

# Diabetes self-management in people with severe mental illness

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diabetes is the commonest type of diabetes and accounts for around 90% of cases. This condition typically develops during adulthood, usually in people over the age of 40 years, but younger onset is becoming increasingly common. The disease is characterised by poorly regulated blood glucose levels, which may arise from defects in insulin secretion (insulin deficiency), or in its action (insulin resistance), or both. Therefore, the aim of treatment is to manage blood glucose levels to alleviate short-term symptoms and prevent or delay the development of long-term complications. Raised glucose in the blood, known as hyperglycaemia, can initially be controlled by lifestyle management such as changes to diet and exercise, but given the progressive nature of type 2 diabetes it is likely that most individuals will ultimately require pharmacological intervention as well. This may initially be with oral hypoglycaemic drugs to increase the production or uptake of insulin and, if the disease remains uncontrolled, insulin therapy.

People with a severe mental illness (SMI), such as schizophrenia and bipolar disorder, are a vulnerable population who commonly experience health inequalities (Thornicroft, 2011); they have poorer physical health and die on average 10-15 years younger than people without SMI (Chang et al., 2011). Prominent amongst these physical health problems is an almost two-fold risk of developing diabetes compared with the general population (Osborn et al., 2008). This increased risk has been attributed to the effects of anti-psychotic medications, pathophysiology of SMI and lifestyle factors, such as poor diet, obesity and physical inactivity (Osborn et al., 2008; De Hert M. et al., 2009); and high rates of smoking (Lawrence, Mitrou,

## Background

Diabetes is a common and a serious global health problem, currently affecting an estimated 8.3% of adults - 382 million people worldwide, and taking up 11% of international health expenditure (International Diabetes Federation, 2013). Type 2

& Zubrick, 2009). In people diagnosed with diabetes, those with SMI have been found to have higher mortality (Vinogradova, Coupland, Hippisley-Cox, Whyte, & Penny, 2010) and a greater risk of needing to go to hospital for hypoglycaemia or hyperglycaemia (Becker & Hux, 2011) than people without SMI.

Evidence varies regarding the equity of diabetes care between people with and without SMI. For example, Goldberg et al. (2007) reported that people with SMI are less likely to receive all of the six recommended diabetes health checks than those without SMI. However, two studies in the UK found that much of diabetes management in primary care is similar for those with and without SMI (Mathur, Hull, Boomla, & Robson, 2012; Whyte, Penny, Phelan, Hippisley-Cox, & Majeed, 2007). The study authors did, however, acknowledge that these findings were based on people registered at a GP practice, and those not registered (which could include some with SMI) could be those experiencing poorer care and worse outcomes. The existence of significant health inequalities is nonetheless evident. Mathur et al. (2012) in research conducted in East London, our local population, found that those with SMI and diabetes were more likely to smoke, be obese and less likely to have had retinopathy screening than those without SMI. In addition, less than half of the population with SMI met the glycaemic control target of HbA1c <7.5%.

The World Health Organization (WHO) (2013a) has recognised the important role of mental disorder in contributing to the global burden of non-communicable diseases such as diabetes and has highlighted the need for equitable access to effective programmes and health care interventions for people with mental illness. The WHO mental health action plan for 2013-2020 (WHO, 2013b) states that developing good-quality mental health services requires the use of evidence-based protocols and practices. The plan suggests that health workers must not only deliver interventions that aim to improve mental health, but also attend to the physical health

needs of people with a mental disorder, and vice versa for diabetes health workers. The European Psychiatric Association (EPA), supported by the European Association for the Study of Diabetes (EASD) and the European Society of Cardiology (ESC) has also issued a position statement on cardiovascular disease and diabetes in people with SMI, identifying the need to improve care for this population (De Hert M. et al., 2009).

## Diabetes self-management

In common with other long-term conditions, a crucial part of diabetes care involves the person changing their behaviour and adjusting to the consequences of living with the disease. There is widespread acknowledgement that the management of long-term conditions requires a particular focus on the support and facilitation of self-management approaches within a collaborative patient-clinician relationship. Considering the importance of lifestyle in the management of type 2 diabetes, it is essential that patients possess the necessary skills to manage their condition. In the UK NICE guidelines for type 2 diabetes (National Institute for Health and Clinical Excellence, 2008) recommend that structured education is integrated into routine care and should be offered to all patients. In addition, the NHS report for the commissioning of mental health and diabetes services in the UK (NHS Diabetes, 2011) clearly states that people with SMI who develop diabetes should have access to appropriate diabetes care.

Despite evidence to suggest that diabetes self-management programs have a positive impact on clinical, lifestyle and psychosocial outcomes in the general population (Deakin, McShane, Cade, & Williams, 2005; Pal et al., 2013; Steed, Cooke, & Newman, 2003; Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012; Thorpe et al., 2013), an examination of recent systematic reviews suggests that many trials either exclude those with SMI or do always not specify their inclusion criteria in relation to SMI. In

those that do not exclude on the basis of mental illness, there tends to be no examination of whether a diagnosis of SMI has an impact on the effectiveness of such interventions. Goldberg et al. (2007) found that in the US people with SMI were less likely to receive diabetes education than people without SMI. There is however a lack of data on the proportion of people with diabetes and SMI who are referred for structured diabetes education in Europe. Research does however suggest that in primary care health education is not a common feature of consultations with people with SMI (Reilly et al., 2012), and it is therefore possible that many service users are not given the opportunity to attend such programmes, even if they were effective in this population.

For people with a SMI, physical health may be a low priority (Buhagiar, Parsonage, & Osborn, 2011), motivation to change may be limited, and instability of psychiatric symptoms may present additional challenges for successful diabetes self-management (El-Mallakh, 2006; Ogawa, Miyamoto, & Kawakami, 2011). It cannot therefore be assumed that the findings reported in existing primary research studies or systematic reviews of diabetes self-management interventions will generalise to those with SMI. A systematic review of diabetes self-management interventions for those with schizophrenia or schizoaffective disorder found that approaches delivered in both inpatient and outpatient settings can be effective in managing type 2 diabetes, particularly those that address diet and exercise behaviour, but concluded that intervention packages need to be tailored to the unique challenges associated with decreased cognition and motivation, limited resources, as well as the loss of energy and the weight gain associated with the use of antipsychotics (Cimo, Stergiopoulos, Cheng, Bonato, & Dewa, 2012).

In order to help address these disparities in care we are currently undertaking a programme of work in order to develop effective self-management education and support for people with type 2 diabetes and SMI. Although there is an expanding evidence base to help

inform interventions to improve diabetes management in the general population (Deakin et al., 2005; Pal et al., 2013; Steed et al., 2003; Steinsbekk et al., 2012; Thorpe et al., 2013), there has to date been limited consideration of diabetes care and self-management among people with SMI. Therefore, we are leading on a number of research studies that aim to identify how, when and where to intervene with this population in order to improve outcomes.

## Complex interventions

An extensive literature exists on the range of potential approaches to changing behaviour (National Institute for Health and Care Excellence, 2014; National Institute for Health and Care Excellence, 2007), as well as consideration of the 'active ingredients' of such approaches (Michie et al., 2013). NICE guidelines for behaviour change state that "All interventions need to be developed and evaluated in stages, using an established approach such as the Medical Research Council's (MRC) framework for the development and evaluation of complex interventions" (National Institute for Health and Care Excellence, 2007).

The programme of work we are undertaking is following the MRC guidance (Craig et al., 2008) in order to develop an appropriate, theoretically underpinned, model of care for this population. The MRC guidance recommends a structured approach to the development, evaluation and implementation of complex interventions (see Figure 1) and stresses the importance of undertaking each stage thoroughly; the research we are currently undertaking is within the development stage of this framework and is working towards a larger programme of work to assess feasibility, evaluate the intervention and, understand and aid implementation.

The MRC guidelines recommend that interventions are developed based on a good theoretical understanding of how the intervention is likely to bring about the desired change(s) in behaviour. It is

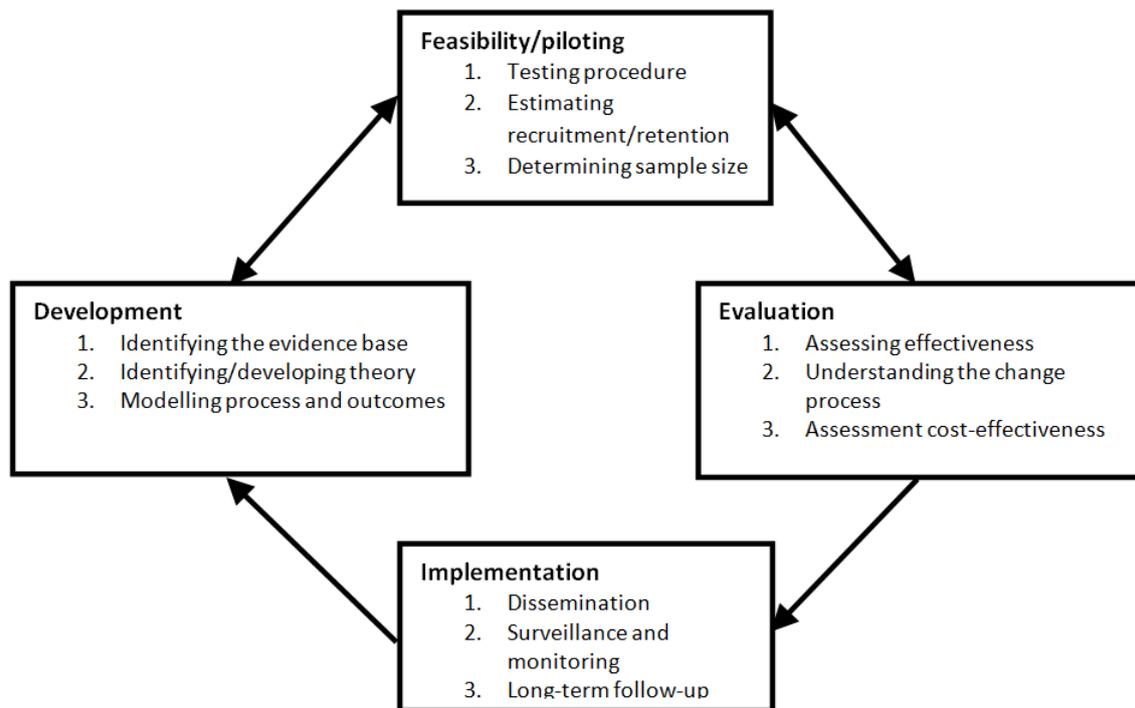


Figure 1: Development, evaluation and implementation of complex interventions (Craig et al., 2008)

therefore necessary to first understand from a theoretical perspective the factors that can act as barriers or facilitators to performing diabetes-related behaviours and model these in order to identify the psychological factors that are amenable to change and can therefore be targeted in an intervention to change behaviour.

The MRC guidance does not provide details of which theoretical perspective is most appropriate and many overlapping theories of behaviour change exist. Therefore, we will be using a number of methodological techniques in order to identify the psychosocial concepts which influence the performance of diabetes self-management, the theories that these psychological concepts tap into and hence the behaviour change techniques (BCTs) that need to be adopted within the intervention in order to change behaviour. This approach will allow us to develop a diabetes self-management intervention for people with SMI that has strong theoretical underpinnings.

## Development of a diabetes self-management intervention for people with SMI

In order to meet the various stages of the MRC guidance (Craig et al., 2008) for developing a complex intervention we are currently undertaking and planning a number of research studies in order to identify the evidence base and theory, and model the processes and outcomes relevant to this clinical context.

### *Identifying the evidence base and theory*

#### *Systematic review*

We are currently undertaking a Cochrane review in order to assess the effectiveness of diabetes self-management interventions for people with type 2 diabetes across a broader range of SMIs (McBain et al., 2014). This will extend the scope of the previous

review undertaken by Cimo et al. (2012) to include people with personality disorder, bipolar disorder and depression with psychotic features. In addition to looking at the evidence for their effectiveness, the review will also provide us with the opportunity to describe, using established reporting systems (Michie et al., 2013; Michie & Prestwich, 2010), the active components of these interventions and the theoretical frameworks within which they were developed.

The Behaviour Change Technique Taxonomy (BCTTv1) (Michie et al., 2013) will be used to specify the content of these interventions. The BCTTv1 contains 93 BCTs clustered into 16 hierarchically structured groups and will be used alongside a coding system to assess the different ways that these behavioural interventions have employed theory (Michie & Prestwich, 2010). Use of these coding systems will therefore enable us to systematically identify and document the content of diabetes self-management interventions for people with SMI and type 2 diabetes and establish which components and theories are most effective in changing behaviour and improving outcomes. This will be achieved by undertaking subgroup analyses by these intervention characteristics.

### *Qualitative exploration*

Self-management of diabetes is complex and the demands of managing diabetes when living with SMI present additional challenges for both service users and healthcare professionals. In spite of this, very little research has asked people with diabetes and SMI about what they find most challenging when trying to manage their diabetes and their perceived barriers and facilitators to successful diabetes self-management. A small number of UK studies have discovered role ambiguity concerning the responsibilities of mental health nurses (Blythe & White, 2012; Robson, Haddad, Gray, & Gournay, 2012) and primary care health professionals (Lester, Tritter,

& Sorohan, 2005) in providing both physical and mental healthcare and another investigating the diabetes training needs of nurses (Nash, 2009). One additional study interviewed seven people with diabetes and SMI about their experience of diabetes care and identified stigma, diagnostic overshadowing and a purposeful splitting of physical and mental health by health professionals as barriers to the delivery of effective care (Nash, 2014). However, no other European studies have asked people with diabetes and SMI about how they manage their diabetes and the difficulties they experience in doing so.

Enabling people with SMI to manage their diabetes effectively could involve intervening to change their behaviour, that of healthcare professionals, or both and these qualitative studies aim to help identify how and where best to intervene by exploring the topic from a range of perspectives. The team are therefore undertaking qualitative semi-structured interviews with both people with SMI and type 2 diabetes, and a group of healthcare professionals who are involved in the care of this population. This includes psychiatrists, care coordinators, practice nurses, GPs, diabetes specialist nurses and mental health nurses.

The research will explore service users' experiences of the elements of self-management that they find most challenging and the barriers and facilitators which enable them to manage their diabetes. It will also explore healthcare professionals' recommendations for how best to facilitate self-management and the psychological factors which impact on them delivering diabetes care. The interview topic guide for these semi-structured interviews is based on the Theoretical Domains Framework (TDF) of behaviour change (Cane, O'Connor, & Michie, 2012), with additional questions designed to allow participants to discuss topics most important to their experience of diabetes and mental illness. The TDF (Cane et al., 2012) was developed to integrate the different theories of behaviour change. The framework consists of 14 domains that have been found to influence behaviour: knowledge; skills;

beliefs about capabilities; beliefs about consequences; emotions; environmental context and resources; social influences; memory, attention and decision processes; social/professional role and identity; reinforcement; intentions; goals; optimism; behavioural regulation. The interview topic guides include broad questions with additional prompts and probes to cover each of these 14 domains and data will be coded using this framework. This process will allow us to identify the key behaviours people with diabetes and SMI find most challenging, as well as the specific beliefs, which patients and healthcare professionals hold, which may impact upon effective diabetes self-management and the theoretical constructs and models which determine these behaviours.

### *Modelling processes and outcomes*

In order to understand how these beliefs impact upon behaviour, a cross-sectional survey with healthcare professionals and people with SMI and type 2 diabetes will follow these qualitative interviews. Using statistical modelling, we will be able to identify the beliefs that are most strongly associated with performance of diabetes-related behaviours. Following established methods for developing behaviour change interventions (Francis et al., 2009), the beliefs identified within the qualitative semi-structured interviews will be mapped onto theories of behaviour change and the constructs within these theories will be included for operationalization in this questionnaire study.

The questionnaires will identify the psychological constructs that predict, in the case of patients, the performance of diabetes self-management behaviours such as self-monitoring of blood glucose, adherence to dietary behaviours, exercise, adherence to medication, titration of insulin (if relevant), foot care and attendance for regular screening including diabetic retinopathy and general check-ups. For healthcare professionals the questionnaire will provide a better understanding of what current

practices are being implemented for this population by the various professions and provide an understanding of the psychological constructs that predict performance of these practices.

## Summary

The management of type 2 diabetes in people with SMI presents serious challenges for a group of people who may view their physical health as low priority and have very little motivation to change their behaviour. There also appears to be confusion and role ambiguity concerning the responsibilities of both physical and mental healthcare professionals. Together this may be contributing towards the poorer physical health of this population and higher mortality. In order to empower people with SMI to manage their diabetes, evidence-based interventions need to be developed that meet the needs of this population. Together the studies we are currently undertaking will inform the development and evaluation of an intervention(s) that we hope will enhance diabetes self-management in this clinical context.

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