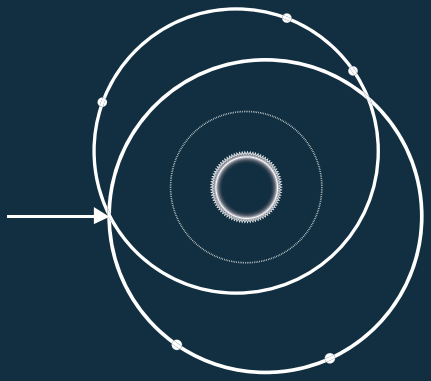


A Person-Centred Vision of Care for People Living with Multiple Long-Term Conditions

for The Modern Outpatient Programme

INNOVATION SCHOOL
THE GLASGOW SCHOOL OF ART

DIGITAL HEALTH & CARE INSTITUTE

Project Summary →

Relative.
Lynda.
GP PRACTICE
Choice of partner to share data
Share Data
Third Sector/ voluntary
ACTIVITIES
JOURNEY FOR PEOPLE LIVING WITH MULTIPLE LO

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 hospitals

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

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

Team:

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

Locations:

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

2017-2018

18 Hours Lab time

7 Hours Interview time

8 Hours Pop-up public engagement time

6 Hours Internal Lab time

Outputs:

- 2 Reports x2
- 2 Videos x2
- 6 Visualisations x6

Tools & Artefacts:

4x Interview mapping tool
6x Current care maps
6x Person-centred care maps

multimorbidity

person-centred

future vision

Key Findings:

1 Caring for the whole person rather than each individual condition.

2 The importance of knowing the person's story and goals, and using these to shape their care.

3 Care focused on supporting the person to get on with living life: doing the things they want to do and feeling productive.

+ a wealth of new ideas for supporting people to self manage, and new tools for health and care professionals

BACKGROUND

The project was funded by the Digital Health and Care Institute (DHI), a Scottish Funding Council initiative between The Glasgow School of Art, the University of Strathclyde and NHS24. At The Glasgow School of Art, our research involves working with health and care professionals and the public to explore challenges in health and social care to come up with new ideas for improving services here in Scotland. In this project, we responded to a challenge set by The Modern Outpatient Programme at the Scottish Government, to identify opportunities to innovate care for people living with multiple long-term conditions.

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. Currently our specialist care is delivered in hospitals, with each condition treated separately. This way of organising care requires people living with multiple conditions to attend many different appointments, which impacts on their lives and can be very tiring, and also represents an inefficient use of NHS resources. This project asked the questions:

How could our health system be organised around the person living with multiple long-term conditions rather than around individual conditions? How would this change their experience of care?

PROJECT AIM

The aim of the project was to develop a person-centred vision for the future of 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 health professionals experience in supporting people living with multiple long-term conditions within the current health and care system;
    c) The challenges of innovating 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.

WHAT WE DID

Public Engagement

We visited the outpatient reception areas of Raigmore Hospital in Inverness and Dr Gray's Hospital in Elgin, to chat to the public about what they value about their care, and gather ideas to improve their experience. We took along some ideas based on insights from our previous work with people living with long-term conditions, along with the opener, 'What if...? Share your ideas for improving outpatient care'. Our conversations were recorded as sketches and post-its, and we took all the gathered ideas and comments along to inspire NHS staff at our co-design workshops.

Interview maps

We interviewed four people living with multiple long-term conditions. In each interview, we worked together to make a visual map of their experience, recording how they currently manage their conditions as part of their daily life. We looked back to their experience of diagnosis and learning about their condition, and looked forward to understand their aspirations, and what future care they would value. Experiences of living with conditions such as diabetes, angina, depression, epilepsy, Crohn's disease and arthritis were explored. The interview maps were used as the central inspiration for our workshops with NHS staff.

Workshops

Three workshops with NHS staff took place in Glasgow, Forres and Edinburgh. These sessions brought together consultants, GPs, nurses, allied health professionals, telehealth experts and managers from six NHS regions, to consider the current experience of services for people living with multiple long-term conditions. We shared the stories of the people we interviewed using the visual maps. The participants were asked to place a chosen individual at the centre, designing care around their needs and aspirations.

KEY 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.**

Through the workshops 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**. These ideas are presented in the following pages.

PERSON-CENTRED JOB DESCRIPTION

Reflecting on the aspirations for future care people shared during the interviews, we generated a 'person-centred job description', specifying the activities, expertise and skills people were seeking from their health and care professionals. We shared this with NHS staff at our co-design workshops, and tasked them with designing the ideal future care team to fulfil the aspirations of people living with multiple long-term conditions.

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.

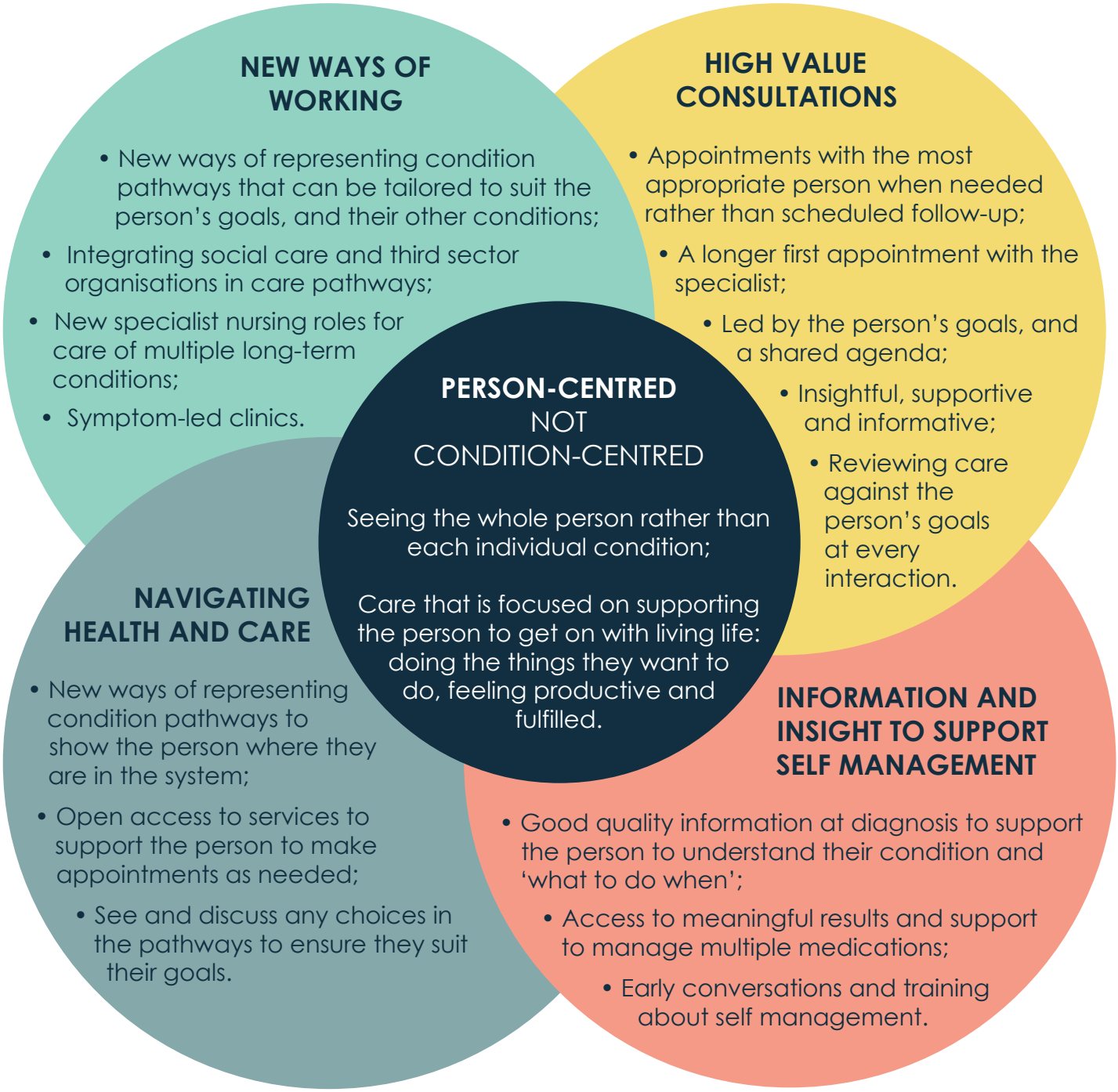
Skills and expertise:

- 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.

FUTURE VISION



DESIGN CONCEPTS

TOOLS TO SUPPORT NEW WAYS OF WORKING

There are opportunities for new digital tools to support staff caring for people living with multiple long term conditions supported by access to person-owned data.

TOOLS TO SUPPORT 'GOOD CONVERSATIONS'

Using access to the person's own 'health story' to support clinicians to use best practice approaches (like House of Care and Teach Back) in their consultations.

Aligned to this are resources to help the person reflect on their agenda before the appointment and get the most from their time with the clinician.

PERSON-CENTRED DATA SHARING THROUGHOUT THE CARE TEAM

OWNED AND CONTROLLED BY THE PERSON

TOOLS TO NAVIGATE HEALTH AND CARE

There are opportunities for new visual ways of communicating clinical pathways for specialists, staff in general practice and for people using the service.

This could use person-owned data to personalise the pathways, showing people where they are in the system, and communicating choices to support decision making based on their goals.

TOOLS TO SUPPORT SELF MANAGEMENT

'What to do when'
A resource to support 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 (a bit like a lightweight Anticipatory Care Plan).

Aligned to this are resources to support people to understand their results and medications.

Thank you...

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 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 public engagement sessions in their busy outpatients foyers, and to all the citizens and staff who engaged with us to share their views.

Further Information

For more information about this project please contact:

Gemma Teal G.Teal@gsa.ac.uk
Cate Green C.Green@gsa.ac.uk

To see the full report including maps of the current experience and future vision, and the project video please visit:

www.futurehealthandwellbeing.org/modern-outpatients

Gemma Teal
The Innovation School
The Glasgow School of Art

May 2018

INNOVATION SCHOOL THE GLASGOW SCHOOL OF ART

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