



**Improving health outcomes for adults with severe mental illness and comorbid diabetes: is supporting diabetes self-management the right approach?**

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Review

**Improving health outcomes for adults with severe mental illness and comorbid diabetes: is supporting diabetes self-management the right approach?**

**Key words**

Psychosis, severe mental illness, diabetes, self-management, structured education, multi-morbidity

**Introduction**

Diabetes is a common problem in people with severe mental illness (SMI is an umbrella term used to describe disorders in which psychosis occurs, and includes schizophrenia and bipolar disorder), and is associated with poor health outcomes and reduced life expectancy (Holt and Mitchell, 2015). Prevalence estimates pooled across 42 international studies suggest that around 13% of the SMI population has diabetes (Ward and Druss, 2015), a figure more than twice that in the general population (Shaw, *et al.*, 2010) . This inequality is likely to increase, as recent analyses of primary care data show diabetes prevalence increasing year-on-year for the whole population, with the *difference* between people with and without SMI widening (Reilly, *et al.*, 2015, Ward and Druss, 2015).

We have established a multidisciplinary research programme called DIAMONDS (**D**iabetes and **M**ental Illness: Improving **O**utcomes **a**nd **S**ervices), which aims to increase understanding about the comorbid relationship between diabetes and SMI, and develop effective interventions for people living with both these conditions. In this paper, we explore whether supporting diabetes self-management, which is the cornerstone of good diabetes management, offers the right approach. We draw on evidence from the diabetes and mental health literature to outline why improving

1  
2 diabetes care for people with SMI is important; consider why diabetes self-management  
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4 education offers the potential to improve health outcomes; discuss the risks of using this  
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6 approach for people with SMI; set out the key research questions that need to be  
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8 answered in order to make this approach work; and consider the implications for mental  
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10 health nursing.  
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### 13 14 15 **Why is it an important area?** 16

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18 People with SMI have poorer physical health and a reduced life expectancy by around  
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20 15-20 years when compared to the general population (Brown, *et al.*, 2010), with higher  
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22 rates of modifiable cardiovascular risk factors (Osborn, *et al.*, 2015), and increased  
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24 prevalence of a range of chronic health conditions including metabolic syndrome,  
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26 diabetes, cardiovascular disease, stroke, and asthma (Reilly, *et al.*, 2015). The increased  
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28 risk of developing diabetes and its associated complications, (which include  
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30 cardiovascular disease, retinopathy, cerebrovascular disease, nephropathy and  
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32 neuropathy), contributes significantly to the poor physical health and shorter life  
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34 expectancy seen in people with SMI compared to the general population (Vinogradova,  
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36 *et al.*, 2010).  
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40 Reasons for the comorbid relationship between diabetes and SMI are related to a  
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42 combination of factors, which are likely to be synergistic and interactional in ways that  
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44 we are yet to understand (Ward and Druss, 2015). These include: genetic features and  
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46 symptomology associated with the mental illness; metabolic side effects of psychotropic  
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48 medications; lifestyle factors, such as higher rates of smoking and alcohol intake,  
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50 physical inactivity and poor diet; presence of other physical co-morbidities; and wider  
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52 socio-economic inequalities (Holt and Mitchell, 2015, Ward and Druss, 2015). The  
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54 organisation of health services also plays a part, meaning that, for people with SMI,  
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56 their physical health needs are often neglected (Crawford, *et al.*, 2014). Explanations for  
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2 this include poor assessment, monitoring and recording practices; diagnostic  
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4 overshadowing, whereby physical health problems are attributed to the underlying  
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6 mental illness; ineffective co-ordination between primary and secondary care; and  
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8 ambiguity about who should manage the physical health needs of this patient group  
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11 (Lawrence and Kisely, 2010, Blythe and White, 2012, Crawford, *et al.*, 2014).  
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14 As with other multi-morbid populations, individuals with co-existing diabetes and SMI  
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16 are reported to receive fragmented and ineffective care (Scott, *et al.*, 2012). Diabetes  
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18 services for the general population vary considerably, and an international survey of  
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20 people living with diabetes, their carers, and healthcare staff, identified a need to  
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22 improve the provision of and access to appropriate diabetes care across all 17 countries  
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24 taking part (Holt, *et al.*, 2013, Nicolucci, *et al.*, 2013). Diabetes care for people with  
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26 SMI is likely to be even more variable, as it will depend on who provides their mental  
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28 health care and the level of knowledge among these clinicians about how to support  
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30 diabetes management (Blythe and White, 2012, Reilly, *et al.*, 2012). Additionally,  
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32 healthcare professionals can sometimes make unfounded assumptions about why people  
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34 with SMI have poor physical health, attributing blame to poor lifestyle and life choices,  
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36 and therefore fail to address other pertinent issues (Happell, *et al.*, 2012).  
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41 Tackling diabetes is a global priority, the cost of which accounts for approximately 12%  
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43 of the world's total health expenditure (Zhang, *et al.*, 2010). A large proportion of this  
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45 relates to treatment of complications that could be prevented through improvements in  
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47 diabetes management (Hex, *et al.*, 2012). The psychosocial impact of having diabetes  
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49 adds to the disease burden, with an increased risk of depression and distress reported in  
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51 numerous studies across varying patient populations (Nicolucci, *et al.*, 2013, Snoek, *et*  
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53 *al.*, 2015). Costs of diabetes in the SMI population have not been estimated, but are  
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55 likely to be disproportionately high given its increased prevalence and complications,  
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and underlying psychological vulnerability and associated burden of care (Bajor, *et al.*, 2015).

The World Health Organisation is committed to improving the physical health of people with SMI (World Health Organisation, 2013), and there is growing interest in developing lifestyle interventions to help achieve this (McGinty, *et al.*, 2015), mirroring developments in the general population through the national diabetes prevention programmes (Ali, *et al.*, 2012). Focusing on diabetes management is equally as important because achieving even modest improvements in key biological markers of diabetic control, including HbA1c, blood pressure and cholesterol, reduces the risk of complications and mortality, and associated healthcare costs (Kontopantelis, *et al.*, 2015). However, there is little evidence to suggest that this broader approach helps to improve diabetes management in addition to promoting lifestyle changes (Schellenberg, *et al.*, 2013). Additionally, there are few targeted diabetes interventions for people with SMI, and little understanding about how to effectively support this vulnerable patient group (Chwastiak, *et al.*, 2015).

### **Why focus on diabetes self-management education (DSME)?**

Self-management aims to provide people with “the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life” (Coulter, *et al.*, 2013). In diabetes, self-management has been a core component of clinical management since the 1950’s, aimed at improving glycaemic control through lifestyle changes, self-monitoring of symptoms, and medication. Diabetes self-management refers to the skills, practices and behaviours that a person with diabetes engages in to protect and promote their health. These include: improving diet; increasing physical activity; smoking cessation; monitoring glycaemic control, blood pressure and lipids; preventing complications; and improving treatment adherence (Ahola and Groop, 2013).

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A growing number of systematic reviews provide evidence that, for diabetes and other long-term conditions such as chronic obstructive pulmonary disease and hypertension, (which are also more prevalent in the SMI population (Reilly, *et al.*, 2015)), interventions targeting self-management have clinically significant effects on a range of important health outcomes (Taylor, *et al.*, 2014). In diabetes specifically, recent systematic reviews of DSME programmes provide evidence that patients receiving these interventions show significantly improved self-management, and more importantly, diabetic control (as measured by HbA1c) when compared to patients receiving routine care (Fan and Sidani, 2009, Steinsbekk, *et al.*, 2012, Chrvala, *et al.*, 2015).

DSME is already supported by international policy (International Diabetes Federation, 2012). Additionally in the UK, general practitioners are offered financial incentives (as part of the Quality and Outcomes Framework) to refer patients for DSME, and there are a number of established DSME programmes rolled out in practice, delivered by trained dieticians, nurses and other healthcare staff (National Diabetes Audit, 2014). Adapting an intervention that is already acceptable and feasible is more likely to be adopted by healthcare staff and their patients (Greenhalgh, *et al.*, 2004). Being able to draw on existing packages, resources and staff with the skills to deliver these also offers a distinct advantage over developing new interventions, the feasibility of which is unknown and may inadvertently increase rather than decrease existing health inequalities.

Adopting a behavioural approach such as DSME may also be more acceptable than offering adjunctive pharmacological therapies to alleviate the metabolic side effects of anti-psychotic medications. It may also be preferable to the alternative of switching from an anti-psychotic that has proven effectiveness in preventing relapse in SMI for an

individual, to one which has uncertain efficacy, but a more favourable metabolic profile (Chwastiak, *et al.*, 2015). Multiple drug therapy is increasingly used for managing SMI and is associated with poorer health outcomes (Correll, *et al.*, 2015). Compared to people with diabetes alone, people with SMI and comorbid diabetes are more likely to be prescribed multiple medications, which may change over time and interact in ways that require careful monitoring (Ward and Druss, 2015). Although problems with medication adherence, (the extent to which patients take their medications as prescribed by their healthcare provider (Osterberg and Blaschke, 2005)), is reported across many patient groups and health conditions, evidence suggests that it is a particular problem for people with SMI (Kreyenbuhl, *et al.*, 2010). DSME programmes offer the potential to address barriers to medication adherence encountered in this population.

A further advantage of this approach is that people who successfully self-manage their diabetes are less likely to experience diabetes-related distress or depressive symptoms compared to those who do not, although the evidence to support this is somewhat contradictory (Snoek, *et al.*, 2015). This is particularly important for people with SMI, due to their underlying psychological and emotional vulnerability, and their increased risk of comorbid depression and other affective disorders (Buckley, *et al.*, 2009).

Finally, focusing on improved self-management may have positive effects on SMI management. In chronic health, the self-management model “lays emphasis on following essential process elements: (a) building self-efficacy; (b) self-monitoring; (c) goal-setting and action-planning; (d) decision-making; (e) problem-solving; (f) self-tailoring; and (g) partnership between the views of patients and health professionals” (Du, *et al.*, 2011). These behavioural strategies are commonly used in effective behavioural therapies for treating SMI, which are known to be acceptable to patients and those who support them (Jauhar, *et al.*, 2014).

**What are the risks of using this approach for people with SMI?**

Although supporting diabetes self-management may offer advantages over pharmacological and other behavioural approaches, many people struggle to make the necessary lifestyle changes to prevent complications (Ahola and Groop, 2013, Nicolucci, *et al.*, 2013). People with SMI face additional barriers to managing their health and having the confidence to do so (Roberts and Bailey, 2011). For example, illnesses like schizophrenia and bipolar disorder are characterised by disturbed thoughts, perception, affect, and behaviour, resulting in loss of motivation, impaired self-efficacy and poorer self-care (Chen, *et al.*, 2014). SMI is also associated with wider inequalities across a range of domains, with individuals obtaining fewer qualifications, more likely to be out of work and experience poverty, and to lack social support and live alone (Department of Health, 2011).

These features impact on lifestyle choices, for example people with SMI are more likely to smoke and engage in risky behaviours such as drug taking and alcohol abuse, have poorer diet and higher levels of physical inactivity (McGinty, *et al.*, 2015). People with SMI may therefore need to make multiple lifestyle changes upon being diagnosed with diabetes, and it may be that a gradual approach focusing on one aspect at a time, e.g. diet, exercise or medication adherence, is more appropriate than an intervention modelled on existing DSME, which tends to address multiple lifestyle factors (Steinsbekk, *et al.*, 2012). DSME programmes also expect people to attend regular group sessions, and there is some evidence to suggest that group-based DSME is more effective than an individual approach (Hwee, *et al.*, 2014). Unfortunately, this can be especially problematic for people with SMI who despite having more frequent and sustained contact with health services (Reilly, *et al.*, 2012) report numerous barriers to



engaging in health interventions, for example not having support from others, or lacking the financial resources or transport to attend regular sessions (Kaufman, *et al.*, 2012).

Barriers to access are an important concern. In the general population, many people with diabetes are often not referred for DSME (Holt, *et al.*, 2013), and anecdotal evidence suggests that people with SMI are less likely to be referred or to attend DSME programmes unless they are appropriately adapted. For example, ambiguity about who is responsible for managing the physical health of people with SMI may mean that individuals supported by specialist mental health services may not be in regular contact with their general practitioner, who often acts as the gatekeeper to diabetes services. Conversely, patients who are only supported in primary care, which are reported to be around 20-30% of people with SMI, may not benefit from interventions situated within mental health (Reilly, *et al.*, 2012).

A further risk of adopting this approach is that DSME programmes tend to be predicated on normative assumptions about health literacy (defined as “the degree to which people have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Parker, *et al.*, 2003)), and there is some evidence to suggest this is compromised in people with SMI (Clausen, *et al.*, 2015). DSME interventions require participants to play an active role in managing their health as well, and commonly employ techniques such as goal setting, problem solving, and self-monitoring (Presseau, *et al.*, 2015). Although people with SMI may be familiar with these strategies through management of their mental health, they may well have lower self-efficacy and be less activated to make the necessary lifestyle changes (Hibbard and Gilburt, 2014). People with SMI can also experience multiple relapses of their mental illness, and may have chaotic lifestyles and cognitive

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impairments which affect their ability to incorporate self-monitoring regimens into their daily routines (Harvey and Strassnig, 2012).

Recent developments in DSME may be problematic for this patient group too. For example, a growing number of programmes are using mobile phone and online technologies to support lifestyle changes and medication adherence (Pal, *et al.*, 2014). Although this approach has shown some promise in the SMI population, these patients are less likely to own a smart phone than the general population and may have financial constraints that compromise the feasibility of delivering an intervention that requires users to regularly access the internet on their mobile phone (Naslund, *et al.*, 2015). How to effectively utilise the increasing opportunities available through mobile health technologies therefore requires careful consideration; however, at the same time not using this technology may increase health inequalities if people with SMI are excluded from an approach increasingly used to monitor and manage chronic health conditions.

Furthermore, while DSME interventions have shown some promising results, there is considerable heterogeneity between individual studies, and few conclusions can be drawn about the causal mechanisms and active ingredients that might be transferable to specific populations (Fan and Sidani, 2009, Steinsbekk, *et al.*, 2012, Chrvala, *et al.*, 2015). For example, although the trial evaluation of DESMOND (a programme commonly used in the UK) demonstrated greater weight loss and lower levels of depression at 12 months, it in fact showed no significant improvements in diabetic control (as measured by HbA1c) compared to usual care (Davies, *et al.*, 2008). In a three-year follow up, there were no significant improvements in any of these outcomes, which highlight uncertainties about the long-term effects of DSME, and the challenges individuals face in sustaining lifestyle changes (Khunti, *et al.*, 2012). Additionally,

these interventions have not been tested in real world settings, where the positive effects are sometimes not realised in practice (Ali, *et al.*, 2012).

### **How can we make sure this approach works?**

We know that DSME programmes can be effective for improving diabetes outcomes, but we do not know how to make this approach work for people who are diagnosed with diabetes alongside SMI. There is a risk that unless current strategies to improve diabetes self-management are adapted to take account of the particular characteristics and needs of people with SMI, inequalities in morbidity and mortality experienced by this population may widen as generic DSMEs are scaled up to meet international recommendations for diabetes care.

We propose that a bespoke DSME programme for people with SMI has the potential to improve diabetes outcomes and reduce modifiable cardiovascular risk factors. Such programmes may also lead to better mental health through improved illness management and lifestyle changes. However, there are some key research questions that need to be answered in order to develop an evidence-based DSME intervention that is acceptable to people with SMI and those who support them, and also effective in both a trial and real world setting.

### **What are the determinants of self-management in people with SMI?**

We already have a good understanding of the motivational, cognitive and psychological deficits associated with SMI, and can speculate on how these might influence diabetes management. Nevertheless, there are gaps in knowledge about the factors that inhibit or alternatively enhance good diabetes management in people with comorbid SMI. These include key characteristics about the population and their diabetes outcomes and care;

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determinants of good and poor diabetes self-management; and the role of carers and others who support them, including, for example, mental health services.

Thanks to the increasing availability of large databases containing anonymised individual patient healthcare records, we have new opportunities to understand more about the factors that may influence diabetes onset and outcomes in people with SMI; including identifying which people with SMI are likely to receive poor diabetes care and are at greatest risk of poor diabetes outcomes (Herrett, *et al.*, 2015). We can also learn more about the potential mechanisms of action for improving self-management through configurative synthesis and modelling of multiple evidence sources (Gough, 2013). This approach to reviewing the literature and combining different evidence types can help to identify the most promising components and strategies to include in an intervention, as well as shed light on other important features that are likely to increase successful implementation and adoption.

Understanding the lived experience of diabetes alongside SMI is equally as important; and we are aware of only one qualitative study exploring diabetes experience in people with SMI (Blixen, *et al.*, 2016). Further research is required to explore barriers to accessing healthcare and support for diabetes; opportunities to exploit existing healthcare resources and new mobile health technologies to ensure feasibility of the programme; and consider whether a support or assets-based approach is needed due to the psychological and social vulnerabilities in this population. Including the views of health service staff, managers and commissioners will also allow for an exploration of the opportunities for delivering the intervention within secondary mental health, where staff already have the skills to effectively support people with SMI, and an appreciation of the motivational deficits and barriers inherent in this population.

### What are the active ingredients for an effective DSME programme?

The combination of educational and behavioural elements distinguishes DSME, which aims to increase self-management behaviours, from traditional forms of didactic patient education, which tend to focus primarily on improving patient knowledge (Bodenheimer, *et al.*, 2002). Unfortunately, a significant proportion of published evidence in diabetes self-management fails to report interventions in sufficient detail, including not specifying which behaviour change techniques (BCTs), (defined as a “component of an intervention designed to alter or redirect causal processes that regulate behaviour; that is, a technique is proposed to be an “active ingredient” (e.g., feedback, self-monitoring, and reinforcement)” (Michie, *et al.*, 2013, p.82)), are used to effect change (Presseau, *et al.*, 2015). This lack of detail makes it difficult to select suitable existing interventions to adapt for populations who have particular comorbidities or motivational deficits requiring a more targeted approach.

With increased knowledge of the determinants of and resources for diabetes self-management in our target population, we can identify BCTs and other important components and delivery mechanisms that are likely to be most effective. This knowledge will also help us to consider how to utilise mobile health technologies to deliver tailored DSME, and to ensure that people with SMI do not miss out on the increasing opportunities to manage their health and illness remotely. For example, mobile phones may be used for goal setting, or providing feedback or practical support, which are commonly employed BCTs for diabetes management (Presseau, *et al.*, 2015). Modelling effective BCTs for diabetes self-management that correspond to key determinants of self-management behaviour in people with SMI offers a promising approach, already successfully employed for smoking cessation in this population (Gilbody, *et al.*, 2015). Using this approach also helps to ensure that any intervention

we develop can be replicated by others and implemented effectively (Craig, *et al.*, 2008).

**What is acceptable and feasible for people with SMI?**

Because of the limited evidence in this area, there is little known about what is acceptable for people with SMI and comorbid diabetes, and what is feasible to deliver and implement for a patient population receiving care from primary, mental health and diabetes care providers. To address issues of acceptability and feasibility, it is essential to work in partnership with service users, carers and healthcare professionals in addition to using qualitative enquiry to increase knowledge about what is needed. In the DIAMONDS programme mentioned above, we plan to use co-design methods to ensure that the bespoke intervention, including its goals, mode of delivery, structure and content, is acceptable to people with SMI and diabetes, and to maximise future take-up and engagement (Boyd, *et al.*, 2012).

Identifying and agreeing goals and outcomes is an essential step of intervention planning (Bartholomew, *et al.*, 2011) and can enhance implementation success by ensuring that the needs of different stakeholders are accounted for (Greenhalgh, *et al.*, 2004, Taylor, *et al.*, 2015). There is little consensus, however, about what to measure for people with multiple morbidities (Barnett, *et al.*, 2012), including comorbid diabetes and SMI. It will therefore be important to work in partnership with service users and carers, healthcare staff and others involved in managing and commissioning services to agree goals and outcomes to support future evaluation and implementation of interventions that are developed (Williamson, *et al.*, 2012).

Clinical adoption is also an important consideration (Greenhalgh, *et al.*, 2004), as mental health, primary care and diabetes clinicians are likely to be involved in

1 identifying a need for supporting diabetes self-management and referring patients for  
2 appropriate interventions. Finally, while user and frontline staff acceptance is a key  
3 driver of our work, we are also mindful to develop an intervention that can be  
4 implemented into a changing healthcare landscape in which commissioning  
5 arrangements and service priorities are continually evolving. Local commissioners will  
6 therefore need to be involved to ensure that financial, technological and procurement  
7 barriers, including intervention costs, are addressed as part of developing the  
8 intervention (Taylor, *et al.*, 2015).  
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### 20 21 22 **What are the implications for mental health nursing?** 23

24 The interplay of biological, psychosocial, economic and healthcare factors that  
25 contribute to poor diabetes outcomes in people with SMI highlights the need to develop  
26 targeted support for people living with both conditions, to reduce unacceptable health  
27 inequalities and improve life expectancy for these patients. Diabetes is increasingly  
28 common in the SMI population, and mental health nurses and other staff involved in  
29 supporting people with SMI therefore need to have appropriate skills and knowledge to  
30 support patients living with comorbid diabetes. This could be achieved through  
31 increased opportunities for training and professional development around management  
32 of physical health conditions common in SMI, or by attending DSME programmes  
33 alongside individual patients where skills and knowledge need improving.  
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47 Having diabetes can cause diabetes-related distress and depressive symptoms,  
48 potentially impacting on SMI management and psychological wellbeing. Mental health  
49 nurses and care co-ordinators, therefore, have an important role to play in addressing  
50 individual patient barriers to accessing and attending DSME programmes and other  
51 diabetes care interventions, and identifying the resources and additional support that  
52 patients may need to make and sustain positive lifestyle changes, self-monitor their  
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diabetes symptoms, and adhere to new treatments. Better monitoring of the effects of new medications used to treat SMI alongside diabetes, due to the metabolic side effects of anti-psychotic medications and the unknown effects of combining multiple medications for more than one health condition, is also needed.

More broadly, there is a need to better monitor diabetes risk in the SMI population, not only to allow patients at high risk of diabetes to benefit from the growing number of diabetes prevention programmes being rolled out in the UK and other countries, but also to ensure that patients are diagnosed early and offered support to manage their diabetes. This will require an integrated and collaborative approach between primary, mental health and diabetes care providers, and mental health care co-ordinators have an important role in facilitating this. Finally, the metabolic effects of anti-psychotic medications are now well known, and associated weight gain can happen very rapidly for people prescribed these medications. Mental health nurses have an important educational role to ensure that patients are aware of this risk, and to help them manage the metabolic side effects alongside managing their mental illness.

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