London Diabetes Transformation Board – Cover Sheet

Programme/:	Diabetes & Eating Disorders	**Reporting period:**	
Lead / Author :	Shaun Crowe		

Summary of request:

- Following an invitation from the NHS Diabetes Programme Board, London as a region has been awarded [redacted] one of two national pilots to trial, test and evidence the impact of an integrated diabetes and mental health pathway for the assessment, referral and treatment of diabulimia.
- This PID sets out key information on how the pilot will be rolled out in London.

Decision or action requested of Formal SMT:

For information of board members to discuss and comment

Additional information supporting request:

Involvement from Medical and Transformation involvement at both Regional and National level

Integrated Physical and Mental Health Pathway:

Type 1 diabetes and eating disorders

Pilot Initiation Document: Project Diabulimia

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Background

- Eating disorders are more common in people with type 1 diabetes than those without (Jones et al, 2000) and there is an emerging understanding of ‘diabulimia’ as a diabetes-related eating disorder.

- Although diabulimia is not yet formally recognised as a medical or psychiatric disorder, the term is in increasing use in both academic literature and social media. It is recognised as having the following diabetes-related characteristics - particularly points (b) and (c) below:

  (a) Dietary and insulin restriction (most similar to anorexia);
  (b) Overeating and binging on high carbohydrate foods and omitting insulin to prevent weight gain or induce weight loss and / or self-induced vomiting; and
  (c) Grazing frequently or eating normally and omitting bolus insulin in a harmful way for fear of weight gain.

- There have been a number of recent high profile deaths reported in the media which has been linked to a lack of clinical awareness. The latest NICE guidance on eating disorders includes reference to diabetes and its management – the first time these have been mentioned – but does not specifically reference diabulimia.

- Following an invitation from the NHS Diabetes Programme Board, London as a region has been awarded £345,000 as one of two national pilots to trial, test and evidence the impact of an integrated diabetes and mental health pathway for the assessment, referral and treatment of diabulimia. This PID sets out key information on how the pilot will be rolled out in London.

Case for change

Prevalence of Type 1 diabetes is growing and is the most common chronic long term condition in childhood.

Eating disorders are more common in people with type 1 diabetes than those people without (Jones et al, 2000).

An increase in the type 1 diabetes population suggests that the number of people requiring support for eating disorders – including specialist treatment – will continue to grow.

The long term consequences of eating disorders can lead to increased mortality, morbidity, chronic complications, critical incidents and health care utilisation.

Diabulimia is not recognised as a medical or psychiatric condition but is increasing in 'face validity' due to an increased usage in the academic literature, media and by patient representative groups.

A combination of limited epidemiological data to fully understand need, a failure to clinically agree a title or name of the condition, a difficulty in professionals identifying and treating diabulimia has made it difficult to commission and provide an identified clinical pathway.

There is no cure for type 1 diabetes, and modern management to achieve optimal blood glucose control is complex and demanding with lifelong replacement with insulin doses adjusted to match carbohydrate intake, exercise activity, correction of high or low blood glucose levels.

Optimising good glycaemic control can often lead to weight gain, which in turn may trigger a set of critical unhelpful cognitions and negative emotions. These may include a fear and loathing of insulin as the perceived cause of this weight gain, distorted body image, loss of self-worth, perceived loss of control, and sense of failure. Subsequently, in addition to anorexia nervosa and classical eating disorders, insulin omission and dietary mismanagement may be used by individuals as a weight control strategy

Shaban (2013) suggests that there is a higher prevalence of people with T1 diabetes with an eating disorder due to patients under reporting. Evidence implies that as many as 140,000 children and young people display dangerously high blood glucose levels (Davidson, 2014). .

The evidence suggests:

- Insulin omission for fear of weight gain is associated with a three-fold increase in the risk of death compared to non-diabetes individuals (Goebel-Fabbri et al, 2008; Callum, 2014)
- ~ 30% of people with type 1 diabetes have some insulin restriction/omission secondary to fear of weight gain, also termed diabulimia, disordered eating, eating disorder
- ~ 10% of people with type 1 diabetes have dangerous levels of insulin restriction/omission and likely to develop advanced diabetes complications within 5-10 years
- ~5% of people with type 1 diabetes have extremely dangerous levels of insulin restriction/omission leading to weight loss and recurrent admissions and high risk of mortality in the next 2-5 years (n~100-150 patients across 30 London acute hospitals)
- Among type 1 diabetes related deaths for patients aged under 30, 54 - 76% can be attributed to diabetic ketoacidosis (Fazeli Farsani et al, 2017).

There have been a number of recent high profile deaths reported in the media which has been linked to a lack of clinical awareness (BBC, 2017). The latest NICE guidance on eating disorders includes reference to diabetes and its management - but does not specifically reference diabulimia nor offer diabetes focused guidance. Diabulimia is associated with people with type 1 diabetes overeating and binging on high carbohydrate foods and omitting insulin (bolus and / or basal) to prevent weight gain or induce weight loss and / or self-induced vomiting; and grazing frequently or eating normally and omitting bolus insulin in a harmful way for fear of weight gain. Diabulimia is mostly prevalent in young women creating a societal impact through: significantly reduced educational attainment; loss of work productivity; and a huge amount of carer burden.

This pilot will trial and test an integrated diabetes and mental health pathway to support the diabulimia population and stop people falling through the 'net'.

Scope

In scope

The key purpose of the pilot is to:

- trial, test and evidence the impact of a integrated diabetes and mental health pathway for the assessment, referral and treatment of diabulimia (*).
- publish an independent evaluation of the integrated pathway, a replicable hub and spoke model and make recommendations for regional rollout across the country
- share lessons learned and collateral to support the development of the integrated pathway and hub and spoke model

Out of scope

- trial, test and evidence the impact of an integrated service for people with type 1 or type 2 diabetes with dietary and insulin restrictions

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(*) Diabulimia is associated with people with type 1 diabetes overeating and binging on high carbohydrate foods and omitting insulin (bolus and / or basal) to prevent weight gain or induce weight loss and / or self-induced vomiting; and grazing frequently or eating normally and omitting bolus insulin in a harmful way for fear of weight gain. Diabulimia is mostly prevalent in young women creating a societal impact through: significantly reduced educational attainment; loss of work productivity; and huge amount of carer burden

Design principles

- **The majority of the funding should resource the multi-disciplinary team members.** As the main purpose of the pilot is to trail, test and evidence the impact of an integrated diabetes and mental health pathway then the majority of the funding should fund the team.

- **The pilot aims to provide an operational pathway for as long as possible to maximise learning from this new way of working.** We aim for the pathway to be funded and fully operational for 18 months (Plan A). We have also factored in options for a 15 month operational period (Plan B) and a minimum 12 months period (Plan C). Plan B and Plan C therefore provides a 3 month contingency period should we experience delays in recruitment or need time for procurement. See below.

- **If procurement is required then it should be light touch.** A teaching hospital providing the only service in London with specialist expertise in this area has already come forward. The trust wants to lead the development of the 'hub and spoke' model and enable pan-London coverage. If NHS Diabetes Transformation Board feels that market engagement is necessary then we would encourage the adoption of the model used by NHS England in commissioning the services of Operational Delivery Networks. This involves a 'light touch' Expression of Interest process and panel selection, chaired by the Medical Director and SRO, to determine a preferred provider. We aim to complete this process in 3 weeks.

- **Approximately 10% of the total pilot budget will be used to fund an independent evaluation.**

- **There are two key phases to making this pilot project a success.** These are the mobilisation phase (stage 1) and the delivery phase (stage 2). For these reasons, the project manager will be employed by the London Clinical Networks. This is so we can offer prospective candidates a 1.0WTE fixed term contract and will help us navigate the crucial mobilisation stage in delivering our primary objective of providing an operational pathway for a 18 month period. It is expected that the project manager will be based at the provider site for 3 days a week.

- **The provider will identify an appropriate operational lead to support the project manager in their work.** These costs will not be funded by the pilot and will be resourced by the provider.

Pilot outputs, outcomes and impact

Outputs

Integrated diabetes and mental health pathway developed and tested

Replicable ‘hub and spoke ’ regional model trialled and tested in London

Service specification for shared diabetes and mental health multi-disciplinary team developed and operational from one “centre of excellence” and interdependent local diabetes centre(s)

Risk stratification, assessment and referral criteria documented and communicated

Training programme developed and received by diabetes and mental health professionals

Independent evaluation report published to evidence impact of the integrated pathway, hub and spoke model and make recommendations for regional rollout

Target Outcomes

To improve professional and public understanding of diabulimia as a medical or psychiatric disorder and the needs of people with type 1 diabetes and diabulimia

To increase professionals’ awareness of diabulimia assessment, detection, referral pathways and interventions

To improve multi-disciplinary team working and expertise; psychiatric knowledge and psychotherapeutic skills in diabetes professionals; and knowledge of associated impact of calorie intake, exercise and insulin use in people with type 1 diabetes within mental health teams

Up to five people with diabetic ketoacidosis and chronic hyperglycaemia receiving acute inpatient care at any one time

Up to 240 emergency hospital admissions received in 12 months

Up to 50 people receive outpatient care in 12 months

To reduce advanced complications (diabetic ketoacidosis and chronic hyperglycaemia) and length of stay in type 1 population with diabuilimia

Evidence of impact through independent evaluation enables hub and spoke model to be adopted in London and spread to the other nine English regions

Target Impact

Primary Impact

The most critical 5% of type 1 diabetes population in London are identified with diabulimia and access integrated diabetes and mental health care

TBC% reduction in diabetes advanced complications in people with dangerously high levels of insulin restrictions/ omissions as a result of the integrated diabetes and mental health pathway over the course of the pilot

TBC% reduction of hospital admissions due to diabetic ketoacidosis and chronic hyperglycaemia

TBC reduction in the number of inpatient bed days for the treatment of diabetic ketoacidosis and chronic hyperglycaemia

Service-user and carer experience

Secondary Impact

TBC% reduction in PHQ-9, GAD-7 or scores of an alternative measure of mental wellbeing in both service-users and carers

TBC% reduction in mortality and risk of mortality in people identified as high risk of mortality over the course of the pilot

Pilot Timeline: 15 months of operational delivery

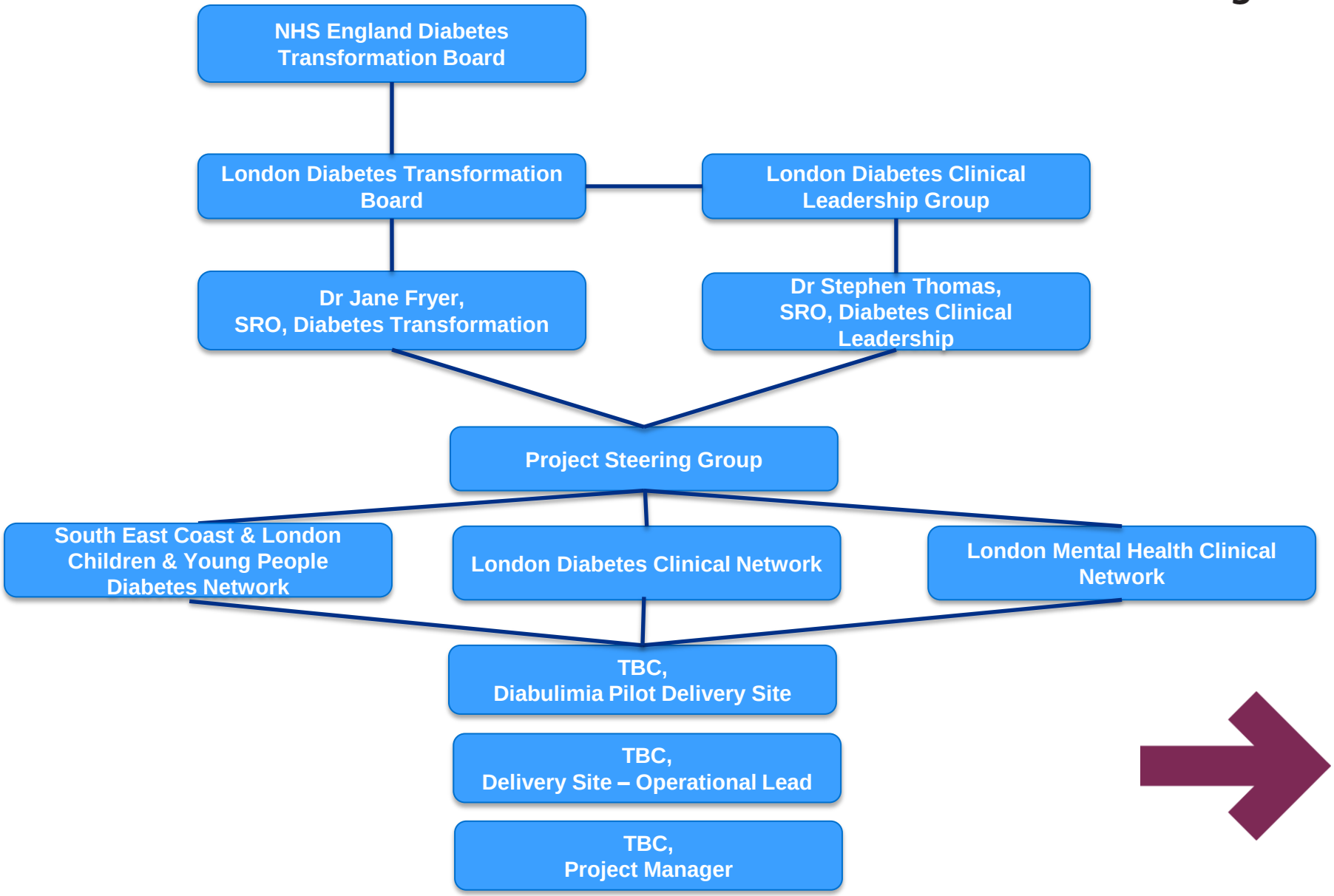
Phase 1: Mobilisation

Milestone	Date
Pilot Initiation Document approved	Aug 2018
Funding confirmed by NHS England	Aug 2018
Project steering group established	Aug 2018
Teaching hospital with established psychiatric liaison service appointed	Sept 2018
Inpatient bed capacity and geographical location of beds confirmed	Sept 2018
Local diabetes centre appointed	Sept 2018
Diabetes and mental health multi-disciplinary team service specification documented	Sept 2018
Project Manager recruited	Oct 2018
Training programme produced	Oct 2018
Diabetes and mental health multi-disciplinary team members in post	Nov 2018
Case manager appointed and trained	Nov 2018
All MDT members complete training	Nov 2018
Clinical supervisors appointed	Nov 2018
Diabetes patient safety protocols developed	Nov 2018
Risk stratification, assessment and referral criteria and process agreed	Nov 2018
Patient safety risk assessment carried out	Nov 2018
Equalities impact assessment carried out	Nov 2018
Evaluation partner recruited	Nov 2018
Evaluation framework approved by steering group	Dec 2018

Phase 2: Delivery

Milestone	Date
Risk stratification, assessment and referral criteria/ process communicated to primary and secondary care teams	Dec 2018
Choice of psychotherapeutic modalities offered to diabulimia patients on the pathway	Dec 2018
Case management implemented	Dec 2018
In team, hybrid and outreach intervention models implemented	Dec 2018
Regular clinical supervision implemented	Dec 2018
Diabetes patient safety protocols implemented and monitored	Dec 2018
Start of operational delivery: Inpatient service operational	Dec 2018
Start of operational delivery; Outpatients service operational	Dec 2018
Monthly data reporting submitted to evaluation partner	Dec 2018
Six-weekly highlight report prepared for London Diabetes Transformation Board	Dec 2018
Quarterly highlight report submitted to NHS England Diabetes Programme Board	Dec 2018
End of operational delivery at 15 months	Mar 2020
Final evaluation report published	May 2020
‘Hub and spoke model’ and other project outputs shared to support wider regional adoption	May 2020

Project Governance



Risks

	Description	Likelihood	Impact	Risk score	Mitigating Actions	Likelihood	Impact	Risk score	Owner
1	Delays in recruitment to key MDT posts postpones the implementation of the integrated pathway. This compromises the overall volume of patients receiving treatment and restricts the overall evidence available to assess impact.	4	4	16	Arrangements have been made by NHS England (London) to commence the mobilisation phase immediately after funding has been confirmed with a choice of 'go live' timeframes of Oct 2018 or Dec 2018. In addition, we have factored in 3 months contingency into the overall delivery timeline (Plan B & C) and therefore enabling the pathway to be operational for shorter period of 15 months and 12 months period, respectively. This will provide sufficient time to evidence outcomes and assess impact of the pilot.	2	4	8	Jane Fryer, SRO
2	A requirement to follow formal NHS England commercial procurement processes through open market engagement and competitive tendering delays the start of the pilot.	4	4	16	One teaching hospital, with expertise in this area and an existing service has already come forward expressing interest in getting involved in the pilot. Should procurement be required then NHS England (London) would recommend the approach adopted the Specialised Commissioning in setting up Operational Delivery Networks, by using 'light touch' Expressions of Interest and a selection panel to determine a preferred provider. As this will take 3 weeks to complete, it makes Plan A, B and C all viable.	2	4	8	Jane Fryer, SRO

Further information