

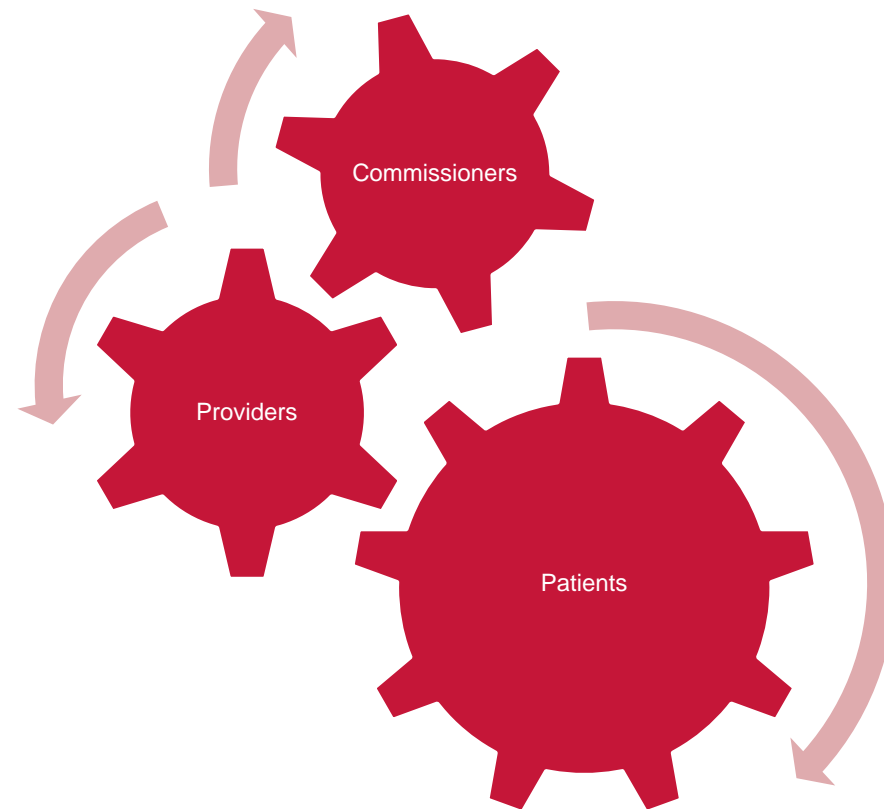
# Person-centeredness in the integrated care context

## Lessons from an evaluation of the Integrated Care Pilot in North West London

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## Making integrated care work



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Ideas that change  
health care

Lessons from experience

## Making integrated care happen at scale and pace

Authors  
Nick Goodwin  
Anna Dixon  
Geoff Anderson  
Walter Wodchis

January 2014

Providing integrated care for older people with complex needs  
Lessons from seven international case studies

TheKingsFund>

nuffieldtrust  
evidence for better health care

## A report to the Department of Health and the NHS Future Forum

Integrated care for patients and populations:  
Improving outcomes by working together

TheKingsFund>

Ideas that change  
health care

Authors  
Angela Coulter  
Sue Roberts  
Anna Dixon

October 2013

Delivering better services for people with long-term conditions  
Building the house of care

## Co-ordinated care for people with complex chronic conditions

Key lessons and markers for success

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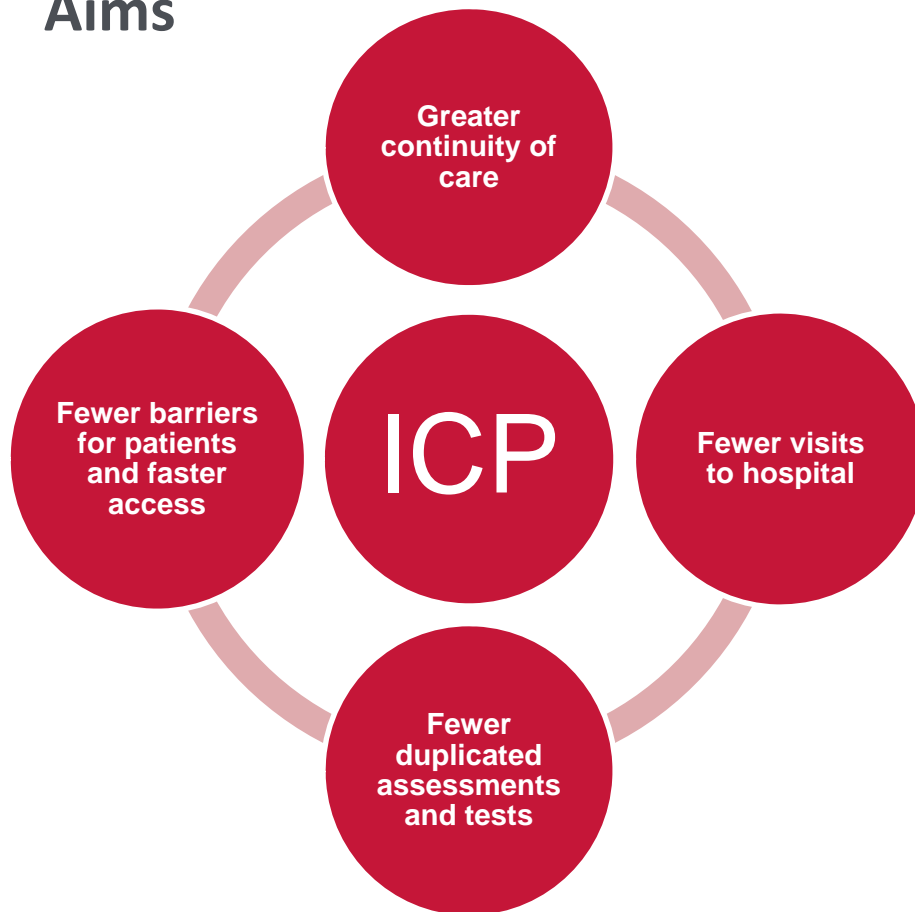
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## Integrated care

What is it? Does it work? What does it mean for the NHS?

## NW London Integrated Care Pilot (ICP)

### Aims



### Drivers

- Proactive care planning
- Multidisciplinary discussion groups
- Information sharing tool
- Shared governance

## NW London Integrated Care Pilot (ICP)

- Launched in June 2011
- Targets at patients with diabetes and >75 years (550,000 people)
- Links >100 general practices, 2 acute care trusts, 5 primary care trusts, 2 mental health trusts, 3 community health trusts, 5 local authorities, and 2 charities.

## Diabetes

- 347 million people worldwide with diabetes
- Increase from 1.4 to 2.9 million cases in UK (1996 to 2012), estimated to increase to 5 million in UK by 2025
- 10% of NHS budget spent on diabetes – £9 billion a year (2007/08)

## Evaluation

- Implementation intensity
- Financial evaluation
- Health outcomes
- Patient, carer & professional experience

## ICP Aims

### **Greater Continuity of Care**

- organised across levels and settings
- involving several professionals working together as an extended team

### **Fewer barriers for patients and faster access:**

- remove artificial barriers
- speeding up the patient journey

### **Fewer visits to hospital**

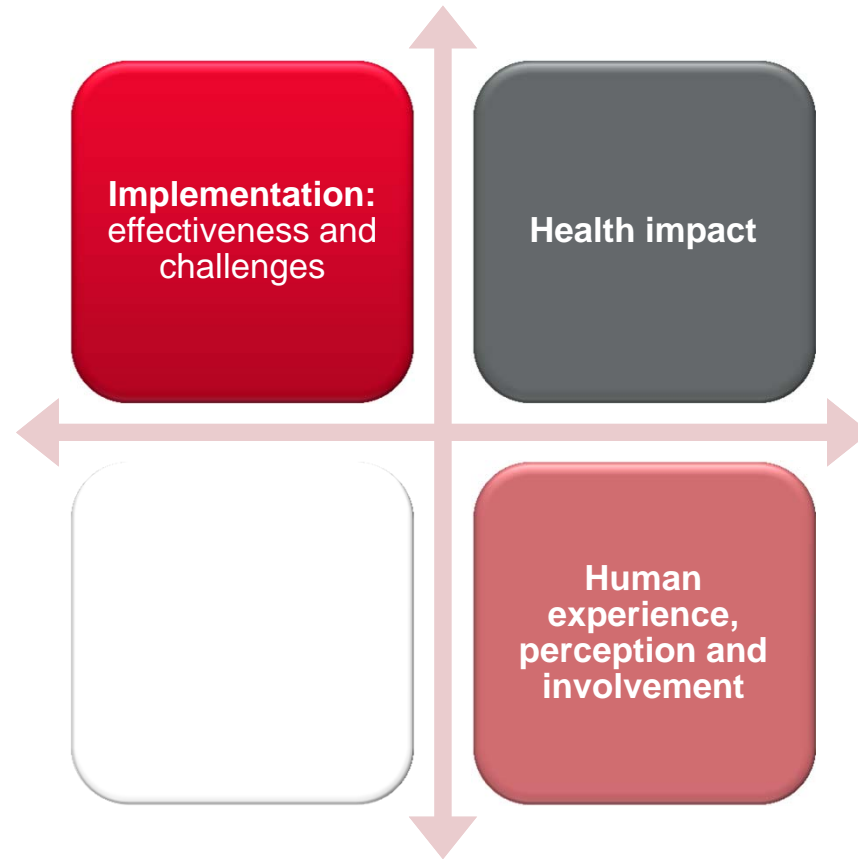
- one-stop clinics
- working together within one co-ordinated system

### **Fewer duplicated assessments and tests:**

- improved information flow between professionals and levels of care, using interoperable systems and shared guidelines



## Evaluation to address four critical areas



## Evaluation - four critical areas

**Implementation intensity** – service metrics from existing datasets

**Financial evaluation** - rates of emergency hospital admissions, numbers of hospital bed days, and cost over time

**Health outcomes** - intermediate outcome measures (HBA1c, cholesterol and blood pressure control)

**Patient, carer & professional experience** focus groups, surveys, semi-structure interviews



**Six month review:** Early assessment on questions of cost effectiveness, clinical outcomes and patient experience – short report.

**Full evaluation:** Full evaluation on all questions – longer report to be published on impact of ICP on recorded improvements in cost effectiveness, hard clinical outcomes and patient experience.

## Person-centeredness in the integrated care context

The *International Journal of Integrated Care* dedicated in 2010 a whole volume on person-centered medicine (Mezzich et al. 2010).

Person-centeredness is being implemented in mainstream provision in integrated care models in only 2 out of 9 European countries (Leichsenring 2004).

User views are rarely evaluated in integrated care programs (Briggs, Capdegelle, and Garner 2001; Ouwens et al. 2005)

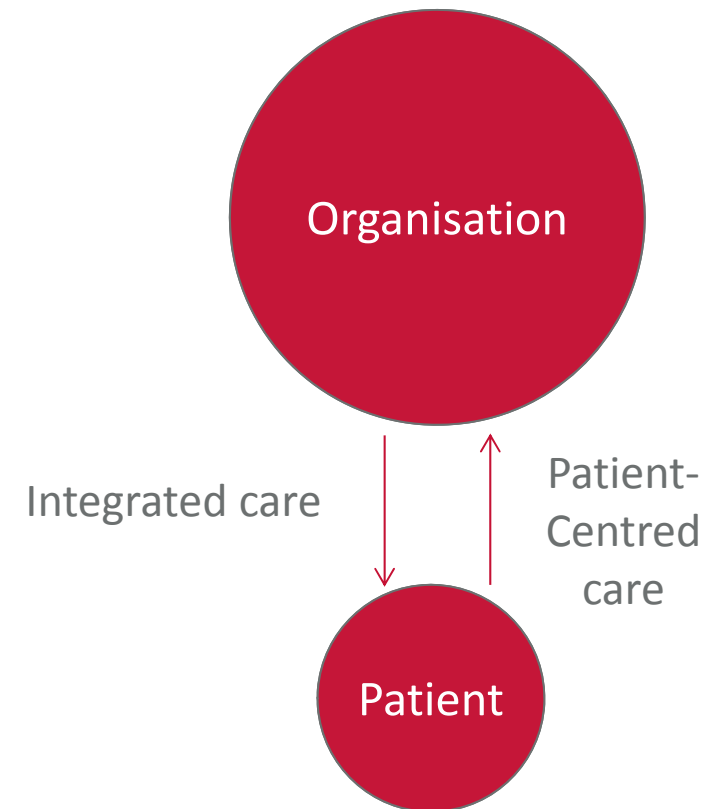
Patients are rarely involved in designing, implementing or evaluating patient-centered care interventions (Amati et al. 2012).

## Patient experience

Person-centred care emphasises the benefits of a **holistic, humanistic approach** that puts patients first and at the centre of clinical care, and is considered a **core element** of integrated care.

Typologies of integrated care mainly describe **how patients fit within integrated services**, rather than how services fit into the **patient's world**, and it is unclear how 'person-centeredness' is realized in integrated care.

We aimed to explore patient narratives on person-centeredness in the integrated care context.



## Person-centeredness in the integrated care



**7th Geneva Conference  
on Person Centered Medicine**

*Person- and People-Centered Integrated Care for All*

April 26 –30, 2014

Geneva University Hospital

## Method

- Part of a large-scale mixed-methods evaluation of the ICP.
- **Study design:** A phenomenological, qualitative study, including semi-structured interviews.
- **Participants and sampling:** 22 patients registered in the Northwest London Integrated Care Pilot.
- **Analysis:** Thematic content analysis.

## Patients welcomed the integrated care

*“Well, if it works it will be a heaven - if it works... that would be ideal”.*

*“...I personally believe that **that could revolutionise the whole medical process,...** it's a fundamental different shift in emphasis. ... you have all these wonderful experts doing fantastic research but nobody's tying all the bits together”.*

*“I understand that it's **a scheme which will spark off any other future developments in patient care**”.*



## But...were hardly engaged with the pilot

- Vague understanding of what is the pilot all about
- Hardly recalled being registered
- Only one could notice any change in care

## What is 'integrated care'?

- Two main features: 'All in one place' and 'Professionals working together'.
- Identified many **benefits**: improved communication and co-ordination between providers, continuity of care, safety, and patient empowerment.

*"That would solve a lot of problems: in fact the main problem, **which is communication**. ...there is very little they can do individually"*

*"What I understand is the integrated care is, **it's a team of doctors that will have to work together**"*

*"What's fantastic with the ICP is that it has this wonderful word inclusive, **together**"*

## What is **person-centred** integrated care?

*I want to be treated as a whole person,  
to be able to speak, to tell my unique story.*

*I want to be seen by the  
same doctor each time.*

*I want to be involved in my  
care, to be informed, and  
make decisions.*



*I want to be acknowledged as a unique,  
respected, equal person, and to be treated  
with respect and dignity.*

*I want to be listened to and get proper  
attention, to get comprehensive clinical  
judgment, and to have enough time to  
express my needs.*

*I want to be cared with authentic emotional empathy, warmth and compassion.*

## Patient narratives on person-centeredness

### Holism

- *“I mean, I think they know... **not just about my diseases**, but they know about my family life and I know about the doctor’s children and, you know...I count them as friends, to tell you the truth...**It’s always a pleasure to come here**”.*

### Naming

- *“My biggest complaint is that bureaucracy business. If only, **if only they would take time to think that they’re talking to people** and people want to know what’s happening to them, instead of this terrible silence between even booking clerks who make appointments for you. **I mean they’re talk to you as if you’re a number!**”.*

## Patient narratives on person-centeredness

### Heed

*“It’s partly because of the rapport and partly because he listens. **He has time.** He doesn’t... I don’t see the note and I don’t see the prescription pad on the desk with the pen at the ready.”*

*“...every time we go to GP, you are rushing, so queue behind, you have 20, 30 people. **Everything is angry in the waiting rooms...you are under pressure, always that...You don’t have enough time with your GP to talk, to discuss your problems...**”*

### Compassion/caring

*“**Care, the word care, says it all.** Care is care, and if you are in the care of somebody, you do things for them. You try to improve, right? It’s like if I know that person is in my care, the first thing I will feel for that person is **love and compassion** because he is an elder, because he cannot do the things herself...”*

## Patient narratives on person-centeredness

### Agency and Empowerment

*“Would I like to be more involved; I would like to be able to ask my doctor that I’ve heard about such and such medication or project or research program, or whatever, and I would like to be able to ask my doctor that is it possible for me to avail of this and find out more about it and what’s going on and, maybe, even partake in it”.*

### Continuity of care

*“...Okay, you’re not going to believe this but one of the most maddening thing of all is you go into the GP’s surgery and there’s about ten different GPs in the practice, **you don’t know who you’re going to see, you know, different doctors coming and going, and I felt ...if something goes wrong now, who really knows about me?**”*

## Patient narratives on person-centeredness

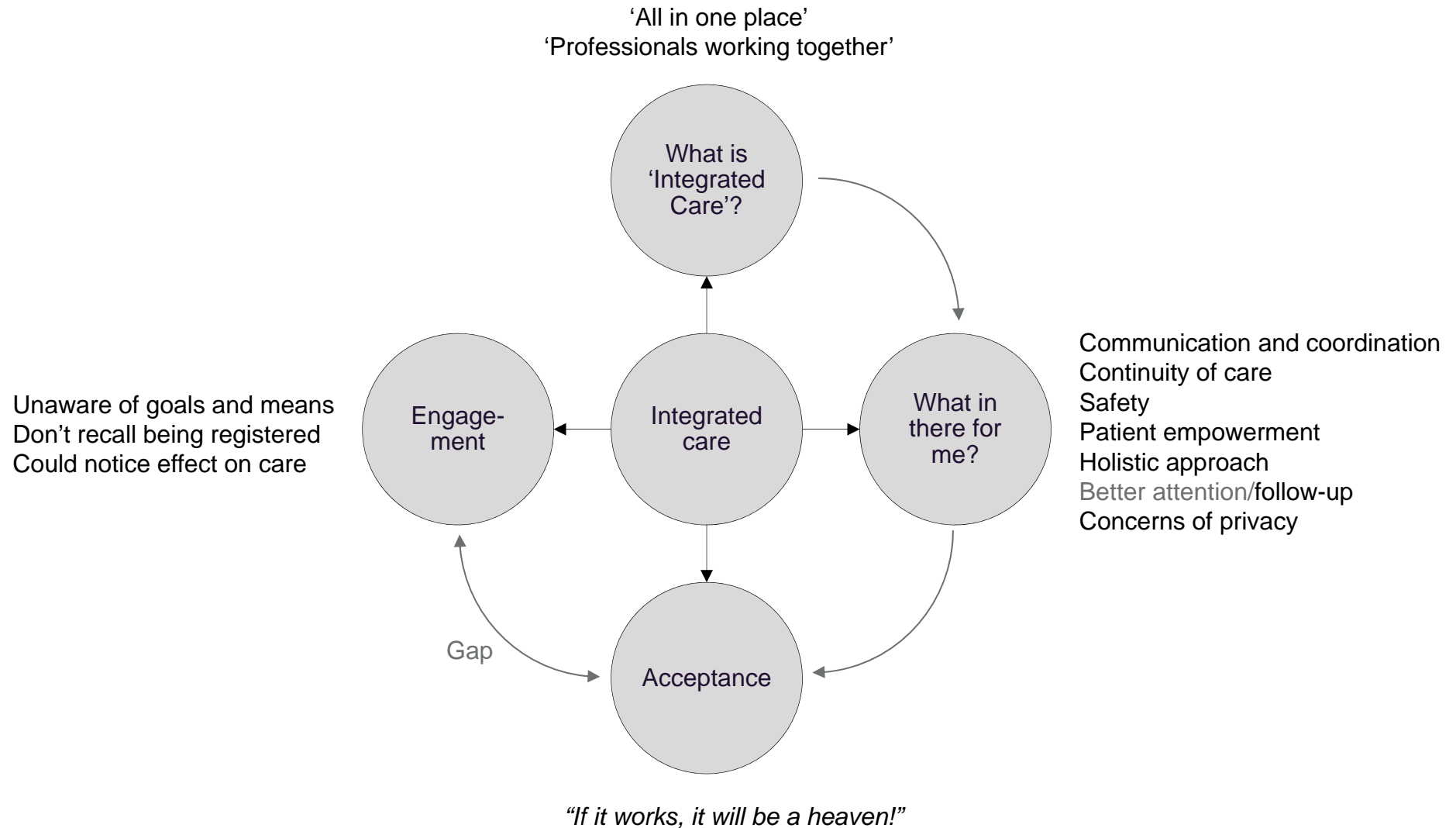
### Space

- Feeling 'seen' and heard
- Unrushed visit to be able to tell their story
- Acknowledged as a unique, equal, respected, whole person
- Being authentically, warmly and compassionately cared
- Being heeded.

### Translucence

- Feeling invisible, unheard, unimportant, ignored, patronized, overlooked
- Feeling treated as a set of clinical symptoms instead of a whole person
- A 'number' instead of a named person
- Feeling rushed;
- Feeling that providers do not really care about them;
- Can't see the same clinician overtime.

## Patient narratives on integrated care





We asked them about integrated care, but they talked about person-centredness!

*“...Because when you come it’s pleasant. They **speak** to you and talk to you and **they ask** you what your problems are and then **the doctor is the same**. She takes a little time and that she’s very sweet, goes through all **your things very carefully**, and that’s what I want.”.*

*“I think the bureaucracy of the National Health booking system needs an overhaul...if they were able to give you more information at the time **instead of leaving you for months not knowing what’s happening...** I mean, when I’ve been getting treatment it’s been first class. It’s just the lack of... **It’s infuriating, because you get so fed up with them you want to scream at them sometimes: **Wake up, wake up! It’s me! It’s my life!*****

## Towards person-centered integrated care: integrating the patient into integrated care

- Patients welcomed integrated care
- Patients within the context of integrated care, as in other contexts, strive to have their own unique physical and emotional 'space' to be 'seen' and heard.
- Integrated care models can benefit from incorporating person-centeredness as a core element.
- Initiatives are now taken to involve patients in the co-design process of the ICP's successor, the Whole-System Integrated Care pioneer.

Thank you for listening!

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