Capturing the views of patients and carers about their experiences of care co-ordination

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The **highest quality** health and social care for all, *always*
Why is it important to measure people’s experiences of co-ordinated care?

What should be measured?

How can people’s perspectives of co-ordinated care be measured?
Why is it important to measure people’s experiences of co-ordinated care?
“to measure is to know” & “if you cannot measure it, you cannot improve it”\(^1\)

We must see “through the patient’s eyes”\(^2\)

We must “put patients at the heart of healthcare”\(^3\)

“Patient experience is the most powerful lever [for choice and quality] and will be used for service improvement”\(^4\)

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1: Lord Kelvin, 1883  
2: Gerteis, M., 1993  
3. NHS Plan, 2001  
4: Lord Darzi, 2008
Patient experience is related to…

- Better staff experience
- Higher clinical effectiveness & better patient safety
- Lower complication rates
- Reduced likelihood of adverse drug events
- But also distinct:
  - “Although there are associations between clinical quality and measures of patient experience, the 2 domains … remain predominately distinct”

3 Black, N. (2014). Relationship between patient reported experience (PREMs) and patient reported outcomes (PROMs) in elective surgery. *BMJ Qual Saf, 23*(7), 534.
As populations age and the prevalence of chronic ill health rises worldwide, it is becoming crucial to improve the coordination of care. Many older people with chronic conditions often receive poor care because of the disjointed way in which services are delivered to them.

Individual providers collect substantial amounts of data on the outcomes and experiences of patients and users who access individual services, but there is an absence of information about what happens when people receive services across organizational boundaries from multiple providers.

The way care is provided is changing. For example, sustainability and transformation plans (STPs) - place based systems of care.

It is only patients, carers and their families who fully understand and experience the reality of fragmented services.
But...understanding how people experience care co-ordination can be difficult due to the many different services and staff interacted with.
“Too often patients experience gaps in service provision, failures in communication, and poor transitions between services”

My care experience
# My care experience

<table>
<thead>
<tr>
<th>Touchpoints</th>
<th>Tuesday 29th</th>
<th>Wednesday 30th</th>
<th>Thursday 31st</th>
<th>Friday 1st</th>
<th>January</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>Ear plug stuck in ear</td>
<td>No phone call</td>
<td>No phone call. Removed ear plug myself</td>
<td>No phone call</td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>GP appointment</td>
<td>GP appointment for infected ear</td>
<td>GP appointment for infected ear</td>
<td>GP appointment for infected ear</td>
<td></td>
</tr>
<tr>
<td>Minor Injuries Unit</td>
<td>Trip to the minor injuries unit. Referred to ENT with promise of a phone call to confirm appointment for Thursday or Friday</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
<td>Letter from ENT for appointment in March</td>
<td></td>
</tr>
</tbody>
</table>
Joan’s care experience
# Joan’s care experience

<table>
<thead>
<tr>
<th>Touchpoints</th>
<th>October</th>
<th>November</th>
<th>December</th>
<th>January</th>
<th>February</th>
<th>March</th>
<th>April</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home</strong></td>
<td>Fall at home</td>
<td></td>
<td>Allowed home, cared for by family</td>
<td></td>
<td>Fall at home. Out of hours doctor called</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ambulance</strong></td>
<td>Paramedics called</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Hospital</strong></td>
<td>8 hours spent in A&amp;E. Admitted as an inpatient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care home</strong></td>
<td>Short term rehabilitation in a care home by local authority</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Ambulance service report care home to CQC**
- **Admitted as an inpatient**
- **Family find a care home for temporary care**
- **Fall at care home**
What should be measured?
A Soul Doctor and a Jazz Singer

We need to measure what matters but what does matter…

“What would be a good day for you?”

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. https://www.youtube.com/watch?v=Dnnu43Zt-oA
I’m still me.
...a narrative for coordinated support for older people
Person-centred coordinated care

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.
Narrative for person centred coordinated care…

- My goals / outcomes
- Information
- Transitions
- Communication
- Decision making
- Community Interactions
- Care and support
- Care planning
- Independence
I am recognised for what I can do rather than assumptions being made 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.
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.

I can build relationships with people who support me.

Taken together, my care and support help me live the life I want to the best of my ability.
I tell my story once.

I always know who is coordinating my care.

I am listened to about what works for me, in my life.

I am always kept informed about what the next steps will be.
Joan’s person centred coordinated care…
How people’s perspectives of co-ordinated care can be measured
Experiences of care co-ordination are difficult to capture, and there are limited tools out there to help providers to do so
HOW?

- Observation
- Focus groups
- Social media
- Comment cards
- Kiosk surveys
- Walking the floor
- Public meetings
- Patient stories
- Hand-out surveys
- Telephone surveys
- Postal surveys
- Feedback websites
- Hand-held surveys
- SMS surveys
- Online surveys
What are the most important criteria to consider?

- **Cost** such as money, time, resources

- **Data quality** such as response rates, item completion, coverage of what is important

- **Representativeness** such as sampling – who can be reached?
<table>
<thead>
<tr>
<th>Survey Type</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Postal Survey</td>
<td>• Can collect high volumes of data at an acceptable cost</td>
<td>• Not suitable for those with very low literacy</td>
</tr>
<tr>
<td></td>
<td>• No interviewer – respondents may be more willing to share information</td>
<td>• Not suitable for non-English speakers unless language known in advance or translation service available</td>
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<tr>
<td></td>
<td></td>
<td>• Data entry (manual or scanned) takes time</td>
</tr>
<tr>
<td>Online Survey</td>
<td>• Low costs</td>
<td>• Requires internet access and computer knowledge</td>
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<tr>
<td></td>
<td>• Allows for complex routing</td>
<td>• Requires list of email addresses or invitation to go to a website</td>
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<tr>
<td></td>
<td>• Data entry is automatic allowing for rapid turnaround of results</td>
<td></td>
</tr>
<tr>
<td>Face to face interview</td>
<td>• Can produce richer, more detailed data</td>
<td>• Expensive</td>
</tr>
<tr>
<td></td>
<td>• Allows respondents to express themselves in their own words</td>
<td>• Interviewers must be trained</td>
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<tr>
<td></td>
<td></td>
<td>• Problem of interviewer bias</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Transcribing and data analysis is time-consuming</td>
</tr>
</tbody>
</table>
Postal surveys
DH - Options appraisal on the measurement of people’s experiences of integrated care

Aetna Foundation - Developing a patient reported measure of care coordination

CQC - Building bridges, breaking barriers

DH - Developing measures of people’s self-reported experiences of integrated care
Aim: to assess strategies for measuring people's experience of integrated care.

Consultations with stakeholders from across the NHS and social care sectors. Analysis of selected literature and data sources.

Findings:

- Support for the National Voices ‘Narrative’, namely that integrated care needs to be viewed from the perspective of the person using services.
- Strong demand for indicator(s) capable of driving or informing service improvement, not just to measure performance from the centre.
- A view that indicator(s) should avoid measuring integrated care just from the perspective of one organisation or service type, but explore transitions where care crosses boundaries, within and between health and social care services.
- A good degree of consensus about what kinds of users/patients might be prioritised, including younger and older people with disabilities and long term conditions.
Findings continued:

- **Pragmatism** around the cost and time constraints involved in developing and introducing a new indicator(s), and realism about likely coverage.

- **No single data source** or measure was suitable for measuring user experience of integrated care.

- Good opportunities to establish some baseline indicator(s) in a timely and cost-effective way by **adding to existing collections** such as the NHS Inpatients Survey and the GP Patient Survey (GPPS).
Aim: to provide recommendations for a limited set of new questions to be included in up to seven existing national surveys. Such as:

- GP Patient Survey.
- NHS Inpatients Survey.
- VOICES national bereavement survey.

Evidence review, focus groups, survey owners workshop, question development and cognitive testing.

Evidence found provided support for the domains in the National Voices narrative.

18 questions were developed to cover priority statements from the narrative.

The addition of a few of these questions in national surveys will help providers and commissioners to identify, explore, and challenge poorly integrated care locally.

But space is a premium in national surveys.
Four questions the researchers would put forward for use in existing national surveys:

1. Were you involved as much as you wanted to be in decisions about your care and support?
2. Do you know who to contact if you need to ask questions about your condition or treatment?
3. Do you feel this person understands about you and your condition?
4. Do health and social care services help you live the life you want as far as possible?
Building bridges, breaking barriers 2016

- CQC review to improve understanding of how well health and social care and support services work together to meet the needs of older people, and how this affects people’s experiences of care.

- Gathered evidence from a range of sources, undertook site visits (eight areas) and spoke with older people and their carers to understand how integration across services affected their experiences of care.

- Findings:

  - **A lack of consistency** in the use of assessments and in the sharing of information
  
  - **Monitoring and evaluation** of many of the initiatives in place to improve integration within areas was not carried out locally or was insufficient
  
  - **Widespread commitment** to delivering integrated care and a belief that it is improving

- Recommendation – CQC to explore an integrated care survey. This should take into account work being undertaken by CQC in 2016/17 to understand how to survey people’s experiences of integrated care.

Picker
Aim: to design a survey tool to capture the experience of older people with chronic conditions about how effectively their health and social care is coordinated

Survey content largely based on the domains of the National Voices narrative. Questions grouped around three core areas:

- Care in the home environment
- Planned transitions in care
- Unplanned situations/emergency admissions to hospital

Not just experience questions. Inclusion of outcome-based questions focusing on exploring the respondent’s quality of life.

Piloted the tool in England amongst a sample of recent service users of the age of 65 and above, with one or more chronic condition.

Interest in the survey tool at a national level as no similar survey available for performance management or regulatory purposes. However, primary purpose of the survey is to support quality improvement.

The survey will be free to use.
YOUR HEALTH AND WELL-BEING

1. Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members? (Cross ONE only)
   1. Yes, from someone living in my household
   2. Yes, from someone living in another household
   3. Yes, both from someone in my household and another household
   4. No

2. On the whole, are you able to do the activities that are important to you?
   1. Yes, I can do the activities important to me
   2. I have some problems with doing the activities important to me
   3. I am unable to do the activities important to me
   4. Don’t know / not sure

5. 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
   5. Strongly disagree
   6. Not applicable

6. To what extent do you agree or disagree with the following statement…
   ‘I am supported by health and care staff to be as independent as I can be’
   1. Strongly agree
   2. Agree
   3. Neither agree nor disagree
   4. Disagree
   5. Strongly disagree
Next steps

- Picker will continue to test the measure of care co-ordination. We want to know how well it performs with other population groups.

- Make it available for use, free of charge.

- Explore different ways in which it might be used to assist commissioners and providers in improving the quality of their care co-ordination work, enabling them to understand their progress from the perspective of the end user.
Summary

- Understanding how people experience care co-ordination can be difficult.

- But the new NHS landscape means it's increasingly important that we have intelligence on how well services are co-ordinated.

- But who takes ownership of these experiences?

- It is only patients, carers, and their families who fully understand and experience the reality of fragmented services.
Further reading

A Narrative for Person-Centred Coordinated Care -

Options appraisal on the measurement of people’s experiences of integrated care -

Developing measures of people's self-reported experiences of integrated care -

Building bridges, breaking barriers -

Developing a User Reported Measure of Care Co-ordination -
http://www.ijic.org/articles/10.5334/ijic.2469/
Discussion

- Experiences of care co-ordination
- Views on what matters
- How have you measured experiences