POSITION STATEMENT

An integrated care model for mental health in diabetes:
Recommendations for local implementation by the
Diabetes and Mental Health Expert Working Group in
England

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Abstract

Context: In 2019, NHS England and Diabetes UK convened an Expert Working Group (EWG) in order to develop a Model and recommendations to guide commissioning and provision of mental health care in diabetes pathways and diabetes care in mental health pathways. The recommendations are based on a combination of evidence, national guidance, case studies and expert opinion from across the UK and form other long term conditions.

The case for integration: There is good evidence around the high prevalence of co-morbidity between diabetes and mental illness of all severities and, the poorer diabetes and mental health outcomes for patients when this co-morbidity exists. Detecting and managing the mental health co-morbidity improves these outcomes, but the evidence suggests that detection of mental illness is poor in the context of diabetes care in community and acute care settings and that when it is detected, the access to appropriate mental health resource is variable and generally inadequate.

The Model of integrated care for diabetes: The EWG developed a one-page Model with five core principles and five operational work-streams to support the delivery of integration, with examples of local case studies for local implementation. The five core principals are: Care for all—describing how care for all PWD needs to explore what matters to them and that emotional wellbeing is supported at diagnosis and beyond; Support and information—describing how HCPs should appropriately signpost to mental health support and the need for structured education programmes to include mental healthcare information; Needs identified—describing how PWD should have their mental health needs identified and acted on; Integrated care—describing how people with mental illness and diabetes should have their diabetes considered within their mental health care; Specialist care—describing how PWD should be able to access specialist diabetes mental health professionals. The five cross cutting work-streams for operationalising the principles are: Implementing training and upskilling of HCPs; Embedding mental health screening and assessment into diabetes pathways; Ensuring access to clear, integrated local pathways; Ensuring addressing health inequalities is
Definitions and descriptors

- The World Health Organisation (WHO) defines mental health as ‘a state of well-being in which the individual realises his or her abilities, can cope with the normal stresses of life, work productively and fruitfully and is able to make a contribution to his or her community’.
- Psychological distress— We have used this term to describe the experience of an absence of mental health but not meeting the diagnostic criteria for a mental illness.
- Mental illness— Umbrella term for all diagnosable psychiatric disorders that fulfil the criteria for that disorder as per diagnostic classification systems. Examples include depressive disorder, eating disorder, dementia and schizophrenia.
- Severe mental illness (SMI)— A subset of mental illness which refers to people with psychological problems that are often so debilitating that their ability to engage in functional and occupational activities is severely impaired. Schizophrenia and bipolar disorder are often referred to as SMI.
- Mental health care/mental health pathways— Where care is delivered in order to manage mental illness.

1 CONTEXT

One of the six recommendations in The Too Often Missing Report (2019) was to integrate diabetes and mental health pathways. In March 2019, NHS England and Diabetes UK convened an Expert Working Group (EWG). This included people with lived experience of type 1 and type 2 diabetes, carers of people with diabetes (PWD) as well as professionals from a wide range of disciplines and tiers of service and research across the country. The remit of the EWG was to develop a Model and recommendations to guide commissioning and provision of mental health care in diabetes pathways and diabetes care in mental health pathways. The recommendations are based on a combination of evidence, national guidance, case studies and expert opinion.

2 THE VOICE OF A PERSON LIVING WITH DIABETES

I am a person living with type 1 diabetes. Having spent much time talking about my own mental and emotional health struggles with my own diabetes team, and publicly, I have felt frustration at the lack of access to psychological support, especially specialist psychological support for my diabetes. Annoyance at such long waits for access; or to limited access and to hear those frustrations echoed amongst the HCPS and DUK team were both reassuring and empowering towards the changes we hope this work will make.

It was important for Language Matters to have a focus within this group, not just language applicable to living with diabetes, but when talking about mental and emotional health with people in an empathetic and non-judgemental way. In giving appropriate focus to the way we talk about issues surrounding mental health, we can actually make support more accessible to those who still feel burdened by the outdated stigma attached to it. In addition to this, using language that makes the model accessible to PWD reading it and indeed those with little to no experience of living with diabetes, was a consideration given by all in the working group. This was especially the case for those of us with lived experience, in particular, I feel I have a better understanding of what has been missing from a more rounded perspective and where that’s been further restricted by a number of...
factors; including the covid pandemic. Through being part of this work, I also felt reassured by the knowledge that there are some great examples happening across the UK that helped immensely when discussing the model and implementation plans. These models were shared by both HCPS and PWD and taken into consideration at each stage. I have great hopes for the future of mental healthcare within diabetes services, and the endless possibilities for improvement in quality of life that can bring to all PWD. More so when people living with diabetes are given a seat at the table to co-produce work like this, it is far more meaningful.

3 | INTRODUCTION

For PWDs, the need for good mental health is intrinsic to their ability to self-care and therefore affects their overall health outcomes, yet PWDs are two to three times more likely to experience mental health problems than the general population. For health and social care staff, this poor mental health in PWD can be associated with feeling de-skilled and not having a sense of agency around their roles and the care they deliver. For commissioners, the cost to the NHS, of managing diabetes and its complications is projected to be £39.8bn by 2035/6, with £1 in every £8 in long-term condition spending going on mental health. Conversely, the annual cost to the NHS in England, of managing people with SMI in addition to living with type 2 diabetes is estimated at an additional £115 m compared to managing PWD without SMI.

In this paper, we will describe why and how Integrated Care Systems (ICSs) should follow our core principles to integrate mental health care into diabetes pathways and diabetes care into mental health pathways, in order to improve patient, staff and financial outcomes.

4 | THE CASE FOR INTEGRATION

4.1 | All mental illnesses are more common in diabetes and diabetes is more common in mental illness

Psychological distress and mental illness are more prevalent in PWD compared to the general population. This includes dementia (1.5–2.5 times), depression (2 times), anxiety and eating disorders. The nature of the association is often multifactorial and complex.

Equally, people with SMI like schizophrenia or bipolar affective disorder are two to three times more likely than their peers to develop type 2 diabetes and have poorer glycaemic control. This is due to a number of factors, including side effects of antipsychotic medications, diagnostic overshadowing and poorer access to care. Childhood trauma has also been identified as a risk factor for developing type 2 diabetes in adult life secondary to epigenetic, physiological, emotional and behavioural factors.

4.2 | Poor mental health leads to poorer physical and mental health outcomes

PWD who have poor mental health can have worse blood glucose management than those without mental illness. This in turn has been shown to lead to the development of diabetes complications and early death in people with chronic mental illness.

People with significant childhood trauma and those with SMI are shown to die 15–20 years younger than their peers. Living with diabetes can increase the risk of psychiatric morbidity and suicide, especially in young people transitioning to adult services.

4.3 | Detecting and managing mental health issues in PWD leads to improved outcomes

Systematic reviews and meta-analyses of randomised controlled trials researching a range of psychological treatments (motivational interviewing, counselling, cognitive therapies) in people with type 1 diabetes found evidence of HbA1c improvement in children and adolescents and in people with type 2 diabetes, found evidence of improvements in long-term glycaemic control and psychological distress.

Service evaluations (published and unpublished) of pilot studies which provided intensive biomedical, psychological (e.g., Cognitive Analytic Therapy) and social interventions, also demonstrated significantly improved HbA1c and psychological well-being. These services worked with high-cost and high-risk individuals with very poor glycaemic control.

4.4 | Detecting and managing diabetes and its complications in mental illness may lead to improved outcomes

NICE Guidelines for management of schizophrenia and other SMIs recommend detection and management of diabetes, metabolic disorders and the cardiovascular consequences of these conditions to improve morbidity and mortality rates.
4.5 | Mental health issues are under-detected in diabetes

There is significant under-recognition of psychological distress, depression and anxiety in diabetes, with non-white and older people fairing worst.1,27,28

The reasons for this are multiple: depression being considered as “understandable” and therefore no need to treat it, constraint on clinicians’ time, stigma on behalf of the person living with diabetes leading to late presentations and perceived lack of specialist services to refer to.1,9,28

4.6 | There is inadequate access to appropriate resources

A survey of PWDs found that of those who felt they needed specialist psychological services, 75% could not access it.1 Another survey found that 24% of PWDs who had difficulty managing their diabetes, cited not having sufficient access to emotional and psychological support as a key reason.29 Only 10% of departments are using any screening tools for psychological assessments and 80% of services have no guidelines for referral of people with psychological problems.1

Improving Access to Psychological Therapies (IAPT) is a large-scale nationwide method of delivering digital and face to face therapy for uncomplicated depression and anxiety.30 Although it now has a Long-Term Conditions (IAPT-LTC) arm to the programme, it is only suitable for a proportion of the population and cannot be seen as the panacea for all mental health.31,32 It can only be seen as part of the wider solution.

The UK Association of Children’s Diabetes Clinicians national survey reported that access to mental healthcare and psychological support was highly variable in the UK and recommended that regular accessible psychological assessments with appropriate referral pathways be made available to people with diabetes.33

5 | PRINCIPLES OF AN INTEGRATED MODEL AND RECOMMENDATIONS FOR IMPLEMENTATION LOCALLY

The Model in Figure 1 describes five principles that have an evidence base and/or precedence from diabetes or other long-term conditions (LTCs). The five principles that the EWG agreed on, cover the range of considerations and support that is appropriate for a diabetes mental health care pathway. The Model includes key recommendations within each of the following principles:

- Care for all—describes how care for all PWD needs to explore what matters to them and that emotional wellbeing is supported at diagnosis and beyond.
- Support and information—describes how HCPs should appropriately signpost to mental health support and the need for structured education programmes to include mental healthcare information.
- Needs identified—describes how PWD should have their mental health needs identified and acted upon.
- Integrated care—describes how people with mental illness who have, or at risk of diabetes should have their diabetes considered within their care.
- Specialist care—describes how PWD should be able to access specialist diabetes mental health professionals.

The recommendations in the Model cover the range of ways that health systems should be meeting these principles of care. To support the Model, we have also created a matrix (Table 1) with the rows denoting work streams that can be used by ICSs and provider organisations to commission and operationalise the principles in the Model. This table reorganises the recommendations within each principle by the following five operational streams: training and upskilling HCPs; embedding brief mental health assessment and screening; signposting local mental health pathways; addressing local health inequalities and access to specialist mental health care. It is unlikely that any ICS will be able to address all of these recommendations at once, so we suggest that each ICS assesses its performance against these principles and prioritises those elements of the recommendations that would have the greatest impact in their local health economy in a phased approach.

To further support local health systems, below we signpost the reader to case studies and examples, as well as resources to support local commissioning, implementation and operationalisation of the core principles.

5.1 | Implement Training and Upskilling of non-mental-health professionals

Upskilling is required for the entire MDT that is delivering care along the diabetes care pathway. This includes but is not confined to GPs, primary care nurses, health coaches, podiatrists, dieticians, diabetic eye screeners, occupational therapists and physiotherapists as well as diabetes medical and nursing specialists.

Upskilling is vital because:

a. PWDs describe wanting to be treated by professionals along the entire diabetes pathway, who are mental-health-aware.1
Support and care is delivered by a multidisciplinary team, and may involve services across primary and secondary care including those from mental health professionals, genitourinary medicine, emergency care, social care, substance misuse, learning disability, memory, eating disorder and other services. People affected by diabetes have input into local service development and have a voice and control over the way their care is planned and delivered. It is based on ‘what matters’ to them and their individual strengths and needs.

**Core Principles**

**Needs identified**

- People with diabetes have their emotional and mental health needs identified and acted on.
- Healthcare professionals have been trained in supporting emotional and recognising need, including for those not engaging with services.
- Mental health and wellbeing assessments are embedded across primary care and secondary care, including for those not engaging with services.
- Psychological assessments are conducted by specialists.
- Psychological therapy is available locally and the flow to relevant specialist support is clear.
- Integrated pathways are in place locally.

**Integrated care**

- People with, or at risk of, diabetes who are accessing mental health support in a specialist or primary care setting have considered within their care.
- People with diabetes and anxiety or depression are referred to specialists for assessment.
- Access to Psychological Therapies for people with long-term conditions is improved.
- Specialist diabetes mental health pathways are designed as a multidisciplinary plan that forms part of their broader care package.
- Interdisciplinary care: People are aware of the increased range of services available.
- Mental health support is available for people with severe mental illness and taken into account when new medication or health management interventions are considered.
- There is access to diabetes testing and tailored prevention interventions for people with severe mental illness.
- There is a joint working between mental health, primary care, diabetes, and mental health professionals.

**Specialist care**

- People with diabetes have access to care from specialists diabetes mental health professionals.
- A mental health professional with expertise in diabetes has identifiable local diabetes services – for example, an applied psychologist.
- Referral pathways exist between NICE guidelines and diabetes specialist mental health pathways are supported by the service.
- There is access to diabetes-specific psychology and/or diabetes nurses.
- People with diabetes can access mental health services for diabetes that are integrated with the care.
- Specialist diabetes teams include a psychologist.

**Further refinement**

- There is access to further input from additional services, such as diabetes specialist nurses.
- There are considerations for other people with severe mental illness to access local diabetes services, for diabetes assessment and management.
- There is access to support for people with severe mental illness to access local diabetes support.
- There is enhanced support for people with severe mental illness to access local diabetes services.

**Support and information**

- People with diabetes are supported in finding facts and support, and referred to relevant services.
- Healthcare professional signpost to appropriate information in primary care and support planning care.
- People with diabetes work with the diabetes service to find out what their individual needs and preferences are at diagnosis and thereafter, having diabetes issues, goals, abilities, wishes.
- Support is tailored to specific and vulnerable groups, including people at risk of diabetes, older people, children and young people, people with severe mental illnesses, people with learning disabilities, people with dementia.

**References**


**FIGURE 1** Diabetes mental health pathway.
b. improved mental health skills may improve the sense of agency of non-mental health staff which reduces risk of burnout and staff describe feeling more empowered with this knowledge.

c. there is currently an inadequate mental health workforce to deliver this work and even if adequate funds were available immediately, the pipeline to train sufficient numbers of mental health staff would take years.34,35

There are several free and paid mental health training programmes available that deliver face to face, online or hybrid training modules for non-mental health staff.36–39
### People with diabetes have their emotional and mental health needs identified and acted on

<table>
<thead>
<tr>
<th>People with diabetes who are accessing mental health support in a specialist or primary care setting have diabetes considered within their care</th>
<th>People with diabetes have access to care from diabetes specialist mental health professionals</th>
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<tbody>
<tr>
<td>Healthcare professionals in primary and specialist diabetes care have been trained in supporting emotional well-being and recognising need, including for those not engaging with services.</td>
<td>Mental health and primary care professionals are aware of the increased risk of developing type 2 diabetes in people with severe mental illness and take action to ensure early identification and optimal management.</td>
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In addition to common mental health problems, cognitive impairment, eating disorders, trauma and substance misuse are also considered in psychological assessments. Mental health and well-being assessments are embedded alongside physical checks as part of holistic diabetes care. Clear integrated pathways are in place. Referral pathways exist between IAPT-LTC and diabetes specialist mental health professionals, ensuring people are supported by the most appropriate service. Those with complex needs are referred to other services such as mental health, memory, substance misuse, eating disorders or learning disability services where needed.

There is access to diabetes testing and tailored prevention interventions for people with severe mental illness. People with diabetes in the care of community or secondary mental health services have a diabetes action plan as part of their broader care plan. Enhanced support is considered for vulnerable groups, including, young people at transition between services. Black, Asian and minority ethnic groups, people with severe mental illness, people with learning disabilities and people with dementia.

In paediatric care, an annual psychological assessment takes place. In paediatric diabetes care, a mental health professional is integrated within the service. A mental health professional with expertise in diabetes distress has dedicated input into diabetes services – for example, an applied psychologist or psychotherapist. There is access to further input from additional services, such as diabetes specialist psychiatry, when needed.

In keeping with the Diabetes UK 7As Model (Ask, Assess, Advise, Assist, Arrange, be Aware and Assign), they enhance knowledge, skills and confidence about mental health detection, first responder mental health interventions and motivational interviewing techniques to support improved engagement with diabetes care plans. This is not to replace mental health staff but to create an empowered staff to deliver initial responses. Conversely, there are also freely accessible diabetes training modules and operational frameworks for mental health workers who work in the community and on mental health units.
Creating a training strategy which demarcates differing levels of competence required by different staff and accessing these existing training modules could be a relatively “quick win” for ICSs to start the implementation journey.

5.2 | Embed brief mental health assessment and screening into diabetes care pathway

There are many validated diabetes-specific screening available, including the 20-item Problem Areas in Diabetes (PAID) and the 17-item Diabetes Distress Scale 17 (available in the short-form DDS2 with 2 items) which can be used as routine screening tools as part of the diabetes care plan and/or annual review.44

There are also validated screening tools that are not diabetes-specific, for example the 9-item PHQ9 (with a shorter 2-item PHQ2), 7-item GAD 7 (generalised anxiety disorder scale with shorter 2-item scale GAD2) and these have been combined into a 4-item PHQ4 (2 depression items, and 2 anxiety items). Although less specific to diabetes, these scales have wider applicability across multiple conditions and have greater recognition and utility across multiple tiers of service provision, for example Primary care and IAPT-LTC.

Each ICS will need to balance their local population and service needs to assess whether to use diabetes-specific scales which give detailed information about the relationship between the person, their diabetes and their healthcare professionals versus the more general scales which have wider applicability and transferability in an increasingly complex healthcare system. See Box 1 for case study.45

Detecting cognitive impairment as early as possible can allow evidence-based treatment to be commenced earlier, advanced care planning to be implemented and additional supportive measures to be put in place that allow for better self-care for longer. There are a number of validated screening tools available for testing cognitive impairment. These vary from 30-item scales like the MMSE or MOCA, that require organisations to buy licences and require some degree of training, to shorter scales that do not require training or a licence, for example 6CIT or Mini Cog. These can be embedded into routine/annual care planning after the age of 60.46 We suggest that this should be added to Quality on Outcomes Frameworks as omission of this ignores the brain as one of the organs at risk of potential end-organ damage from diabetes.47

5.3 | Ensure local mental health pathways are well signposted and as seamless as possible

ICSs should commission service mapping to identify the mental health provision (face to face and digital) available locally. This should cover the different levels of mental health needs for their different populations as described in the pyramid of need in the Too Often Missing report.1 The mapping can then be used to define and disseminate Emergency, Urgent and Routine mental health pathways for people with diabetes. They should have clear referral criteria, referral routes and expected waiting times in order to minimise erroneous referrals.

We suggest that mapping wider than core mental health services might provide greater opportunities for access to care, for example bariatric and eating disorders services, which may have access to more psychological interventions, or substance misuse and memory clinics which may help to address issues that could be affecting the person’s engagement with diabetes self-care.

Third Sector providers of services should be fully integrated into the service mapping process as well as local authority provision so that the wider determinants of health are factored into the local understanding of what is available, as well as what is missing.

Mapping of the local mental health and social services provides opportunities to (a) iron out anomalies within interfacing service policies which might cause unnecessary barriers to referral and (b) highlight significant service gaps or variations within the ICS footprint—this can then be used to develop business cases for further targeted mental and social health provision or appropriate reasonable adjustments for people with diabetes where it is missing. (See section E) for specialist provision.

Box 1  system-level screening case study

In the North West London Diabetes Transformation Programme, a compromise was reached after co-production with a wide stakeholder group which included patient groups: for people with type 1 diabetes who were generally under the care of specialist diabetes services, they implemented the Diabetes Distress Scale (DDS2) and for people with type 2 diabetes, who were generally under primary care, they implemented the PHQ4. PHQ4 was a scale that local primary care had been using for many years and was embedded into their electronic patient record systems. These were incorporated into the 10-year integrated service specification and diabetes dashboard in order to embed monitoring and accountability.
5.4 | Ensure health inequalities are addressed and the needs of disadvantaged populations are included in plans. ICBs should ensure that new innovations do not increase existing health inequalities

Core20PLUS5 is a national NHS England and NHS Improvement approach to support the reduction of health inequalities at both national and system levels. The approach defines a target population requiring accelerated improvement.48

Core20 refers to the most deprived 20% of the national population. The PLUS population groups include ethnic minority communities, people with learning disabilities and/or autism, people with multi-morbidities, people experiencing homelessness, drug and alcohol dependence, vulnerable migrants and other excluded groups. The five aspect refers to five national clinical areas of focus: maternity, severe mental illness (SMI), chronic respiratory disease, early cancer diagnosis, hypertension case-finding.

Our Matrix and Model set out a number of areas where targeted interventions will be required to bring outcomes of those populations described in CORE20PLUS5 closer to the national average. There are tool kits to support this, with case examples for various excluded groups, that can be extrapolated from other clinical areas.49,50 In addition, ICSs will need to apply a health inequalities lens to any new interventions they implement to ensure that access disparity is not widened for example, through digital exclusion.51

5.5 | Improve access to specialist diabetes mental health care through commissioning

The ICS service mapping processes used with the matrix (Table 1) should highlight which areas need to be targeted for further specialist diabetes mental health input and support the development of a business case. NHS Education for Scotland and the Improving Access to Psychological Therapies programme commissioned a competence framework for psychological interventions for people with persistent physical health conditions.52 It describes a stepped approach and competency map to the skill sets required by mental health staff for different levels of intervention for people with physical health conditions. This can be used to define the skill set of specialist mental health clinicians such as psychologists, psychotherapists, counsellors, health coaches and psychiatrists. We recommend that attention is paid to provision of services for the people highlighted in the previous section, who fall into the CORE20PLUS5 cohort, addressing addiction disorders, learning disabilities, complex trauma histories.

6 | DISCUSSION

We have described the Model (Figure 1) and recommendations for an implementation plan (Table 1) and how it can be used locally in co-production with PWDs and their carers, community and peer groups, third sector and statutory providers and commissioners. Whilst the Model and the recommendations are specific to England, the principles and approaches should be transferrable to the devolved nations. Indeed, many exemplars and guides that come from the devolved nations have informed in this paper.44,53,54

The recommendations have been designed to apply across services and across all demographics including type 1, type 2 and other types of diabetes, unless stated otherwise. Many of the recommendations can also be applied to paediatric diabetes care, although some may not be appropriate for children and young people—paediatric commissioners and clinicians should adapt the recommendations accordingly for children’s services.1

7 | CONCLUSION

This paper has described the evidence, case studies and experiences of the EWG to support local implementation of recommendations in the Model. The move towards integrated care delivery and commissioning through the development of ICSs is an ideal opportunity to be able to deliver on some of these recommendations. Following our model will also help continue to strengthen the evidence not just for diabetes integration but for other conditions and consider making them applicable across multimorbid syndromes.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this paper.

DATA AVAILABILITY STATEMENT

I confirm that my Data Availability Statement (pasted below) complies with the Expects Data Policy.
sharing is not applicable to this article as no new data were created or analyzed in this study.

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