

The Future of Self Management: A Four Nations Summit

Monday 2 October 2017

LEARNING REPORT



**Self
Management
Summit**



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

50 people from across the four nations of the United Kingdom gathered in Edinburgh on 2 October 2017 to consider the future of self management. The summit, organised by the Health and Social Care Alliance Scotland (the ALLIANCE) brought together

a collective of leaders to consider what collaboration across the UK's four health and social care systems can teach us about "what needs to be done in order that everyone is able to self manage on their own terms?"

By self management, the ALLIANCE means ensuring people are in the driving seat of their health and wellbeing, recognising that everyone has strengths, skills and experience that support their health and wellbeing and enable them to manage the impact of their long term condition(s) or caring role. At the heart of self management is a collaborative relationship between people and those involved in their care and support, to make sure the person feels empowered to live and die well on their terms.


Change the balance of power


Derek Feeley, Chief Executive of the Institute for Healthcare Improvement (IHI), and formerly Chief Executive of NHS Scotland chaired the summit. He established from the outset that the summit should be a forum to drive and capture bold thinking and ideas to support the whole system

change that is needed in health and social care to ensure people are able to live and die well on their terms. For the IHI, this starts with changing the balance of power to co-produce health and wellbeing in partnership with people, families and communities.


Setting the scene across the four nations


Representatives from each nation described the context within which they are working and the enablers and barriers to change as they saw them.

 **In Scotland** Self management has been a core driver of reform in health and social care led by people living with long term conditions. This was set in motion through the co-production of 'Gaun Yersel', the Self Management Strategy for Scotland, which involved people living with long term conditions, coordinated by the ALLIANCE, working together with the Scottish Government. Capacity building in Scotland's communities and third sector has been important in driving learning and change so far.

 **In England** There have been some policy advances from a self management perspective, such as the statutory regulations on care and support planning. Yet self management or co-production are not highly visible, despite major reform in health and social care since 2012. Person centred coordinated care is part of NHS England's Five Year Forward View, and yet self management as a concept has not broken through. Instead, the concept of self-care has had greater impact and this means people knowing and making lifestyle choices that avoid them from needing medical intervention. Whilst it

feels that quite a lot is happening despite the policy environment, the lack of national direction leads to disconnection.

 **In Wales** The Social Services and Wellbeing Act and the Wellbeing and Future Generations Act are helping to drive change in Wales. The 4 principles of prudent healthcare, proposed by the Bevan Commission, have been endorsed by the Welsh Government and establish principally that health and wellbeing should be achieved with the public, patients and professionals "as equal partners through co-production".

 **In Northern Ireland** Long Term Conditions Alliance Northern Ireland has been pushing for policy recognition of self management. The Long Term Conditions Policy Framework published in 2012 referred to self management and ensuring people have the knowledge and skills to enhance or maintain their health and wellbeing. The third sector in Northern Ireland has been successful at working together to push this agenda forward, and yet whilst self management was included in the last Programme for Government, there was no investment or resource committed.

What are we learning about whole system change?

Lost in translation?

Across all four systems there is too wide a gap between policy and implementation. Having enabling policy helps to create a common purpose and can help create the conditions for action. However, the policy process gives insufficient attention to how it will be implemented and the interaction with other policies. It is too often left to the local context to make sense of the policy coming down from governments.

Learning at the event centred around people's experience of implementation with three broad themes emerging:

- 1 The importance of achieving buy-in
- 2 Developing and sharing ideas
- 3 Having a plan and method for implementation

1 The importance of achieving buy-in

Whilst influencing policy is important, of equal importance is the attention we give to establishing a bottom up movement of support along with local champions who are committed to helping drive the change – efforts that help to socialise the concept of self management and build the will for change to happen.

We need to create the conditions that support people's interpretation of what self management means – for people living with long term conditions, their families, our communities, staff working in health and social care and policy makers. This may be different dependent on the perspectives within

the system. People collectively described the power of stories in changing attitudes – that stories can win people's hearts and minds particularly when they describe the benefits of self management. Gathering and hearing such stories will be an important way of raising awareness and achieving buy-in.

People talked about self management as a way of life: something that is integral to everyone's approach to health and wellbeing and not just when people are living with a long term condition. This led to discussions about the societal change that is needed, and moving away from self management being seen as a mechanism for reducing services and support.



One idea that emerged was to jointly develop a set of self management affirmation cards that could be used: to raise public awareness of self management; by health and social care staff for inspiration to care for their wellbeing; as well as being a reminder for health and social care staff of the role they can play in supporting self management.

There are good examples of where people have been supported to be champions of this change.

Bevan Advocates are members of the public in Wales who offer their perspective on services, health, wellbeing and illness, as well as creating conversations to bring about change. Bevan Advocates influence and support the Bevan Commission in its work, offering insights in to the real 'lived experience' of healthcare and health services and feedback on the Commission's thinking as it develops. They help to influence the wider public through dialogue and discussion, promoting wider conversations around prudent healthcare and the Well-being of Future Generations Act (Wales) 2015 with its focus on prevention, collaboration, involvement and thinking for the long term.

The Future of Self Management:



2 Developing and sharing ideas

People spent the day sharing examples of their work to develop support for self management and ways they are working to change the system to embed self management.

We need to explore and identify the values and principles of self management that we want to embed and spread. We need people to be able to come

forward with their ideas for developing support for self management and spreading these ideas. This involves having the time and space to think through challenges rather than reacting to them. It involves enabling risk taking – utilising the resources we have available for this to happen - recognising that there is learning when things don't work that needs shared too.

The **House of Care** provides a useful framing narrative for the sharing of our ideas – placing an emphasis on each of the parts of 'the House' that must be strong to support the conversation at the centre. This includes the 'more than medicine' formal and informal supports which comprise the foundation of the house, and the required resource allocation for such supports. The aim of Scotland's House of Care is that the person is in the driving seat of their care and support, with self management at the heart.

The Self Management Fund for Scotland invests £2 million annually in projects led by third sector organisations that support self management. Since 2009, the Fund has supported over 240 projects and has broadened and enriched understanding of self management in Scotland. The range of projects and initiatives supported through the Fund have all demonstrated the power of co-production in action, the focus on the person at the centre is key to the success of each project individually and of the projects collectively. **"The Self Management Fund was the best investment I ever made. It put the power where it ought to be"** said Derek Feeley.

A Four Nations Summit

2 Oct 2017



Every year, **the ALLIANCE** hosts the Self Management Awards which celebrate the people and work taking place to develop self management in Scotland. This includes a “self management champion of the year” award which recognises the people who are helping to spread the important message of self management within communities and help to make change happen.

Self Management ‘My Condition, My Terms, My Life’ Champions are people living with long term conditions who share their story of self management to help raise awareness with the wider public without stigma or any associated blame.

3 Having a plan and method for implementation

...that builds upon the previous two themes and ideas we generate, then actively seeks to apply and spread this across the health and social care system.

The human and relational aspects need to be at the forefront of whole system change towards self management. This is about changing culture. We need to create a learning environment for this change

that requires people to look inwards, at their own experiences, and bring this into their practice and the professional standards. Equally important is ensuring that we share good practice about supporting health and social care staff to care for their wellbeing so they are more able to offer support and advice to the people they work with.

The Welsh Health and Social Services Minister asked the Social Services Improvement Agency - now **Social Care Wales** – to explore how the views of people could influence and be incorporated and recorded into real time practice and service delivery; *what difference do people feel we are making to their overall wellbeing?* The legislation driving this piece of work is the Social Services & Well-being (Wales) Act. Following a pilot of 18 months, statutory guidance was developed between the pilot councils and Welsh Government policy colleagues.

The shift identified was the need to see the sector as a whole (health and social care), and to consider the wider wellbeing of individuals rather than solely their presenting problems. Case studies clearly show how having different conversations with people help both professional and client reach a better understanding of what is needed to support and move things forward. It is not always about a care package or medical intervention. The sector needs to have support to further develop its skills in this area and Social Care Wales has put this agenda at the heart of its work for the next 5 years. Cultural shift of this significance takes time, commitment and energy.

Self Management UK has been working with healthcare professionals since 2008, one programme being 'having meaningful conversations'. Self Management UK believe that by applying supportive communication skills, approaching each person as an individual, by understanding the different life circumstances they face, and using tools and skills -this can help to motivate people to consider positive changes and make informed choices when developing their care and support plan.

Midlothian Health and Social Care Partnership has made a commitment to reduce inequalities, increase self management and peer support, integrate services, increase the focus on prevention and early intervention and embrace a partnership approach through the development of their House of Care collaborative with NHS Lothian and the Thistle Foundation.

To do this, the wider workforce is being supported to explore new approaches, learn new skills, and introduce 'good conversations' and care and support planning to their practice. There is formal training, seminars, workshops and networking opportunities for agencies to build working relationships together.

Networks are the answer to scale and spread

We need an intentional way of sharing ideas. Building networks across traditional boundaries and taking an asset based approach must underpin the work we spread.

Currently valuable learning is being lost – particularly cross-sector learning. This is not about which sector or organisation we come from, but how we go about designing and delivering our services and support.

Ideas will come from diversity and sharing our learning. Now is not the time for competition. We will need to ask 'what are you prepared to give up in order to achieve the outcomes?'

Developing strong relationships and ways of collaborating across our traditional networks and boundaries is ubiquitous to our collective learning about successful ways to change culture.

The Me, Myself and I Club started out by bringing together a group of older people, carers, social work practitioners and staff to consider how to develop relationship-centred short breaks and provided an opportunity for peer support. They have used the rich learning they have generated to influence services and policies that affect the lives of people with dementia by becoming a member of the **Dementia Engagement and Empowerment Project (DEEP)**. This is a national network which brings together groups of people with dementia from across the UK and supports them to try to change services and policies that affect the lives of people with dementia.

Self Management Network Scotland brings together people with an interest in self management to share learning and experience in order to influence positive change to the health and social care landscape. In 2017 Self Management Network Scotland reached the milestone of 500 members across Scotland, with members based in each Health and Social Care Partnership area. Involving people with lived experience of self management as equal contributors has been shown to support a different type of learning and practice to emerge.

Targets are hopeless for solving complex problems

We need to be clear about the role of evidence in this change process; having 'stronger' evidence is not always going to lead to better implementation.

Rather, evidence is only useful if it answers questions appropriate to this relational, personal outcomes

focused policy and practice context we are working in. We need a methodology that can gather, analyse and use the type of evidence relevant to this. Delegates described a bridge that is needed between quality improvement methods and research evidence.

From the point of diagnosis of rheumatoid arthritis, through the many and varied disease and life stages, good support accompanies the traditional treatment 'pathway'. Alongside the rheumatology team and access to websites, helplines and an online community, **National Rheumatoid Arthritis Society (NRAS)** offer the option of three targeted face to face interventions: two short workshops and a 6 week self management programme.

These face to face interventions are structured to respond to the differing stages depending on each person's needs and circumstances. The intention is that everyone newly diagnosed is able to attend the initial workshop with the option to access the other two depending if and when they choose. NRAS has gathered evidence that each of the three interventions is effective in itself, and are beginning to see incremental benefit for people moving from the first to second workshop but currently have been able to gather limited evidence on which to base a full 'pathway' evaluation as yet. Part of the problem they have encountered is the lack of commissioning to enable better evidence to be collected.

With support from Healthcare Improvement Scotland and NHS National Services Scotland, practitioners and managers from **Midlothian Wellbeing Service** worked to develop an evaluation framework using a theory based approach to evaluation informed by Contribution Analysis. This involved working collaboratively to identify what success looks like for people who use the service. Health economists have also been involved to evaluate impact on health service (primary and secondary care) utilisation. Feedback from people who have engaged in the service, from GPs, family members and other practitioners has been very positive.

Looking to the future

The collaboration on the day demonstrated the value of a network approach that is UK wide to ensure we build on this learning. Our experience of implementing self management in order that people can live and die well on their terms shows the need for this UK wide network to focus on:

- **The importance of achieving buy-in – raising public awareness and making the case for change**
- **Developing and sharing ideas – what does self management mean in practice and how do we support this?**
- **Having a plan and method for implementation – focusing on the human and relational aspects underpinning self management principles and approaches that help us to evidence this**

There was a sense of ambition and shared purpose in the room which is captured by the following statements for the future.



About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. It brings together over 2,100 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.



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