Developing the Long Term Conditions Outcomes Strategy

Summary of accelerated design event – 14th and 15th March 2012

Introduction

1. The Department of Health (DH) is leading on the development of a cross-government Long Term Conditions (LTC) Outcomes Strategy

2. The strategy will consider how people with LTCs, their local networks, voluntary sector, local authorities and Government departments can work together to help prevent LTCs where possible, delay their onset, and provide support at the appropriate times and places in their lives so that if they do develop a LTC they will enjoy more positive outcomes. The strategy is expected to be published towards the end of 2012, and will not be subject to a formal consultation.

3. The DH commissioned the NHS Institute for Innovation and Improvement to facilitate an Accelerated Design Event to inform the development of the outcomes strategy

4. The Accelerated Design Event was held at the Holiday Inn, Bloomsbury in London on 14th and 15th of March. Over 140 people attended over the two day period.

5. This note summarises the key outputs from this event, and outlines next steps.

Key Themes – day one

6. Day one was occupied with a ‘scan’ phase – identifying the most important areas and themes for action. Delegates were placed into groups and identified the key themes for each of the below life stages:
   a. Starting well
   b. Developing well
   c. Living well
   d. Working well
   e. Ageing well
   f. Dying well

7. Following this exercise, the following cross-cutting themes emerged strongly:
   a. All services to be designed with people at their heart.
   b. Joint decision making to be promoted, and people should be treated as experts in their own care; consider new ways of making voices heard
   c. The impact on wider family and carers must be considered at every stage
   d. People need the right information, in the right way – whether this is about prevention, managing their conditions, or getting on with other aspects of their lives

   e. Transitions between all life stages, between stages of a condition, and between services should be seamless, and based around the needs of the person
   f. The need for the wider determinants of health and wellbeing to be considered, addressed and included when planning care – non-medical support can be more important than medical interventions
   g. Inequalities (between areas, backgrounds and conditions) should be identified and tackled
   h. Incentives and money flows must be aligned with desired outcomes in all parts of the system – personal budgets to be explored where relevant

8. These cross-cutting themes were then phrased as provocations to stimulate discussion on day two
   a. **Integration** – why is this so hard to achieve, or is it?
   b. **Information**, from the perspective of someone with an LTC – "it's my data and information not yours, so why can't you trust me with it"
   c. **Transitions –** why should we have to push through boundaries the system creates?
   d. **Technology and self-management –** services aren't keeping up with modern technologies that could improve my life
   e. **£=change** – how do we line up money and incentives in the system to improve outcomes for people with LTCs?
   f. Its **more than just health and social care** – we can't let housing, transport, education etc off the hook
   g. **Out of sight, out of commissioning 'mind'** – commissioners often don't see much of rare conditions or minority groups – how do we ensure they are well catered for?
   h. **Person centred planning and support** – how about I invite your professional expertise into my care planning?
   i. **Prevention** – What can we do to prevent LTCs, slow onset, or prevent crises for those people who have a LTC?
   j. **Self-limiting assumptions** – too often much of the system (users and providers of support) seem to have such low expectations of what is possible.

Key Themes – day two

9. Day two focused on identifying the key barriers to and opportunities for change in the areas outlined above, as well as specific areas for action

10. Some key barriers included:
    a. Protectionism by clinicians – fear of handing over data to patient, fear or pooling budgets or working closely with other organisations
    b. Disagreements over budgets, who pays for what, and money flows
    c. Stigma, culture, attitudes and behaviours
    d. Lack of understanding or education

    e. Financial and other incentives looking at short term results, not longer term improvements

11. Some key opportunities included
    a. Advocacy and empowering individuals
    b. Let the money follow the person
    c. Greater data sharing and access
    d. Designing locally-based integrated services, which include more than just health and social care. Health and wellbeing boards may help promote this
    e. Spreading what works well

12. Key action points included:
    a. Personalised care plans to be the norm – covering all aspects of care
    b. Individuals to have ownership of all their data, and data to be shared more widely between organisations
    c. Third sector, NHS, and other public services to collaborate to produce quality-assured information on conditions
    d. Awareness raising, education and training for professionals in all fields where relevant
    e. Cooperation to provide and commission locally based integrated services, based around individuals' needs. There should be a true partnership between service users (and representative groups) and clinical commissioners in commissioning services
    f. Health and wellbeing boards take responsibility for implementing the LTC Outcomes Strategy, through effective, active localised needs assessment
    g. Design consistent measurement systems with local accountability which enable us to know whether people with long term conditions are living the lives they want
    h. Timely access to appropriate information and advocacy that enables the person to exercise choice and control wherever they are
    i. Incentivise health professionals to work with people so they feel supported and confident to manage their conditions
    j. If person is not diagnosed within 12 weeks they have a right to an urgent referral to speciality diagnostic service

13. And finally, the ambitious aims which delegates came up with were:
    a. Group 1 - Integration
        i. By 2020 all the information I need will be one click away
    b. Group 2 - Information from the perspective of someone with an LTC
        i. By 2020 15 million people in control at last!
    c. Group 3 - Transitions
        i. By 2020 Joe public takes control
    d. Group 4 - Technology and self-management
        i. By 2020 the UK will be the world leader in transforming lives though technology

e. Group 5 - £=Change
    i. 90% of people will be able to manage their lives
f. Group 6 - Its more than just about health and social care
    i. By 2020 Long term conditions – everybody's business
g. Group 7 - Out of sight, out of the commissioning 'mind'
    i. By 2020 everyone with an LTC has got an accurate diagnosis and access to appropriate commissioned services
h. Group 8 - Person centred planning and support
    i. By 2020 Person with LTC forgets they have LTC
i. Group 9 - Prevention
    i. By 2020 staying well, more self-care, less care
j. Group 10 - Self-limiting assumptions
    i. By 2020 100% in living well index since 2012

Next Steps

14. This accelerated design event marked the beginning of the engagement process for the LTC outcomes strategy. We will soon be setting up an online home for the strategy where all relevant information will be gathered, and where people will be able to feed into the strategy as it develops. Information on this will follow once it is operational.

15. We aim to publish the strategy towards the end of 2012

16. Any immediate queries about the event, or the strategy, should be directed to Rebecca Molyneux (rebecca.molyneux@dh.gsi.gov.uk)