

A patient-reported measure of care coordination: experience from England

Ruth Thorlby, Nuffield Trust

**Jenny King, Picker Europe, Veena Raleigh
King's Fund, Nick Goodwin, International
Foundation for Integrated Care, Don Redding,
National Voices**

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Patient Engagement: What is it? Why does it matter? How is it done?

October 3, 2014

Outline of presentation

- Why is a patient reported measure of care coordination needed in England?
- Description of policy context since 2010 in health and social care in England
- Process of developing survey tool
- Reflections on the challenges of delivering and measuring the implementation of whole person, coordinated care

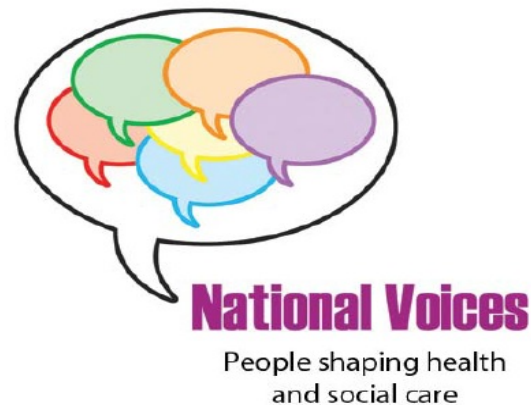
What are we talking about? Integration?



‘Integration is today what waiting times were a decade ago – the challenge that defines modern healthcare’

Jeremy Hunt, Secretary of State for Health, 2014

Or coordinated care?



**A narrative for person-centred
coordinated ('integrated') care**

www.nationalvoices.org.uk

@NVTweeting

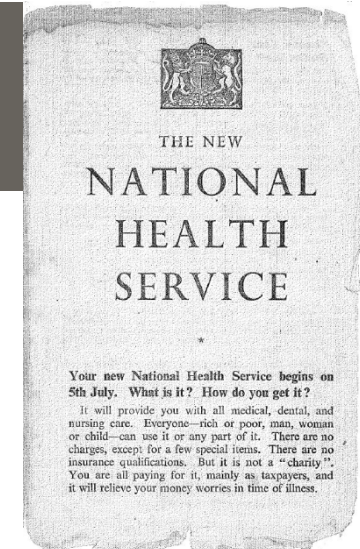
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‘Integrated care means ‘person centred coordinated care’ ’

National Voices, 2012

A bit of background (1)

- Health (NHS) and social care set up separately in 1948.
NHS: universal, free at the point of use, organised by Department of Health
- Social care: means tested and organised through local government since 1948
- Integration: within NHS services and between NHS and social care, a policy ‘priority’ since 1980s. Excellent local examples existed (Torbay), but they are unusual.
- 2010: incoming coalition government publishes “[a] challenging and far reaching set of reforms” in *Equity and Excellence: Liberating the NHS*



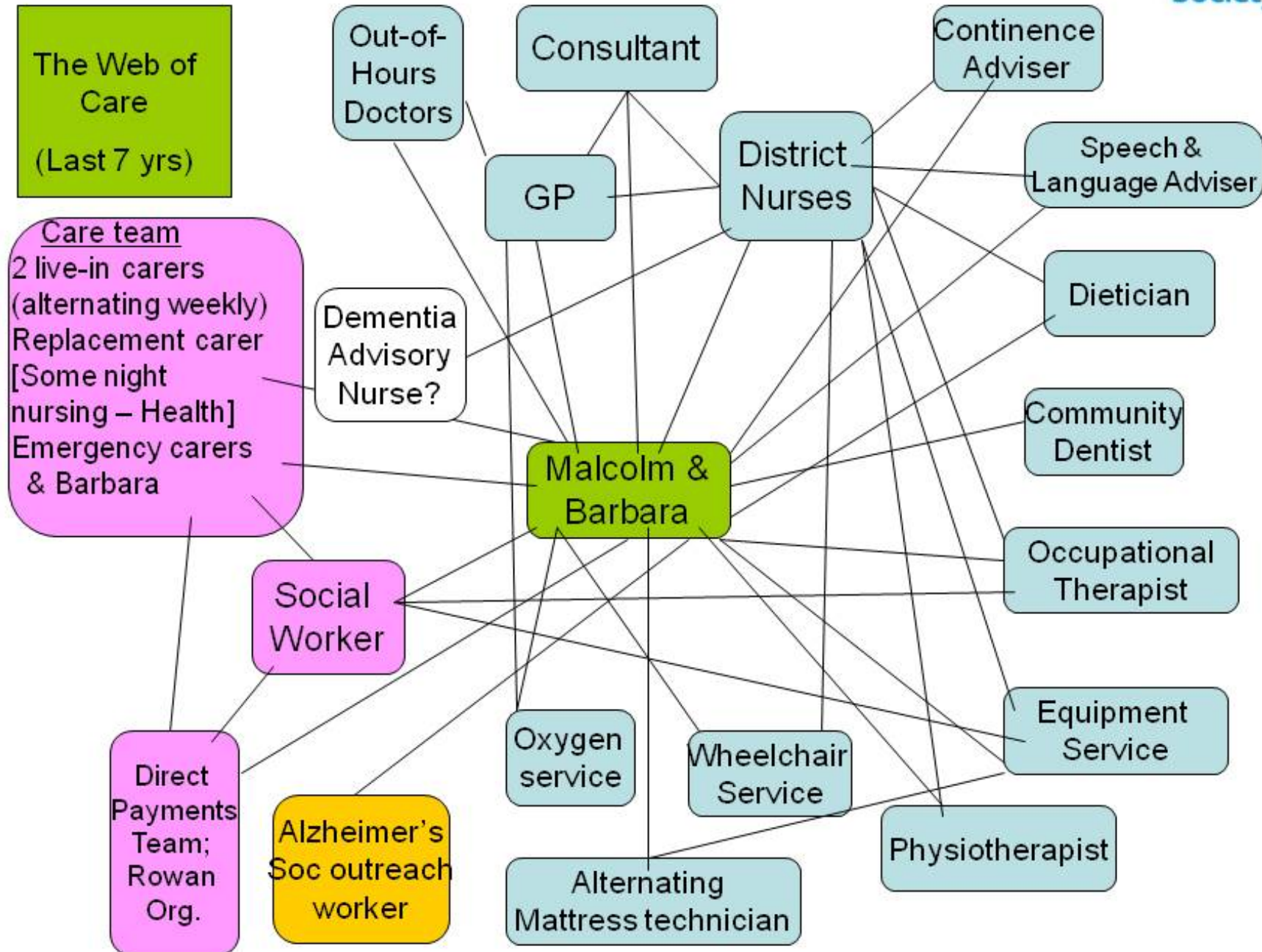
11 & 12 GEO. 6. *National Assistance Act, 1948.* Ch. 29.



CHAPTER 29.

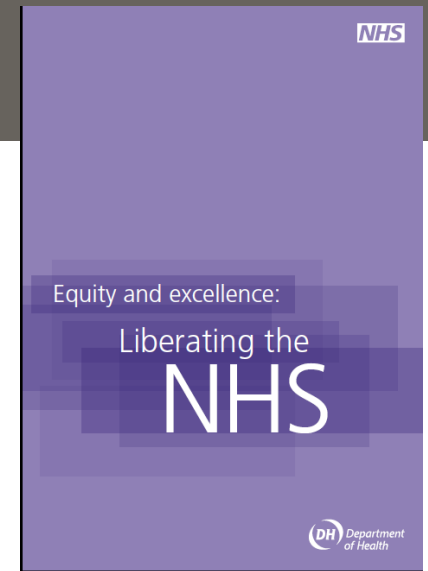
An Act to terminate the existing poor law and to provide in lieu thereof for the assistance of persons in need by the National Assistance Board and by local authorities; to make further provision for the welfare of disabled, sick, aged and other persons and for regulating homes for disabled and aged persons and charities for disabled persons; to amend the law relating to non-contributory old age pensions; to make provision as to the burial or cremation of deceased persons; and for purposes connected with the matters aforesaid.

[13th May 1948.]



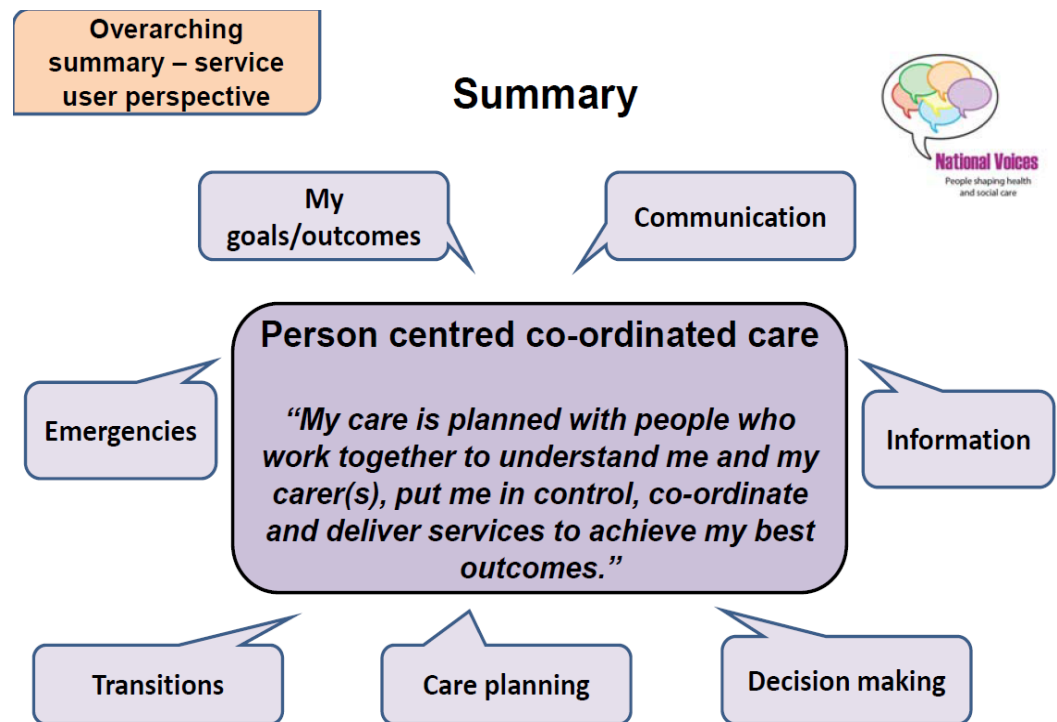
Background (2): confusion sets in..?

- Unprecedented ‘pause’ to legislative process due to outcry over the proposed bill
- ‘Future Forum’ review body proposes much heavier focus on ‘integration’ as a counterbalance to competition in the Bill and recommends a ‘common definition’ of what integration means.
- Resulting Act passed in 2012 has multiple duties to promote ‘integration’ across multiple new bodies
- National Voices, a coalition of health and care charities, commissioned to generate a workable definition of integration (175 definitions found in literature)



Background (3): arriving at a user-generated definition of 'integration'

- 2011 'Narrative' published, with 'I Statements'
- 'Narrative' is based on the statements that patients and service users could make *if* the care they experienced was person centred and coordinated.
- Based on extensive engagement with patients and patient organisations



Example of I Statements: communication domain

C. Generic 'I' statements



Communication

I was always kept informed about what the next steps would be.

→ The professionals involved with me talked to each other. I could see that they worked as a team.

I always knew who was the main person in charge of my care.

I had one first point of contact. They understood both me and my condition(s). I could go to them with questions at any time.

That person helped me to get other services and help, and to put everything together.

→ But: many of these are not straightforward to measure!

Context to our project

- Local examples of integration are evolving fast, using a wide variety of home grown measures and indicators
- New funding: 14 'Pioneers' and £3.8bn 'Better Care Fund' (2015/16)
- Meanwhile, NHS England and Department of Health have been scrambling to develop a national indicator of 'people's experience of integrated care': still under development!
- Our project :
 - Nuffield Trust, National Voices, Picker Europe, IFIC, King's Fund
 - Funded by Aetna Foundation \$250K, 18 months, finishing July 2015
 - Aim: to produce a patient reported measure of care coordination
 - Testing amongst over 65s, at least one chronic condition, England
 - Purpose: quality improvement (will also be of interest to policy makers and regulators)

Methods

- Focus groups with users (over 65), stakeholders (GPs, hospital and local authority providers)
- Access to National Voices' latest work with 'older people's narrative' based on in-depth interviews with 75 older people
- Literature review, including policy and organisational documents from local projects/innovation
- Expert advisory group, with international academic experts
- Cognitive testing n=30
- Piloting: paper questionnaire to approximately 3,000 older people with one chronic condition, accessed via GP lists in 3-4 areas in England, including mix of ethnic groups and income distribution

What we've learned so far

- Definitions and language are problematic: 'integration', 'care co-ordination', 'continuity', 'care transitions' are all specifically defined in the literature, but challenging to translate into a survey
- Roots of this work are in England's policy landscape but it is vital to have questions which can be mapped onto meaningful concepts from the academic research: eg varieties of continuity: relational, management and informational continuity (Haggerty et al 2013) and across the 'lived experience' of patients/users, eg normal care at home, planned transitions in care and unplanned/emergency care
- Whose perspective is paramount? Debate about whether older people's definition (from National Voices work) about non-medical goals/outcomes should come before specific questions about service use

The I statements

Independence

- I am recognised for what I can do rather than making assumptions about what I cannot
- I am supported to be independent
- I can do activities that are important to me
- Where appropriate, my family are recognised as being key to my independence and quality of life

Community interactions

- I can maintain social contact as much as I want

I'm still me

... a narrative for co-ordinated support for older people

Care and support

- I can build relationships with people who support me
- I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me
- Taken together, my care and support help me live the life I want to the best of my ability

Decision making

- I can make my own decisions, with advice and support from family, friends or professionals if I want it

Current questionnaire status

39 questions, organised under headings:

- Your health and wellbeing
- Managing your health day to day
- Support from social services
- Planned care
- Urgent care
- Hospital care

+ standard demographic questions: age, gender, ethnicity, health status

Cognitive testing example: 1

To what extent do you agree or disagree with the following statement...

'Health and care staff bring together services that help me to achieve the outcomes important to me'

1 Strongly agree

2 Agree

3 Neither agree nor disagree

4 Disagree

Findings: people generally understood this concept:

'Co-ordinating - left hand knows what the right hand is doing - what should happen in an ideal world'

'Quite often the person treating you doesn't know what is going on: A doesn't know, B doesn't know and C doesn't care'

Cognitive testing: example 2

In the past year, has there been a time when health and care staff failed to share important information about your medical history or care (such as test results) with each other?

- 1 Yes, once
- 2 Yes, two or three times
- 3 Yes, more than three times

'Don't know - not aware that they have - so unless something goes wrong/if they haven't done it then how would you know?'

'You wouldn't know this happened until you find out later when something happened'

'This has never happened to me. I am not sure I would know if it did. You don't know what they don't share with you until something has gone wrong'

Enduring challenges in implementing integrated care

“The ever-increasing hospitalisation of older people is no answer to the ageing society. Bringing social care in doesn't add to the financial burden. It's the key to unlocking the money”



Andy Burnham MP, Shadow Secretary of State for Health

Concluding thoughts

- Rising hospital admissions is ‘policy problem number one’ in England
- Current ‘integration’ policies aim to reduce emergency hospital use, but there is still a lack of clarity about what is driving the rise in admissions.
- Poor coordination may be the cause in some cases, but there could also be social care-related admissions (not enough services) and primary-care related admissions (not enough staff, diagnostic or other capacity issues, or lack of confidence/skills in treating people at home).
- Our survey aims to be a starting point in helping local providers to diagnose problems with coordination and other contextual factors amongst vulnerable patients, but is not a substitute for patient and carer engagement
- ‘Whole person care’ in England will likely require more public funding as well as ‘integration’ and a radical shift in culture and behaviour amongst health professionals

Coordinated care requires willpower and courage

‘Month after month we sat and listened as our patients catalogued problems that could have been prevented or managed, that had significantly impacted on their quality of life. We saw patients that were three years on from their period of critical illness who had lived with undiagnosed post-traumatic stress disorder. Our patients had had relationships that had completely broken down, jobs that they had lost and financial hardship. We had patients that came back to clinic and just cried. It was heart wrenching’

Excerpt from Northumbria NHS Trust Quality Accounts 2013/14 on Rehabilitation after Critical Illness project (RaCI)

Thank you

October 9, 2014



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ruth.thorlby@nuffieldtrust.org.uk