and communication between people living with long-term conditions and clinicians?
- How can these new representations of pathways enable service innovation? This includes the development of ideas for new pathways led by symptoms rather than diagnosis, how pathways can be combined or personalised for people living with multiple long-term conditions and understanding how new job roles (i.e. ANP for multiple long-term conditions) can support self management pathways.

Insights from clinicians: Referring to the correct clinical pathway relies on the GP asking the right questions – if the wrong pathway is chosen the patient may wait months for an (inappropriate) appointment which leads to a new referral and another lengthy wait before being seen by the correct person.

Insights from people living with long term conditions: Navigating the complexities of the NHS is a challenge to living well with a long-term condition and finding the right support. While some people access clinical guidelines to understand what is advised for their condition, these guidelines are often difficult to understand as they are designed for clinicians. Sharing information about pathways was seen to be particularly important for mental health services as we found that lack of awareness of what support is available and how to ask for help are barriers to seeking help before crisis point. There is also an opportunity to incorporate relevant peer support within the pathway. People value advice and reassurance from the experiences of others in similar situations, but information online is often based around models of care from the USA or from other parts of the UK and is therefore not relevant. NICE interactive pathways (pathways.nice.org.uk) offer a useful starting point for this work.

Potential impact of the innovation: Reducing errors in referral cuts down on delays in diagnosis and treatment, and on wasted appointments. If people are supported to better understand where they are in the system, it could reduce uncertainty and anxiety, manage expectations around waiting times and also support them to make appropriate contact if something has gone wrong.

Methodology: Iterative co-design sessions exploring and developing new ways of representing clinical pathways for each of the different users (outpatient staff, patients, GPs, carers). This could be done separately for different specialities and conditions, while also looking across for synergies and ideas that would inform a set of principles or tools to generate more meaningful pathways.

Links to wider projects:

- Online Dermatology Patient Management Pathways, The Modern Outpatient programme;
- 'Mapping Interactions', one of four key concepts for the DHI Backpack;
- DHI Scottish Access Collaborative project: visualisation and mapping of current clinical pathways and services can provide a baseline for co-design sessions to redesign pathways;
- DHI NHS Lanarkshire Diabetes project: current state mapping and potential for innovation at the intersection between primary and secondary care;
- DHI Atrial Fibrillation project: current state mapping can be used as a baseline.

PROJECT 2

Supporting new and extended job roles

Exploring:

- How can the new tools and ways of working proposed support ongoing work by the Chief Nursing Officer to innovate nursing roles to meet health and social care needs in Scotland (NMaHP)?
- What other new tools and ways of working should be in place to support staff to care for people living with multiple long-term conditions?
- In particular, how can the extended or new roles (e.g. dietitians working as 'diabetes educators', advanced nurse practitioner in multiple long-term conditions') be supported by these new tools and ways of working?

Insights: There is a need for non-condition specific conversations, integrated care options and new ways of working to ensure the goals and aspirations of the person are central to the care that is put in place. There is a lack of guidance and training for clinicians in managing the care of people living with multiple long-term conditions. With changes to the role of the GP contract, there is a need to consider who is the best person to support care that integrates multiple different professionals, medications and diagnostics, and reviews this over time to ensure it meets the needs and goals of the patient.

Potential impact of the innovation: Integrated, holistic and person-centred care is key to supporting self management and reducing dependency on services, DNAs and adverse events.

Methodology: Participatory design approach: Engaging with clinicians, educators, academics and people living with multiple long-term conditions to scope out these new roles, understand what training is required and how to implement this.

Links to wider DHI projects: This project would link to 'Tools for the Specialist Nurse', one of four key concepts for the Backpack which is currently being developed by DHI. The project could also inform the Future of Care programme of work which seeks to understand the impact of personal data and data sharing on new models of care and ways of working for health and social care professionals, exploring the resulting workforce needs e.g. training, new tools etc.

Links to wider projects: In addition to supporting the work of the Chief Nursing Officer, this project could support work to implement the new GP contract which seeks to extend the roles of the wider multidisciplinary team.

PROJECT 3

High Value Conversations

Exploring:

- How can the Backpack support high value conversations between people living with long-term conditions and their health professionals?
- How can the Backpack support the House of Care approach (more specifically 'good conversations' and tools to help the person prepare for an appointment, and conversations about 'What matters to you?' to identify person-centred goals) and the use of Teach Back within the consultation?
- How can the Backpack support review of person-centred goals to ensure the appropriate care and support is in place?

Insights from clinicians:
The House of Care and Teach Back approaches have been developed to support clinicians to have good conversations by encouraging the person to prepare in advance, centring the consultation around what matters to the person, and ensuring they understand what has been discussed and agreed.

The traditional medical history does not gather information that can be used to help the clinician to tailor the conversation and treatment to the person's needs and aspirations. The interview maps shared within the co-design workshop offered valuable insight about the person that could support clinicians to understand the wider context and enable good conversations that lead to person-centred care.

Insights from people living with long term conditions:
Within the Backpack project, people living with Multiple Sclerosis (MS) described having to recount their 'story' every time they connect with a professional or service, which is emotionally draining and time-consuming. A 'Health Story' would provide a space within the Backpack for the person to share their story in their own words, using video, visuals or written narrative, supported by key dates and facts. As such it could be considered as a 'person-centred medical history' in contrast to the medical history taken by a clinician.

Potential impact of the innovation:
Removing the need to recount their health story at the start of every consultation has the potential to save time and emotional cost for the person, and enable the clinician to see the person holistically to deliver person-centred care.

Tools that support the clinician to apply House of Care and Teach Back approaches can spread their use throughout the health and care system and increase the value of consultations. This in turn can increase engagement in self management and reduce reliance on services.

Methodology:

- Engage with experts in House of Care to understand the current process and tools, and identify opportunities for person-owned data stores to support;
- Design Group develop prototypes as provocations for a co-design workshops;
- Prototypes are refined and tested in an Experience Lab (see Project 7).

Links to wider projects:

- Inflammatory Bowel Disease (IBD) SBRI project for The Modern Outpatient Programme;
- MyIBD portal;
- 'Our GP', The Health and Social Care Alliance;
- 'Health Story', one of four key concepts for the DHI Backpack project;
- DHI NHS Lanarkshire diabetes project exploring conversations at diagnosis of type 2 diabetes.

PROJECT 4

'What to do when'

Exploring:

- What is the potential of a new 'what to do when' resource to support people to manage symptoms?

Insights:
This concept emerged as a self management resource to help people understand their condition, know their personal symptoms and triggers; and know what to do to manage symptoms and when (and who) to contact if additional support is required. In addition to storing advice from clinicians, it could also link to practical symptom management advice from peers and third sector organisations.

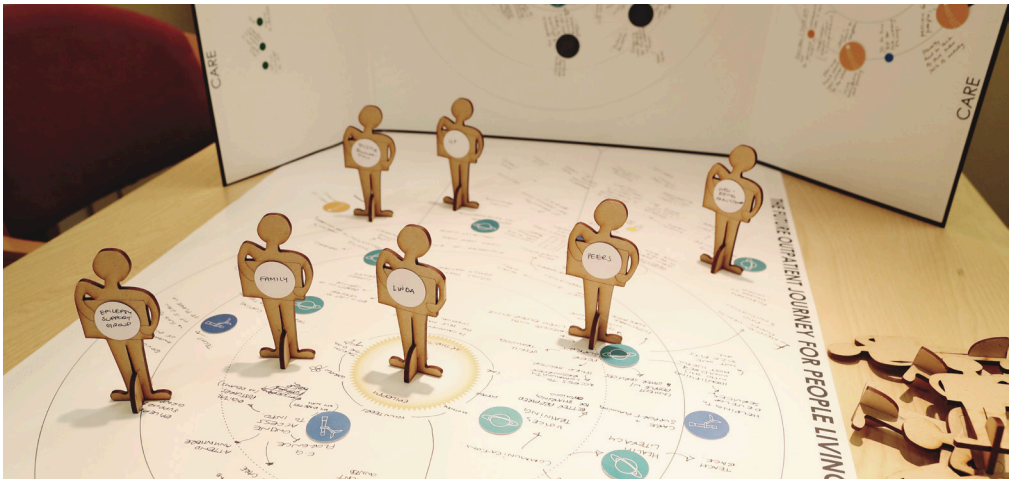
Potential impact of the innovation:
A 'what to do when' resource has the potential to reduce uncertainty in the early stages of learning to self manage by giving an indication of what symptoms can be expected, and what requires investigation or treatment. In describing who to call in instances where more support is needed, the resource could function as a guide for "how to use your NHS", ensuring people see the right person at the right time. It could also offer reassurance and support for family members and carers.

This has some similarities to sections of the Anticipatory Care Planning (ACP) tool which relate to self management (e.g. the section entitled 'What I need to do and who I can contact if I become unwell'), therefore the project should engage with experts at Healthcare Improvement Scotland who have been developing this resource. There are also similarities with an inflammatory bowel disease (IBD) 'Flare Card'* self management tool trialled in NHS Royal Alexandra and Vale of Leven Hospitals, which was found to aid control, improve medication adherence, reduce symptoms and deliver patient-centred care. As with the ACP this resource could be a paper tool or a digital resource, and we would be keen to understand how this could link or be supported by the Backpack. Lessons can also be learned from the NHS Lothian COPD pathway redesign project, which gives people living with COPD resources to identify and act on any symptoms, including diagnostic equipment, rescue medication and seven-day access to a community-based team.

By giving clear quantitative information about what symptoms to be aware of and when to seek help from whom, there has been a significant reduction in hospital admissions.

Methodology:
This idea could be explored as part of the Future of Care work stream within DHI. The concept would be developed and visualised by the Design Group as a (non-functional) prototype to enable early feedback from people living with long-term conditions and clinicians. Feedback would be used to refine the concept which could then be tested alongside other potential innovations.

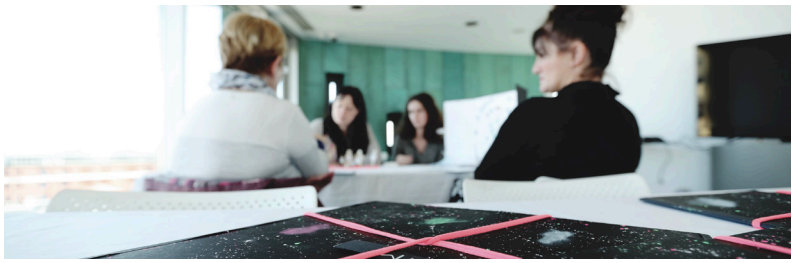
Links to wider projects:
As with the results and medication project ideas (see projects 5 & 6), this could eventually become a resource within the Backpack or Health and Social Care Portal. There may also be links to the DHI diabetes project in Lanarkshire, which will be exploring resources to support conversations about type 2 diabetes following diagnosis.



* Squires, S.I., Boal, A.J., Lamont, S. and Naismith, G.D., 2017. Implementing a self-management strategy in inflammatory bowel disease (IBD): patient perceptions, clinical outcomes and the impact on service. *Frontline gastroenterology*, 8(4), pp.272-278.

PROJECT 5

Communicating Results



Exploring:

- How can test results best be communicated to people living with long-term conditions, clinicians and GPs?
- How can we support the GP to communicate and discuss results to support shared decision making?

Insights from people living with long-term conditions:
Both in the interviews with people living with multiple long-term conditions, and in our previous work with people living with diabetes and MS, we learned that having timely access to results is a key resource for self management. While people did not want to see medical jargon, they would like to see the results and be empowered to share them with other people involved in their care. In particular for people living with diabetes, they wanted to see the results before an appointment to allow them to reflect and consider questions in advance. We also gathered insight about how people living with diabetes would like to see their results presented visually, and how this could be combined with lifestyle data.

Insights from consultants:
Consultants discussed their tendency to use an outpatient appointment to give patients the results of tests, as they lacked confidence in the GP to appropriately explain them to patients. In addition, consultants are presented with a high volume of unfiltered test results (many pages of black and white printed results in small print), making it challenging and time consuming to trawl through them to identify the concerning results to follow up on first.

Potential impact of the innovation:
Supporting people to better understand their condition, reducing the number of outpatient appointments by supporting GPs to give results, and enabling more timely and effective communication of results for clinicians and citizens. This project has the potential to generate insight and ideas for how results should be presented to support people to understand and take steps to self manage or seek support from the appropriate professional (also linking to the 'what to do when' concept, page 34).

Methodology:
Participatory design approach with a person living with a LTC, consultant and GP.

- Pairing a consultant with a person living with a long-term condition from their specialism;
- Individual interviews with the consultant and person living with a long-term condition;
- A co-design session bringing together the consultant, the person living with a long-term condition and a GP;
- Outputs are translated into prototypes to be refined and tested at a second co-design session with the same participants;
- This is repeated for a number of different pairings for different conditions/specialisms;
- A final event brings together all the pairs of consultants and people living with LTC to share their designs, and together design a set of principles for communicating results.

Links to wider projects:
Existing patient portals such as My Diabetes My Way and Renal Patient View already offer people access to a selection of their medical records. Work is currently underway to give all citizens access to their medical records through the 'Health and Social Care Portal'. Having access to test results was a key requirement for the Backpack project, however beyond general requirements we did not get into the specifics of how this would work in practice. This is potentially where the Health and Social Care Portal and Backpack projects intersect.

Project 6

Medication chart

Exploring:

- How can information about medication be presented to people living with long-term conditions to improve self management and medication compliance?
- How can this resource facilitate conversations and shared decision making with clinicians in the MDT in relation to medication?

Insights: A particular challenge of living with multiple or complex long-term conditions is managing multiple medications.

Potential impact of the innovation: A resource that explains the purpose of a medication (e.g. is this treating a particular symptom, or is it treating a side-effect of another medication) has the potential to improve self management and medication compliance. It could also facilitate conversations about medication with health professionals and informal carers, and prompt and enable regular medication review with a pharmacist.

Methodology: This idea could be explored as part of the Future of Care work stream. Following some early engagement with pharmacists and people living with long-term conditions, the concept would be developed and visualised by the Design Group as a (non-functional) prototype. The concept could then be tested alongside other potential innovations in the Experience Lab (see Project 7), enabling early feedback and development.

Links to wider projects: As with the 'what to do when' and results project ideas, this could eventually become a resource within the Backpack or Heath and Social Care Portal.

Project 7

Testing concepts using Experience Labs

Exploring:

- What is the impact of new concepts on the experience of people living with long-term conditions in accessing care?
- How do these new concepts change working practice?

Insights:

A number of innovative concepts have been developed or proposed to improve the experience of people living with long-term conditions. These include the ideas proposed in this report, but also innovations that have been successfully piloted in other areas, and new functional prototypes developed by The Modern Outpatient Programme through Open Innovation procurement methodologies. In order to progress these ideas a safe space is required to understand how the innovations would work in practice and identify any unintended implications for services. Concepts that could be tested within the Experience Lab include:

- Consultant connect: a service implemented in NHS England (www.consultantconnect.org.uk). Experience Labs could be used to understand the potential to implement this in Scotland to support communication between primary and secondary care and identify any different or additional requirements for this new context.
- Smart Online Outpatient Appointment Booking And Triage System: currently in development by the Modern Outpatient programme. Experience Labs could be used to understand the potential to implement this in Scotland, identify any user testing issues and identify any further development work required.
- Projects 1-6 outlined above all propose innovative concepts that could be de-risked and developed through Experience Lab testing.

Potential impact of the innovation:

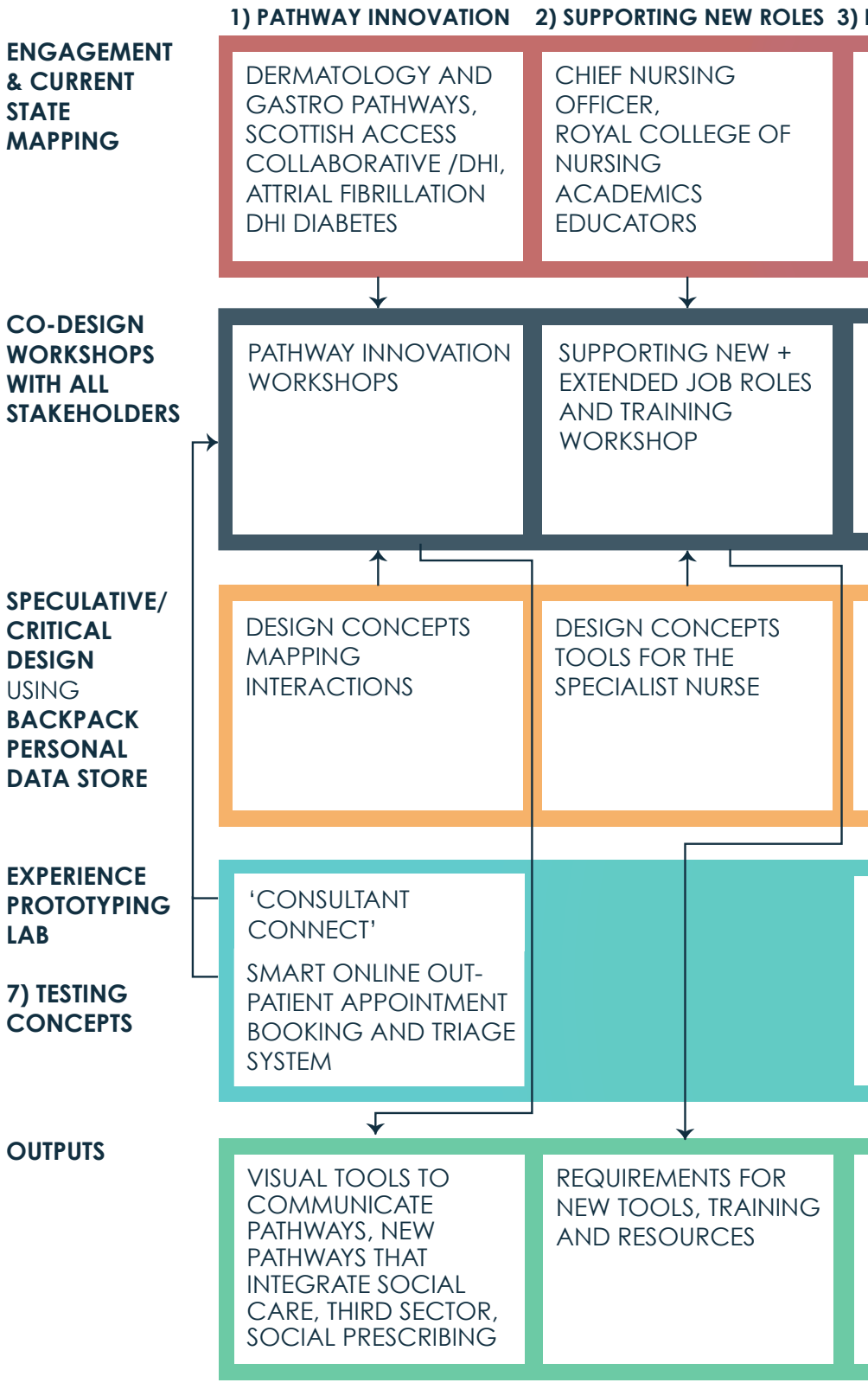
- Engage and involve clinicians and citizens in shaping new technology as part of a change management process;
- Test early to inform development and de-risk;
- Understand any barriers or usability issues, additional development required and unintended consequences.

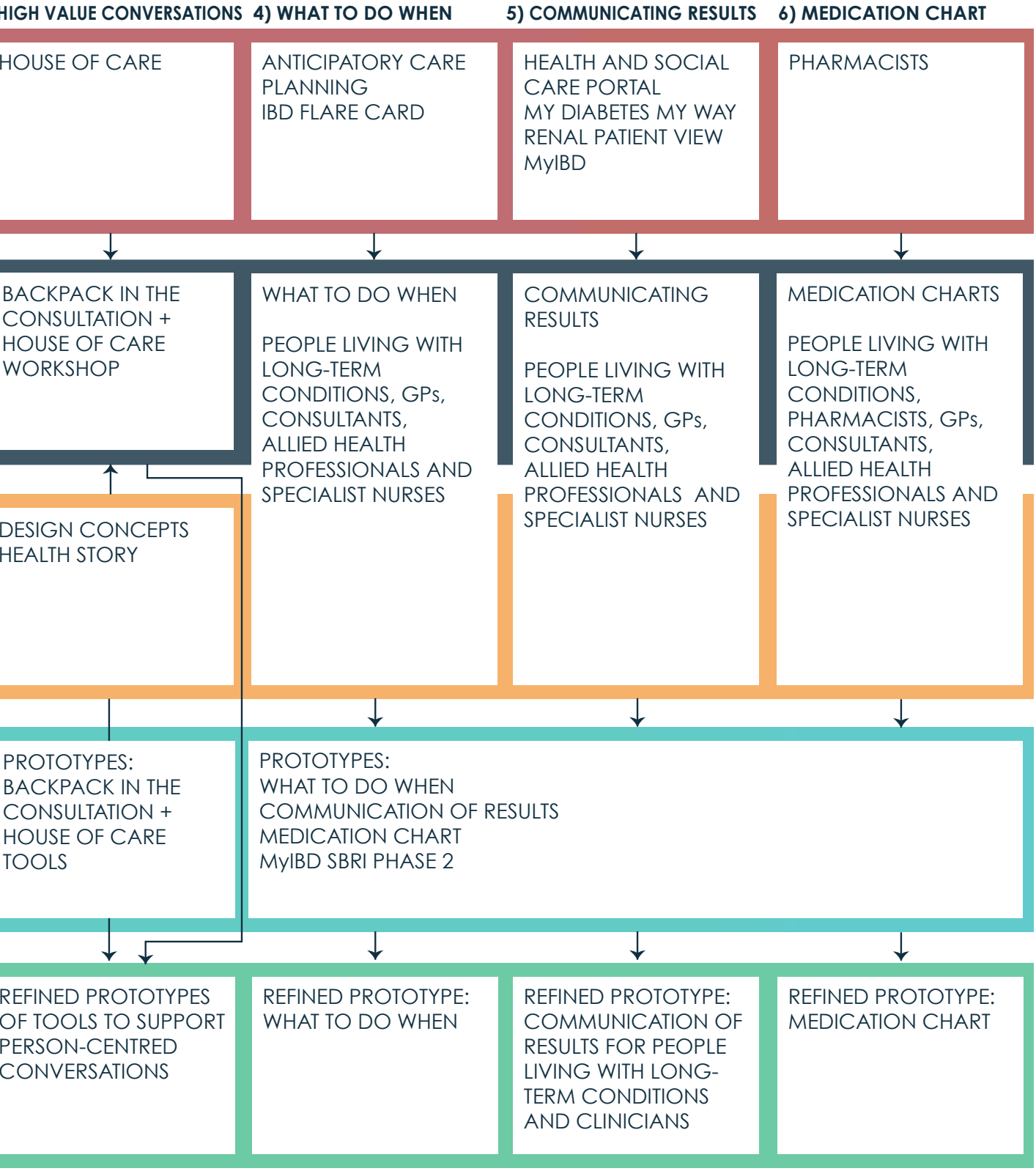
Methodology:

Experience Labs use role play and experience prototyping to engage citizens and clinicians in the iterative development of innovative digital tools. Prototypes of varying fidelity can be tested, from basic paper prototypes through to fully functional systems. Experience Labs enable us to de-risk a design concept early in the development process before investment is made in functional prototypes. They also provide a space to test innovations that have been piloted or developed for other regions or contexts, giving insight into any modifications required and understanding user acceptance, to support local implementation.

THE ROADMAP

Figure 8: An overview of the projects, process and outputs (G. Teal 2018)




HIGH VALUE CONVERSATIONS
4) WHAT TO DO WHEN
5) COMMUNICATING RESULTS
6) MEDICATION CHART
HOUSE OF CARE
ANTICIPATORY CARE PLANNING
IBD FLARE CARD
HEALTH AND SOCIAL CARE PORTAL
MY DIABETES MY WAY
RENAL PATIENT VIEW
MyIBD
PHARMACISTS
BACKPACK IN THE CONSULTATION + HOUSE OF CARE WORKSHOP
WHAT TO DO WHEN
PEOPLE LIVING WITH LONG-TERM CONDITIONS, GPs, CONSULTANTS, ALLIED HEALTH PROFESSIONALS AND SPECIALIST NURSES
COMMUNICATING RESULTS
PEOPLE LIVING WITH LONG-TERM CONDITIONS, GPs, CONSULTANTS, ALLIED HEALTH PROFESSIONALS AND SPECIALIST NURSES
MEDICATION CHARTS
PEOPLE LIVING WITH LONG-TERM CONDITIONS, PHARMACISTS, GPs, CONSULTANTS, ALLIED HEALTH PROFESSIONALS AND SPECIALIST NURSES
DESIGN CONCEPTS
HEALTH STORY
PROTOTYPES:
BACKPACK IN THE CONSULTATION + HOUSE OF CARE TOOLS
PROTOTYPES:
WHAT TO DO WHEN
COMMUNICATION OF RESULTS
MEDICATION CHART
MyIBD SBRI PHASE 2
REFINED PROTOTYPES OF TOOLS TO SUPPORT PERSON-CENTRED CONVERSATIONS
REFINED PROTOTYPE:
WHAT TO DO WHEN
REFINED PROTOTYPE:
COMMUNICATION OF RESULTS FOR PEOPLE LIVING WITH LONG-TERM CONDITIONS AND CLINICIANS
REFINED PROTOTYPE:
MEDICATION CHART

SUMMARY OF FINDINGS

During our pop-up public engagement we learned that **people highly value the health professionals and assistants who listen and understand their needs as an individual**. People told us about incredible doctors, nurses and teams taking great care of themselves or their loved ones. We also learned about the frustrations of parking near to the hospital, and the need for more practical information before an appointment.

From our interviews with people living with multiple long-term conditions, we understood **the importance of a person's experience when receiving a diagnosis.** This can impact on how people feel about their condition, how they engage with health professionals and the time it takes for them to accept, learn and manage their condition. The early stages can be an anxious time, and there is an opportunity to **improve the information shared about what they can expect** from both the condition and the health service.

We also learned that people rarely have conversations with health and care professionals that consider the impact of their multiple conditions and **discuss their health and wellbeing in an integrated way**. These types of conversations are vital in understanding how to self manage, and in supporting people to live well with their conditions.

One of the most insightful moments from the process was seeing **the transformative power of the real stories captured in the interview maps**. Interview participants generously shared their 'health stories' through the maps: NHS staff told us that having this level of **insight into the person's past experiences and aspirations for living well with their condition is hugely valuable in understanding how to design their care.** The insights, aspirations and ideas are summarised in a vision for person-centred care for people living with multiple or complex long-term conditions (Figure 9, above).

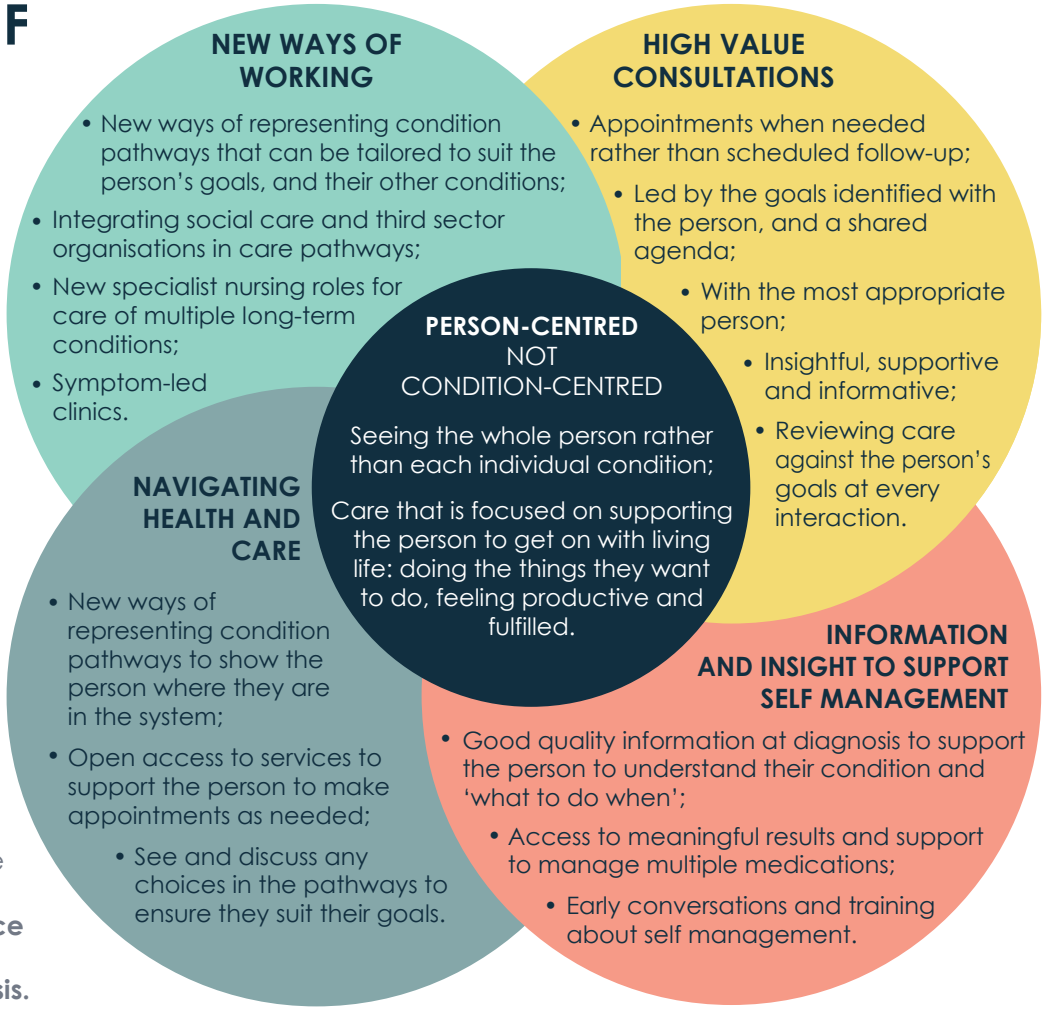


Figure 9: Future vision (G. Teal 2018)

Through the co-design workshop we were able to place these real people at the centre of the service, and through this NHS staff identified many **opportunities to innovate care**. A visual summary of the opportunities to innovate the future of care is presented in Figure 10, opposite.

Figure 10: Summary of design opportunities and concepts (G. Teal 2018)

NEXT STEPS

The design group are currently exploring how the design concepts generated through this project can be taken forward in the DHI 'Future of Care' project. Essential to this process will be the meaningful involvement of people living with long-term conditions and NHS and social care staff to ensure the resulting resources meet the needs of the different users and stakeholders. Early and iterative prototyping will be used to translate the design concepts into tangible forms that can be tested and refined by the intended users to understand how they might support self management, service delivery and positive experiences of care.

Meanwhile, we are continuing to explore the outputs of the Backpack project (see Page 15) and are developing prototypes and demonstrations of new concepts for care enabled by person-owned data. We are also working to translate the project outputs into the DHI Demonstration Environment to allow us to communicate the future vision using 'after' stories to bring the future vision of care to life and show the impact this would have on the lives of people living with multiple long-term conditions.

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