INTEGRATED CARE Bridging the gap: person centred, place-based self-management support

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Placing the person at the centre of their health and care has been a key part of health and care policy for nearly 2 decades. Fundamental to this approach is the role self-management support plays in increasing the confidence, skills and knowledge of a person in manging their health and wellbeing. This practical review article sets out to explore the historical context of self-management in England, its current status and the challenges faced in delivering self-management programmes. The demand on the health and care system continues to grow and so the need to move to a more holistic system of care with the person at its centre is greater than it has ever been before. With an increasingly fiscally restricted environment with which to operate, how can commissioners, health specialists and service providers work together to develop integrated pathways of care that provide the right care, at the right time and in the right place.

KEYWORDS: Self-management, long-term conditions, chronic conditions, sustainability, commissioning

Introduction

Self-management supports a person to have the knowledge, skills and confidence to manage their condition(s) effectively in their everyday life. Originally championed by the voluntary sector, self-management has been available in England since the 1990's, see Fig 1.

The Department of Health (DH) introduced the Chronic Disease Self-Management Programme (CDSMP,) the core programme of the Expert Patients Programme (EPP), into the NHS in 2002. Originating from Stanford University, California, the CDSMP is a generic group self-management programme which aims to give people the skills, confidence and knowledge to better manage their condition on a day-to-day basis and improve their quality of life.

Since the 1990's health policy has increasingly placed emphasis on putting the patient at the centre of their own healthcare and in 1999 the EPP was introduced to help people with long-term conditions maintain their health. In 2002 the initial launch of the EPP was delivered, with the EPP Community Interest Company

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(CIC) (subsequently becoming Self Management UK, a registered charity in 2014) established as the vehicle for delivering the programme.

Building the foundation

Politically the spotlight on self-care and self-management has intensified, with both now being at the centre of more recent policy including the NHS 'Five Year Forward View', 5 where communities are engaged and proactive in deciding how local services are run and delivered. The idea of the engaged citizen is as important as the engaged patient if poor health and inequality are to be tackled effectively.

Most recently the NHS England funded 'Realising the Value' programme set out to establish the steps that need to be taken to deliver the NHS Five Year Forward View vision of a model of care where people and communities are at the centre of health and wellbeing. ⁶ Within this programme of work was the recognition of the role that group self-management education has in achieving this

The structure of health and social care services is changing to reflect the growing demand on health services nationally. A core element to this change is the creation of 'integrated care' models addressing often fragmented services and delivering 'personcentred care' approaches.

This is seen as an enabler in a movement towards a model of care that incorporates the knowledge and experience of patients while ensuring a shared vision exists between those financing, planning and coordinating care. In delivering integrated systems of care, NHS England has recommended Clinical Commissioning Groups (CCG) commission and deliver services based on the 'House of care' model. The model places personcentred care approaches at its centre with a stable structure of clinical, organisational and community support surrounding it. Self-management is one of the key enablers within the model, supported by commissioning.

At the 'House of care' model's centre is the provision of care and support planning. Despite this, only 3% of patients with one or more long-term condition report having a care plan. Although guidance exists for commissioners and practitioners in how to develop care plans, there is no explicit guidance on where the responsibility lies. Any health and social care practitioner can develop a care plan in partnership with the individual, including GPs and social care practitioners but its existence often relies on the patient to manage the communication of their plan across

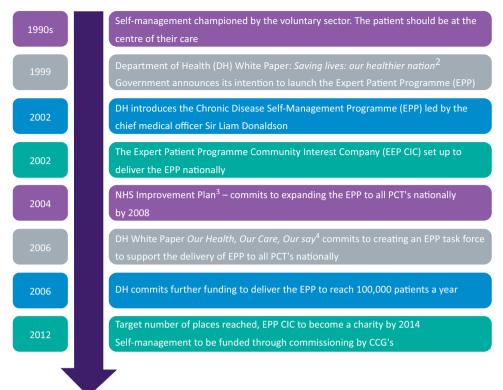


Fig 1. A timeline of the introduction of self-management structured education in England.

PCT = primary care trust

multidisciplined pathways of care, while ensuring health and care practitioners are accurately updating their records.

Increasing the number of patients with a care plan, developed as a shared decision-making process, would provide a framework for the provision of self-management interventions, enabling commissioners to effectively place self-management within a pathway of care.

According to plan?

The evidence supporting the effectiveness of self-management is clear ¹⁰ and effective self-management is seen as an important tool in managing population demands of increasing levels and complexity of long-term conditions. ¹¹ Despite the growing evidence in support of the benefits of effective self-management and its inclusion as a key policy item, fundamental challenges exist in achieving the aims set out in the original NHS Improvement Plan and DH White Paper *Our health, our care, our say: a new direction for community services,* whereby self-management interventions would be available nationally to patients with one or more long-term condition.

Considerable progress has been made in the provision of structured education of those diagnosed with type 1 or 2 diabetes but self-management support for other conditions can be seen as a 'like to have' not a 'must have' health care intervention. 12 Crucially, the National Institute for Health and Care Excellence (NICE) issued guidance for the provision of diabetes structured education in addition to establishing the Quality Outcomes Framework (QOF) indicators for commissioners and providers. 13 Despite the existence of a NICE framework, The National Diabetes

Audit indicates that although 77% of patients were referred to attend a structured education programme during 2015–16,¹⁴ only 7.1% of those referred, attended, although it is acknowledged within the audit that there may be inaccuracies in the recording of attendance data.

While progress has been made in the provision of structured self-management education for diabetes, the provision of support for those experiencing other long-term conditions is inconsistent and lacks sufficient scale to tackle the problem it was designed to address. Although the policy environment is clear in its aims for self-management, it is less clear within local commissioning as to how self-management support should be implemented.

Self Management UK, the successor organisation to the EPP CIC believes a national strategy is required, taking the foundation that the Realising the Value Programme⁶ has provided while providing a framework for embedding self-management interventions within integrated care pathways.

'Guan yersel!' is a phrase used to 'cheer a person on as they embark on a challenge'. It is also the title of 'The Self Management Strategy for Long Term Conditions in Scotland'. ¹⁵ Although in its 10th year of publication, the strategy is a critical part of the Scottish Government's Quality Strategy, which sets out a 2020 Vision for a 'safe, effective and person-centred health service'. ¹⁶

The provision of group self-management support nationally is complex with a wide range of self-management programmes and providers on offer. A national strategy would start to address a lack of consensus nationally as to what 'good looks like' while learning from existing programmes of self-management support such as that of Self Management UK and its national generic

and conditions-specific programmes, Dr Oliver Hart, GP partner at Sloan Medical Practice Sheffield, and Dr Saul Berkowitz, clinical director of the Royal London Hospital for Integrated Medicine, all pioneers in delivering programmes of person-centred care and self-management support.

Self Management UK is one of the only national providers of self-management support in England but coproduces its programmes with the communities it supports, commissioners, general practitioners and clinicians. This approach comes from a need to ensure that its self-management programmes are tailored to and meet the needs of the communities it serves while meeting the appropriate rigour and scrutiny required by its commissioning and clinical partners.

The 'House of care' model's requirement of the right organisational and supporting processes encourages multidisciplinary approaches to the design of local infrastructures allowing for an integrated approach between the person, community, primary care, social care, voluntary and community sector providers. Taking this approach ensures effective buy in from across the local health system and community, allowing for a more efficient referral management process while making sure those populations who would benefit the most, are able to access the self-management support provided.

Often the support available for a person with multiple long-term conditions is fragmented. This makes it hard for the person involved to access the right support at the right time while also presenting challenge to health and care professionals to refer a person to services on offer.

Social prescribing was set up to provide a mechanism to improve the referral to and coordination of community-based support, although its provision nationally mirrors that of self-management and is inconsistent from one area to another. Despite this, social prescribing offers an effective port of call for those looking to access, and those wishing to refer a person to, self-management programmes.

The inclusion of self-management in the national policy agenda should be supported by a widely recognised evaluation framework which allows for the assessment of reductions in unplanned Accident and Emergency (A&E) admissions, better medicines management and unplanned GP appointments.

While many research papers and evaluations have highlighted the personal benefits and better patient outcomes that attending a self-management course can provide, the economic benefits for the NHS and commissioners have not always been so clear. This has led to claims that self-management interventions are not a cost-effective use of resources as they do not have a clear impact on health service use.

Although evidence demonstrating return on investment (ROI) exists, ^{17–22} there is a growing trend towards such ROI to be demonstrated within a 12-month period. A measurable ROI is a necessary part of ensuring the best possible value for money in an increasingly financially restricted environment, but the longer term benefit of better self-management is too often ignored and as a result, so is the person. There must be space for the person's experience and the impact self-management support has had on the person particularly through their quality of life, aspirations and goals.

Currently there is no national consensus on the indicators, with the exception of diabetes, that should be used to measure the effectiveness of the self-management activities offered. Doing so would provide insight to commissioners, policy makers and providers alike and establish widely recognised examples of best practice. Self Management UK works with commissioners to, where possible, fully assess the impact of the self-management support on offer, including the identification of reductions in unplanned A&E admissions and GP appointments, but this approach is not widely recognised or accepted.

Attempts have been made to address the need for a widely recognised outcomes measure with the implementation of the Insignia Health and NHS England supported Patient Activation Measure (PAM)²³ currently being delivered across 50 CCG sites nationally. The PAM survey assesses a person's level of knowledge, skills and confidence in managing their own health and care. It is a significant step forward in creating a widely accepted model for evaluating the effectiveness of support for those with one or more long-term condition, although its use as an outcomes assessment tool for interventions alone denies the full impact the tool can have, particularly where the interventions being measured do not offer the support to increase an individual's level of activation.

It is clear that fundamental challenges exist in delivering widespread provision of self-management support. Guidance exists for design and delivery of self-management interventions, particularly the recommendations set out in National Health Service England's (NHSE) *Realising the value* programme⁶ and the Health Foundations *A practical guide to self-management support.*¹ Both provide valuable guidance for commissioners and providers in the provision of self-management interventions but there is currently very little evidence to suggest the guidance and recommendations are being implemented at meaningful scale nationally.

The future

Long-term conditions continue to place an exceptionally high level of demand on the health and care system nationally. Recently it is estimated that 27.2% of the UK population have two or more long-term health conditions, ²⁴ with multimorbidity increasingly becoming a more widely used indicator of health service demand rather than type of condition. ²⁵ Those populations experiencing socioeconomic barriers demonstrate higher levels of multimorbidity in addition to a greater severity of condition than those living in greater affluence. ²⁵

The benefit that supported self-management can provide to a person's skills, knowledge and confidence in managing their long-term condition and its impact on the wider health and care system has been recognised in national health policy for almost 2 decades and yet the provision of self-management nationally is at insufficient scale and adoption to address the challenges faced. NICE guidance and QOF indicators exist for the provision of structured self-management education for diabetes but this needs to be expanded to incorporate self-management support for other long-term conditions to accompany the independent guidance already in place.

At a national level, NHS England has clearly signalled its intent through work streams included within the integrated care models pathway focused on providing a more person-centred approach to health and care. This can be seen clearly through the work of Dr Alf Collins, clinical director for personalised care at NHS England and pioneer in taking new care models forward within the NHS.

Implementing national strategies at a local level is never easy. There are incredibly successful programmes of self-management

support being delivered throughout England but unfortunately very few examples of self-management being embedded within multidiscipline pathways of care. If collectively we are to tackle the growing demand placed on the health and care system by the increasing prevalence of long-term conditions then local providers, commissioners and health and care specialists need to work together to deliver the right infrastructure allowing for the safe, high-quality provision of self-management support that allows for robust evaluation of the impact of the services offered while ensuring that embedded programmes of self-management provide a platform for sustainable support for the populations at greatest need.

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