Personalisation: Towards evidence that counts symposium

Thursday 22 March 2018
1) Welcome and introductions

Fiona Glen
(Programme director, NICE)
and
Clenton Farquharson
(Chair TLAP Programme Board)
Why we are here.....

• National Audit Office (2016): Personalised commissioning in adult social care:
  • improve the evidence on, and understanding of, the relationship between the different ways to commission personalised services for users, and improvements in user outcomes

• Think Local Act Partnership (2017): Gathering the evidence; Making personal budgets work for all
  • Use existing evidence more
  • Take forward development through co-production
  • Share what works
  • Develop a long term strategy for building the evidence base
Why we are here.....

• Present key findings and recommendations from TLAP’s report

• Consider the main gaps in the evidence base for personalisation and how these might be addressed

• Explain the role and remit of NICE in developing evidence-based guidelines and identifying research priorities

• Consider current research funding and priorities on personalisation

• Identify future priorities for research and evaluation on personalisation

• Explore how these research priorities could be taken forward as funded research
Not everything that counts can be counted, and not everything that can be counted counts.
We're just starting to plan our evaluation. Which methods should we consider?

All of them.
The NICE approach to evidence

What is evidence and how do we use it?

Peter O’Neill – Technical Adviser - Centre for Guidelines

22nd March 2018
Role and remit of NICE

• NICE established in 1999 to reduce variation in the availability and quality of NHS care and end the ‘postcode lottery’ of healthcare in England.

• In 2013 we took on responsibility for developing guidance and quality standards in social care

• NICE is one of seven What Works Centres nationally with a remit to improve the use of evidence in public sector decision-making

• NICE portfolio in 2018 comprises:
NICE guidelines

• Are sets of evidence based recommendations
• Based on evidence of effectiveness and cost-effectiveness
• Cover a wide range of topics: clinical, public health and social care
• Are not mandatory, but intended to guide practice
Social care guidelines
• Guidelines cover a range of topic areas across the health and social care interface and child and adult services – examples of published social care guidelines are:

• Managing medicines in care homes (2014)
• Home care (2015)
• Social care for older people with multiple long-term conditions (2015)
• Transition between inpatient hospital settings and community or care home settings for adults with social care needs (2015)
• Transition between inpatient mental health settings & community or care home settings (2016)
• Intermediate care including reablement (2017)
• People's experience in adult social care services: improving the experience of care for people using adult social care services (Feb 2018)
Social care guidelines in development

- Learning disability and behaviour that challenges - service guidance (publication March 2018)
- Care and support of older people with learning disabilities (publication April 2018)
- Decision-making and mental capacity (publication May 2018)
- Supporting adult carers (consultation February 2019, publication July 2019)
Future social care guidelines

• New topics referred include:

  • Adults with hearing and visual impairment
  • Adults with complex needs: social work interventions
  • Safeguarding adults in care homes
  • Supporting independent living and preventing isolation in adults of working age
  • Advocacy for adults with health and social care needs
### Examples of recommendations on personalisation

<table>
<thead>
<tr>
<th>Guideline</th>
<th>Recommendation(s)</th>
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<tbody>
<tr>
<td>Home care</td>
<td>Give people who use or who are planning to use home care services and their carers details of different funding mechanisms including self-funding and the options available for people with personal budgets and support to manage them. Examples of funding mechanisms include having a managed budget, an individual service fund or direct payment.</td>
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<tr>
<td>Older people with social care needs and multiple long-term conditions</td>
<td>Support carers to explore the possible benefits of personal budgets and direct payments, and how they might be used for themselves and for the person they care for. Offer the carer help to administer their budget so that their ability to support the person's care or their own health problems are not undermined by anxiety about managing the process.</td>
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| Intermediate care including reablement              | Ensure that intermediate care practitioners:  
  - develop goals in a collaborative way that optimises independence and wellbeing  
  - adopt a person-centred approach, taking into account cultural differences and preferences. |
Overview of evidence process

- Recommendations
- Evidence review
- Evidence search
- Review questions
Types of study / evidence
# Best available evidence

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<tr>
<th>Type of question</th>
<th>Evidence</th>
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<tr>
<td>Effectiveness question</td>
<td>Experimental studies with control group – e.g. RCTs</td>
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| Cost-effectiveness question (Value for money) | Economic evaluations  
De novo (new) modelling maybe required |
| Views and experiences                    | Qualitative evidence                                                    |
| Service delivery (e.g. in social care)   | Range of evidence including surveys, audits and evaluations              |
Options when evidence is limited

<table>
<thead>
<tr>
<th>Option</th>
<th>Key points of note</th>
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<tbody>
<tr>
<td>Expert testimony</td>
<td>• Frequently used in social care and public health</td>
</tr>
<tr>
<td>Consensus recommendations</td>
<td>• Frequently used in social care and public health</td>
</tr>
<tr>
<td></td>
<td>• Generally informal consensus (not formal e.g. Delphi)</td>
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<tr>
<td>Research recommendations</td>
<td>• Research recommendations are important to address gaps in evidence</td>
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Taking forward social care research

- Role and importance of good research in health care is widely understood and recognised.
- Established systems and processes are in place for identifying and funding research priorities.
- NICE has arrangements to engage with key funders of healthcare and ensure that research recommendations made in NICE guidelines are taken forward as a priority.
- In the social care guidelines published so far we have made 53 research recommendations.
- We have worked to develop similar arrangements for engaging with funders of SC research.
- We hope NICE SC research recommendations can be a key driver for more and better research in SC.
NICE and the NIHR

• All research recommendations made in NICE guidelines are disseminated to the NIHR
• NICE works with the relevant NIHR programmes to identify the priority research recommendations
• A number of NICE research recommendations from clinical and public health guidelines have resulted in the commissioning of studies / trials to address key gaps in evidence
• For social care calls for evidence from the NIHR have gone out on:
  ➢ Transition child to adult services - What is the most effective way of supporting care leavers in transition from children’s to adults’ health services?
  ➢ Child abuse and neglect - What interventions are effective and cost effective in improving the wellbeing of children and young people who have experienced online-facilitated abuse, including grooming online?
• A call for evidence is also scheduled to go out on:
  ➢ Child abuse and neglect - What interventions are effective and cost effective in improving the wellbeing of young people aged 12 to 17 who have experienced abuse or neglect, including those who are now in temporary or permanent alternative care placements or living independently?
# Research recommendations on personalisation

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<td>People's experience in adult social care services</td>
<td>What approaches have been shown to work in supporting the co-production of research for the purposes of service improvement with people who use services?</td>
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<tr>
<td>Home care</td>
<td>What is the most effective and cost effective way to support people with dementia living at home?</td>
</tr>
<tr>
<td>Older people with social care needs and multiple long-term conditions</td>
<td>What is the most effective and cost-effective way of supporting older people with social care needs and multiple long-term conditions in care homes to live as independently as possible?</td>
</tr>
<tr>
<td>Transition from children's to adults' services</td>
<td>What is the most effective way to help carers and practitioners support young people's independence?</td>
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Any questions?
Personalisation: *towards evidence that counts*

Gathering the Evidence for Personal Budgets: Making Personal Budgets Work for All

Alex Fox OBE, CEO Shared Lives Plus & TLAP Programme Board Member
Background

- The NAO report found a lack of evidence for personal budgets
- Response from TLAP as convenor of the care and support sector
- July 2017, Gathering the Evidence: Making Personal Budgets Work for All
- Key messages, framework for analysis, gaps in the current evidence, conclusions, and recommendations
Key Messages

- Personal budgets are part of a wider system of change
- Requires a plurality of approaches to ‘evidence gathering’
- Centrality of people with lived experience (what matters most)
Towards Evidence That Counts
Aims and Objectives

- A longer term strategy: coherent, sustainable and proportionate
- Focus on what works for whom, in what circumstances and why.
- Concentrate on the ‘big’ questions e.g. personalisation and wellbeing?
Towards Evidence That Counts

Approaches

- Avoid the ‘evidence trap’ where innovation stalls through a perceived lack of evidence
- Uphold rigour but accept and use of multiple methods so we can ‘innovate the evidence’
- People as active participants in design and conduct of research
Annex

Gaps in the Evidence

• **Outcomes and experience** - Current statutory collections focus on activity, rather than outcomes & experience

• **Personal budgets and wellbeing** - Little evidence on the effect of personal budgets on wellbeing, despite central to the Care Act 2014.

• **Understanding personal budgets** - Understanding how PBs (and the mechanisms around them) can be made to work better for all, particularly older people where the evidence is less strong at present.
  - Including the vital part played by well delivered (and received) information, advice and support
  - How personal budgets meet equality objectives
Gaps continued

• **Market supply and innovation** - In the context of the market shaping duty in the Care Act, there is a need to better understand the relationship and interaction between individuals receiving care and support and supply and innovation in the market, including the role of local commissioning. This should extend to the role of councils in creating the conditions for people to directly commission their own care and support, including when they choose to pool their budgets and collectively commission.

• **NHS and council commissioning** - Not enough known about how personalised approaches can be consistently implemented in services directly commissioned by councils and the NHS.

• **Personal budget and personalisation** - Understanding the relationship between PBs budgets and the rest of personalisation, particularly the spread of strengths-based approaches and building community capacity (social capital) in the context of wider whole system change. Concerning the latter, the field of understanding change in complex systems is still emergent.
Gaps continued

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- **Co-production** - The role and impact of co-production with people with lived experience, including carers.
5) Research/Evidence

Fiona Glen
(Programme director, NICE)
5) Research/Evidence

Building on the Gathering the Evidence report:

• What are the key questions on personalisation that need to be answered through research and evidence?

• What are the barriers and facilitators to collecting evidence and undertaking research to answer these questions - and what are the solutions?

• Identify the top three priorities for research and evidence
6) Future priorities

Professor Martin Knapp
(Professor in Social Policy, London School of Economics and Political Science)
7) Close and next steps

Fiona Glen
(Programme director, NICE)

and

Clenton Farquharson
(Chair TLAP Programme Board)
Data hackathon...