

## **NICE / TLAP Symposium**

### **Personalisation: towards evidence that counts**

22 March 2018

#### **1. Introduction**

The National Institute for Health and Care Excellence (NICE) and Think Local Act Personal Partnership (TLAP) held a symposium in March 2018 to develop a shared understanding of the gaps in evidence about what works in personalisation, how these could be addressed, and potential future research priorities. The half-day symposium brought together nearly 50 people from a range of key stakeholders, including people with lived experience, national organisations, academic research institutions and social care research funders (Appendix 1).

The event was organised as one of the recommendations in TLAP's report (2017) ['Gathering the Evidence: Making Personal Budgets Work for All'](#) (2017), which was a response to the National Audit Office report (2016) 'Personalised commissioning in adult social care'.

#### **2. Presentations**

The symposium was chaired by Clenton Farquharson, Chair of TLAP Programme Board, and Dr Fiona Glen, from NICE's Centre for Guidelines. Presentations are available from this email address: [SocialCare@nice.org.uk](mailto:SocialCare@nice.org.uk):

- The NICE approach to evidence – Peter O'Neill, NICE
- Gathering the Evidence for Personal Budgets: Making Personal Budgets Work for All – Alex Fox OBE, Shared Lives Plus and TLAP Programme Board Member
- NIHR School for Social Care Research: activities and priorities March 2018 – Professor Martin Knapp, NIHR SSCR, LSE

#### **3. Discussion and priorities for research**

Five groups discussed future research priorities to address the main gaps in the evidence base for personalisation, and the barriers and potential solutions to collecting evidence. This paper summarises the key points.

## **4. Future priorities for research on personalisation**

### **4.1 Wellbeing and what matters to people and their families**

It was suggested many of the participants that any research should focus on what matters to people and their families – what makes people happy and improves their wellbeing, and what the components of wellbeing are. Researchers need to look at the individual's experience but also identify what can be generalised to other groups of people.

### **4.2 Research on the whole system of care and support**

All the groups highlighted the importance of any research looking at the whole system of care and support around a person, rather than focussing on how best to meet specific needs. Particular aspects discussed included:

- The role of social networks and community capacity in supporting people (in relation to personalisation and more generally).
- The broader mechanisms for sustaining personalised care and support, including how best to support people using personal budgets
- The skills, knowledge, competencies and attitudes to risk of health and social care staff – in particular commissioners - which are needed to support personalisation.
- The effectiveness of small-scale solutions to support personalisation was highlighted as important by some groups.
- The role of leadership and the influence that leaders have in the health and social care system was also considered as an area where more research is needed.

### **4.3 Prevention and maintaining independence and wellbeing**

Prevention of the need for social care and support, and the maintenance of independence and wellbeing were seen by all the groups as really important areas where there are gaps in the evidence base. However, it was suggested that prevention is a difficult area to carry out research, at least in part because the health and social care system undergoes change on a frequent basis. Any research in these areas would need to look at the wider costs of unmet needs, as many people do not receive a service until a crisis occurs. It was also suggested that research is needed to investigate the preventative benefits of personalised care and support, particularly identifying the changes over long periods and reducing long-term reliance on care and support services.

### **4.4 Specific groups of people where more research is needed**

A number of groups agreed that personalisation is different for different population groups, and that research needs to respond to this. In particular researchers shouldn't just focus on people who have local authority-funded social care and support; it is important that research considers self-funders and person-centred care and support. Older people and people with more complex needs were felt to be groups where more research on support for personalisation is needed. One group discussed a gap in the evidence around personalisation in care homes.

## **5. Methods**

A number of groups emphasised that specific types of research are needed. In particular it was suggested that there is a need for longitudinal studies which can capture the long-term picture, as it was recognised that personalisation does not happen quickly. Such research would need to understand people's journeys over the long term and as they move through different experiences, including points of transition. The value of comparative studies were emphasised, and one group suggested that learning from international experience is important. Participatory research and involving the community as researchers were suggested by one group as important approaches.

Some groups considered the relevance of theory. One group emphasised that there is a need to develop a conceptual framework of personalisation, to provide clarity about what is meant by personalisation and the different aspects included. This should be co-produced through a coalition of researchers, people who use services and others. It was suggested that this should include logic modelling.

Some participants raised the importance of addressing barriers to understanding the relevance of both quantitative and qualitative evidence, and the value of carrying out both types of research.

There were a number of suggestions around the need for better use of existing data around personalisation, including the collecting, sharing and interpreting data. There was a suggestion that the use of generic indicators such as the ONS4 wellbeing measure could be added to other measures, and used much more widely, including at an intervention level.

## **6. Addressing barriers and enablers for research and evidence in personalisation**

### **6.1 Accessing people to take part in research studies**

Several groups discussed the importance of access to people who use social care services to carry out social care research. The importance of local authorities here was discussed, and the need for researchers to recognise the constraints local authorities work under. Data protection and the new General Data Protection Requirement was discussed as an additional barrier to carrying out research, and the need to find ways to be able to share information more broadly.

There was a suggestion that researchers should explore new ways of gaining access to people through social care providers and voluntary and community organisations, although the difficulty of recruiting people living in care homes was raised by some participants. Gaining access to self-funders was discussed by several groups as a key area, which requires more innovative methods such as making use of social media to recruit participants. There was also some discussion about the challenge of research ensuring people are representative of people with care and support needs.

It was suggested that researchers need to be clearer about the benefits of taking part in research and develop an offer of feedback and support for putting research into practice to encourage local authorities and others to take part. The potential role of national bodies in helping to bridge the gap between researchers and local authorities was emphasised.

## **6.2 Co-production of research**

All of the groups emphasised the importance of research being co-produced and involving all relevant stakeholders – people, practitioners, commissioners, providers and researchers. The need for a real partnership between local authorities (and other stakeholders) and the research community was discussed and emphasised, along with the importance of involving the frontline workforce. This will help ensure that research can take place, and that the research findings will have impact and can be fed back into practice.

## **6.3 Social care research community**

A number of groups highlighted that the social care research community is very fragmented. It was felt that there is a need to support development of this community, such as through promotion of the NIHR social care research blog site. A lack of funding and infrastructure for social care research and complex research governance were raised as barriers by some participants.

## **7. Sharing of research findings and getting evidence into practice**

Participants commented that there is a need for coordination of research findings so that practitioners can more easily find the messages coming out of research on personalisation. It was suggested that coordination between research bodies could facilitate this to support better sharing of research findings.

There needs to be thought given to how research can bring about culture-change and how researchers can support the use of evidence in practice to bring about change. One possibility might be to present research in different ways, such as through the use of videos aimed at practitioners. It was suggested that there is evidence on getting research into practice which shows that coproduction is effective.

## 8. How do we take this forward?

The plenary discussion explored the ideas above in more detail, and also discussed how these suggestions could be taken forward.

- It was agreed that the research priorities discussed during the session will be shared with the main social care research funders, for consideration in development of their research priorities. This will in particular include the National Institute for Health Research (NIHR), which in addition to the NIHR School for Social Care Research has a wider focus on social care research, and the Economic and Social Research Council (ESRC), which is expanding its social care research funding.
- The priorities identified for research on personalisation will also be shared with the Department for Health and Social Care, and in particular fed into the adult social care green paper consultation
- NICE is looking at how real-world data could be used in answering some of the issues raised during the discussion. This will be taken forward through a data hackathon, and participants at the symposium were invited to get involved.

## Appendix – List of attendees

Organisation	Name
Association of Directors of Adult Social Services (ADASS)	Mark Hill
Age UK	Joel Lewis
Alzheimer's Society	Ian McCreath
Alzheimer's Society	Zoe Campbell
Carers UK	Dame Philippa Russell
Centre for Disability Research, Lancaster University	Professor Chris Hatton
Coalition for Collaborative Care (C4CC)	Anna Severwright
Coalition for Collaborative Care (C4CC)	Catherine Wilton
Community Catalysts	Sian Lockwood
Creative Minds, South West Yorkshire Partnership NHS Foundation Trust	Debs Taylor
Creative Minds, South West Yorkshire Partnership NHS Foundation Trust	Phil Walters
Disability Rights UK	Sue Bott
Economic and Social Research Council (ESRC)	Naomi Beaumont
Institute of Local Government Studies, University of Birmingham	Catherine Mangan
King's College London	Dr Martin Stevens
Lincolnshire County Council	Chris Erskine
Local Government Association (LGA)	Brigid Day
London School of Economics and Political Science	Professor Martin Knapp
London School of Hygiene & Tropical Medicine	Stefanie Ettelt
Mencap	Zac Taylor
National Audit Office	Dr Andy Whittingham
National Co-production Advisory Group (NCAG)	Caroline Waugh
National Co-production Advisory Group (NCAG)	Rachel Mason
National Development Team for Inclusion (NDTi)	Anna Marriott
NHS Digital	Mark Nicholas
NHS England	Martin Cattermole
National Institute for Health and Care Excellence (NICE)	Dr Fiona Glen
National Institute for Health and Care Excellence (NICE)	Hayley Collman
National Institute for Health and Care Excellence (NICE)	Holly Irwin
National Institute for Health and Care Excellence (NICE)	Jane Silvester
National Institute for Health and Care Excellence (NICE)	Peter O'Neill
People's Voice Media	Gary Copitch
Policy Evaluation and Research Unit, Manchester Metropolitan University	Professor Chris Fox
Research in Practice for Adults	Katy Shorten
Shared Lives Plus	Alex Fox
Skills for Care	Marie Lovell
Social Care Institute for Excellence (SCIE)	Susanne Gibson
Social Care Workforce Research Unit (SCWRU), King's College London	Dr John Woolham
Think Local Act Personal (TLAP)	Caroline Speirs
Think Local Act Personal (TLAP)	Catriona Duncan-Rees
Think Local Act Personal (TLAP)	Clenton Farquharson

Think Local Act Personal (TLAP)	Tim Parkin
University of Central Lancashire	Professor David Morris
University of Huddersfield	Professor Barry Percy-Smith
Voluntary Organisations Disability Group	Robin McGhee