


Living with Type 1 diabetes - Finding an Eating Disorder



Sara Crowley

@Type1Hurdles



**Nowhere in my medical notes will you find
mention of an eating disorder.**

Except in my HbA1c history,
if someone looked beyond my numbers.

**Therefore, I have never been able to
access any formal help.**

Because nobody saw
beyond my numbers.



**If I was missed, how many more people
like me are not accounted for?**

The scale of the problem is unknown,
because it can't always be measured.

Or we simply get missed.



I'm lucky - I helped myself to recover.

Please note: Only one professional has ever asked if I have a history of an eating disorder.

This came in 2017, from my dentist.

This talk isn't to point fingers
or throw blame at anyone.

**But I hope it changes practice –
because I believe there are varying degrees of insulin
omission in every diabetes clinic, right in front of you.**

And it can start subtly, rather than intentionally.



‘Rather than **living** with my **condition**, my condition **lives with me** and **everything I want to do**. I won’t let it **stop me** from attempting to live my **life to its fullest**.

It has given me **reason** to **appreciate** all aspects of my life, it’s been my **greatest teacher** and I **believe** I’m a **better person** for it, but pictures can often be **deceiving**....

Even with a **positive attitude**,
I struggle.

And when I do, **I don’t feel there is support** in the **way I need it**.
I understand how my **pancreas should work**,
and **what I should be doing**
but I **don’t always understand my brain.**’

Vulnerable points: **High School through University**

- **Why I believe we have to better the way we support young adults.**

Signs of insulin manipulation from as early as **year 8/9** (12-14 years old)

Which only **worsened** the **older I became.**



My last school photograph. **(17)**

**'T
R
A
N
S
I
T
I
O
N'**



Visit home, first year of university. **(19)**

I couldn't do what was **expected of me.**

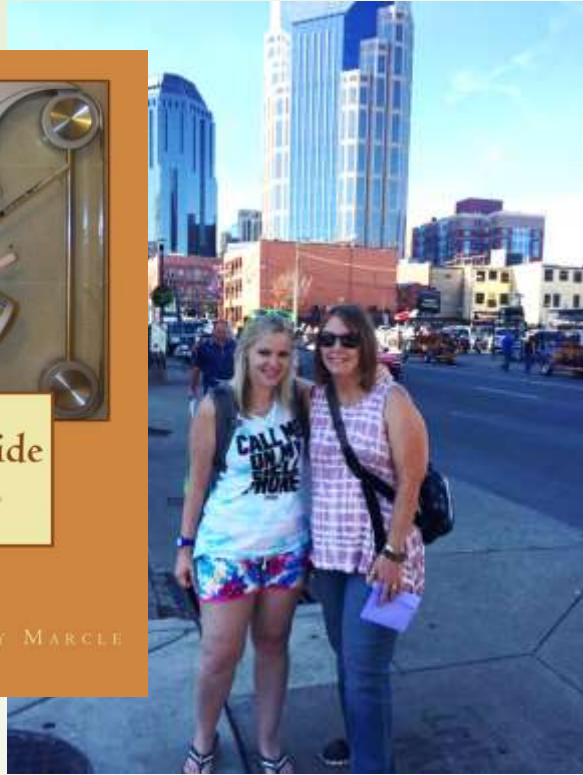
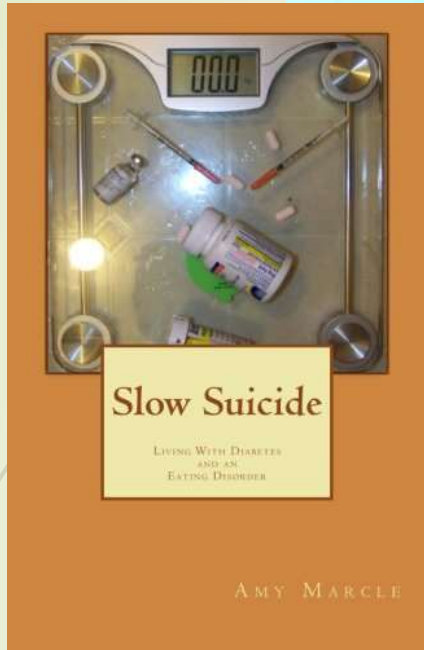
I couldn't **'control'** my condition as my **life stepped up a gear** as a **young adult.**

But **I could control ...being uncontrolled.**

This **picture** was taken within the first year or so of being under **adult care**. I never disengaged from services, I would not have been known to be a 'frequent DNA-er' as I was **going to my clinic appointments**, but I **never** found them **particularly useful**. It was more an afternoon of feeling like what they were asking of me was **unrealistic** and **unachievable** and I'd just go to **not feel good enough**,
Leave clinic and feel **even worse**.

This became a path of **destruction** and **unknown unintentional self-harm**.






I **travelled** to
Nashville on Aug 3rd
2017 to meet **Amy** and
her **family**.

I **thanked** her in **person**.
She **saved** my **life**.

It took a **book** written by someone in the
United States, living with **Type 1**
diabetes who was also **facing** the
same struggles as me to **realise** I was
not alone.

Not one **clinician** ever **explored** my
insulin intake or my **behaviours**
around my condition, it was always **all about**
the numbers, but with a **HbA1c** at almost
15mmol/mol, the **warning signs** were
there, but the **support** in the way I
needed it **wasn't**.

Again, I never felt **good**
enough.



Missed signs or symptoms

Are you seeing these in your clinic?


- Constant high HbA1c [9+ (74) is a sign, mine was almost 15 (140)]
- Dishonesty and lies - made up numbers in log book, 'forgot my meter' etc.
- Unexplained weight loss & weight fluctuation (but BMI is useless!)
- Persistent thirst & frequent urination (multiple times through the night)
- Interrupted sleep, fatigue & lethargy - needing frequent naps
- 1 DKA & but hundreds of near DKA episodes (that aren't accounted for anywhere)
- Frequent yeast infections – thrush
- No period for 6+ months
- Stock pile of unused insulin & prescriptions at home
- Face always looked gaunt – rosy cheeks, no colour
- Cuts not healing – scarring over body
- Self-harm - not in the way most consider 'self-harm' leading to addiction (bulimia)



Behind the numbers of HbA1c

- **Underneath the surface**

- Resentment towards my condition, turned to resentment towards myself
- Stopped checking my blood glucose for months
- Refused to take any diabetes related 'stuff' out with me
- Refused to talk about 'my' diabetes – pushed parents away
- Stopped taking basal insulin completely
- Reduced insulin to the minimum amount that kept me out of hospital
- 'Inject' in another room – usually my bedroom
- 'Inject' in front of people but the plunger wasn't touching the insulin
- Limit the number of injections, conscious of my 'lop-sided' stomach
- Hated clinic: I was in the room, but I was disengaged
- Distrust with professionals – they were forever 'tweaking' my insulin, but obviously unable to 'see' I wasn't taking in the first place.



Behind the numbers on the scales

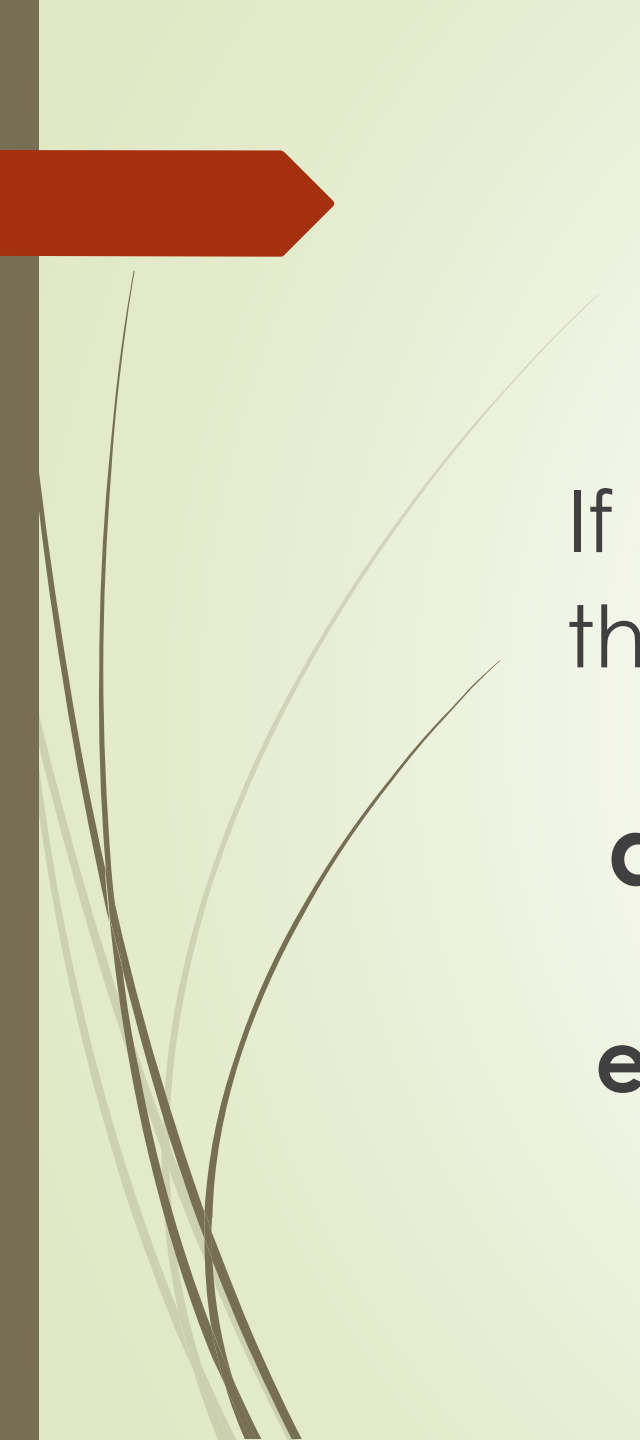
- **Underneath the surface**

- I felt overwhelmingly controlled by food because of my diabetes regime
- Stigma – in particular with ‘obesity’ and society thinking ‘I did this to myself’
- Restrict food to lose weight → hypo → guilt/failure → low self-esteem → binge → guilt → purge → repeat cycle.
- Insulin omission, or ‘mis-matched insulin’ breaks this cycle
- The ‘worse’ the food, the higher my blood glucose = the more weight I lost
- It goes against everything society tells us about ‘dieting’
- ‘Diabulimia’ wasn’t recognised so nobody would question – lethal combo
- Comments on my weight loss and my clothes hanging off me felt good
- This, made me feel good – at a time I couldn’t feel good anywhere else
- This spiralled out of control until I was also vomiting multiple times a day



Other factors or potential triggers **That are too important to be overlooked**

- Power imbalance between professionals and people living with diabetes
- How clinic made me feel about myself including being weighed so often and being asked how often I exercise when excessive exercise was one of my triggers
- I feel I've been conditioned to chase perfection – 4-7mmol/l
- I was coming to terms with sexuality, when LGBT+ wasn't as accepted
- Unhealthy relationships that made me feel worthless
- Isolation (even though I always had friends/support around me)
- Lack of acknowledgement of the impact Type 1 diabetes on mental health
- Negative language – around diabetes, weight, food, complications, health
- Intense feeling of failure
- Body image & clothing including triggers like changing rooms



If someone is **unhappy** in **their own skin** or if they have **low self-esteem**, where do they **find** such **strength, motivation** and **determination** to look after something as **intense** as **Type 1 diabetes**, when the **expectation is perfection** and the **reality** of it is **impossible**?



Tips/Things that have helped me 😊

- I have found my own regimen of what individually works for me and my life
- I don't avoid a single food group – everything in moderation
- Finding my voice – and developing the confidence to use it
- Being open with my current partner (she is amazing beyond words!)
- Diabetes tech – introduced when I was (mentally) ready to use it
- Trained myself to rethink numbers, and better still, the glucose line and arrows
- Setting my own expectations and knowing my limits
- Practicing and exploring different ways of self-care
- It's hard, but I had to make friends with myself and learn to like myself
- I got rid of scales and full length mirrors in my house (re-introduced, not in view)
- I've learned when to challenge my thoughts and when to listen to them
- And when all else fails, there is nothing like being able to turn to peer support...

If you 'don't want to open a can of worms.'

- Eating disorders thrive on secrecy

We all need to understand **mental health**
and be able to **support** and **talk about** it.

Of the long **list** of '**diabetes complications**' I was warned about, **why wasn't mental health one?**

Not addressing this has certainly **led** to me to the physical **complications** they warned me about.

This **picture** is **just one**.

But, **you** can **change** this for **others like me**.
(Attitudes and language don't require any funding! 😊)





Breaking the stigma **@Type1Hurdles**

Diolch am wrando
Thank you for listening

**‘My worth never was, never can and never will
be measured in my HbA1c or weight.’ – Sara**

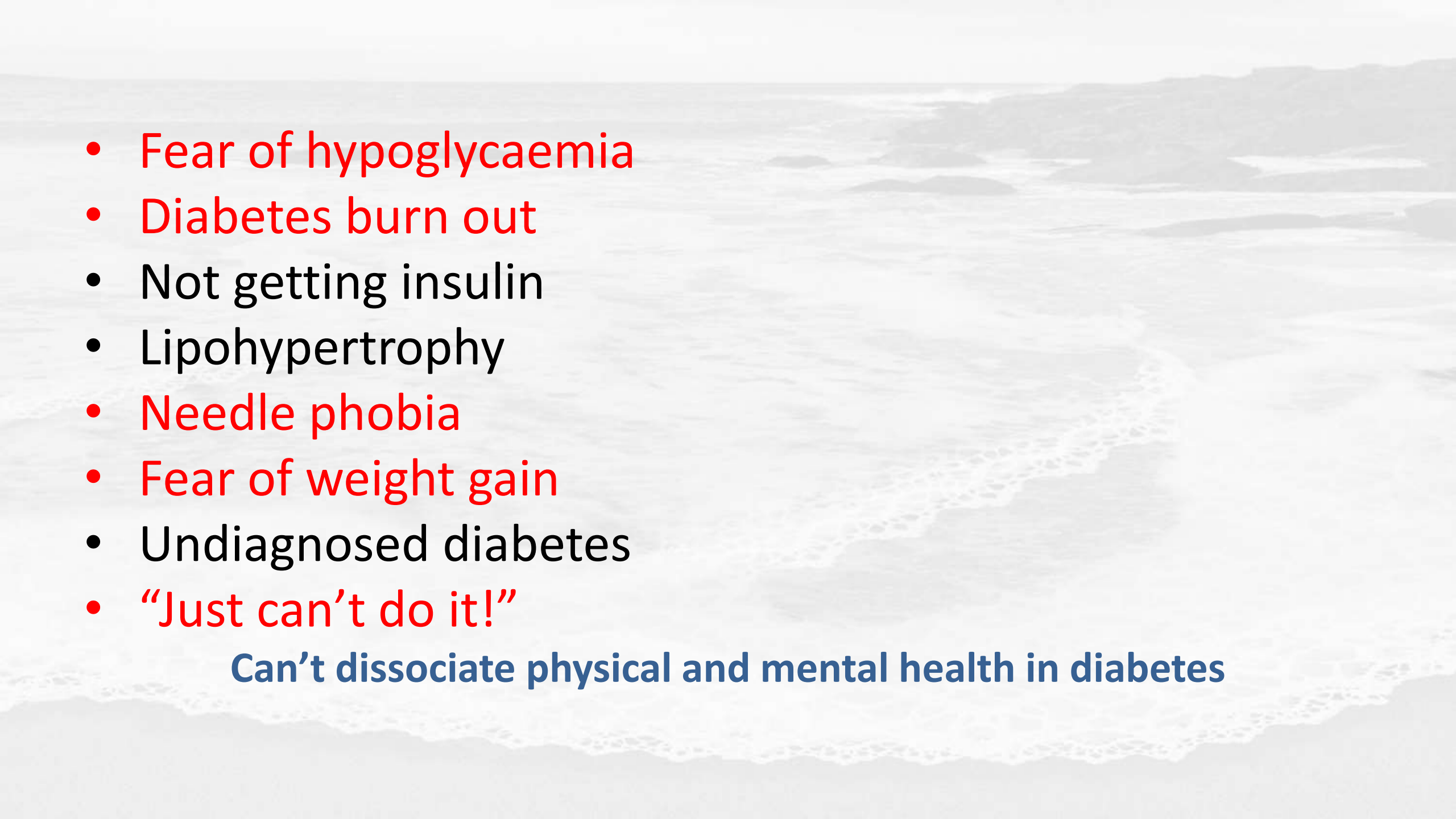


The ComPASSION Project

**Combined Pathway for Assessment and Support for
the Syndrome of Insulin Omission –Type 1 diabetes
Wessex Pilot**

**Dr Helen Partridge
Consultant in Diabetes
Royal Bournemouth Hospital**

**Dr Carla Figueiredo
Consultant Psychiatrist
Dorset Eating Disorders Service**

- 
- Fear of hypoglycaemia
 - Diabetes burn out
 - Not getting insulin
 - Lipohypertrophy
 - Needle phobia
 - Fear of weight gain
 - Undiagnosed diabetes
 - “Just can’t do it!”

Can’t dissociate physical and mental health in diabetes

Disordered eating

- Frequent dieting, anxiety associated with specific foods or meal skipping
- Chronic weight fluctuations
- Rigid rituals and routines surrounding food and exercise
- Feelings of guilt and shame associated with eating
- Preoccupation with food, weight and body image that negatively impacts quality of life
- A feeling of loss of control around food, including compulsive eating habits
- Using exercise, food restriction, fasting or purging to "make up for bad foods" consumed

Why is disordered eating common in T1D?

- having to carefully read food labels
- the focus on weight at clinic
- having to eat to treat hypos, which can cause weight gain and guilt
- being constantly aware of carbohydrates or calories in food
- feeling shame over how diabetes is managed
- a bad relationship with healthcare team
- difficulty keeping to a healthy weight.
- Significant weight loss at diagnosis

3 P's of eating disorders

- **Predisposition** –genetic, environment, temperament
- **Precipitating** –Weight loss, trauma, chronic stress & negative affect, lifecycle transition, peer group, media, bullying
- **Perpetuating** –Malnutrition, social isolation, emotional responses, cognitive difficulties, body image disturbance, behaviours that maintain the problem

When disordered eating become an eating disorder?

And what do we call it?

- Syndrome of Insulin Omission? T1DE?
- Criteria
 - Type 1 diabetes
 - Significant Diabetes Distress (>6 on DDS?)
 - Pervasive concern around weight gain and body image
 - Insulin omission to prevent weight gain

? Markers of severity

What are we trying to do?

Wessex Hub and Spoke model

- Joint working in MDT Bournemouth
 - Consultant diabetologist and consultant psychiatrist
 - Diabetes nurse specialist
 - Specialist dietician
 - Psychologist
 - Eating disorders specialist practitioner
- Spokes at Portsmouth, Poole and Dorchester
 - Consultant Diabetes
 - Eating disorders specialist practitioner
 - Specialist Diabetes nurse/ dietician

So how are things going?

- Questionnaire to identify at risk/ screening tool for use in general type 1 diabetes clinic/ community
- Joint clinics with diabetes and eating disorder teams –shared care
- Weekly clinical MDT
- 3 monthly CPA
- Monthly joint calls with London Hub
- National Type 1 / Eating disorders conference
- Developing SOPs and protocols for clinical practice (joint with London)
- Developing Day Case provision
- Peer supervision
- Regular review of processes
- User involvement in service design and development

Education Program

- Language
- Awareness
- Communication skills
- Education
- Online Patient Partner Network
 - Peer to peer online support and mentorship?
 - Resource area for HCP
 - Support area for carers and family

Important things we have learnt!

- Diabetes teams need to learn about eating disorders
 - confidence in asking difficult questions
 - **communication skills and MI techniques**
- Eating disorders teams need to learn about diabetes
- Most other clinicians need to learn about both!
- Be open minded about phenotypes
 - Most people are of normal weight/ BMI initially
 - HbA1c may not be significantly elevated at first
 - May have comorbid psychopathologies
 - May have multiple behaviours
 - Insulin omission
 - Food/ carb restriction
 - Bingeing/ purging

Need to look like we know what we're doing

Important things we have learnt!

- Single point of contact with team decision making and communication
 - Give people time to assimilate emotions and concepts
 - Take small steps and celebrate them
 - Awareness that we may not cure everyone
 - VERY emotional, difficult, frightening time
 - Need to develop therapeutic relationship
- “I started to move forwards once I really believed that you were all on my side”

Wessex Team

- Jacqueline Ryder –Diabetes Specialist Nurse
 - Lindsey Rouse –Diabetes Psychologist
 - Nicola Stacey –Diabetes Specialist Nurse
 - Micki Bennet –Eating Disorder Specialist Practitioner
 - Claire Pinder –Eating Disorder Specialist Dietician
 - Caroline Cross –Project Manager
-
- Poole –Dr Adam Nicholls, Sarah Alicia
 - Dorchester –Dr Fiona Wotherspoon, Kerri Hampton
-
- Portsmouth –Dr Eveleigh Nicholson, Lorraine Avery, Linda Gerrard-Longworth

Pioneering better health for all

T1DE Pan-London Collaborative

Diabetes Professional Conference
October 2019

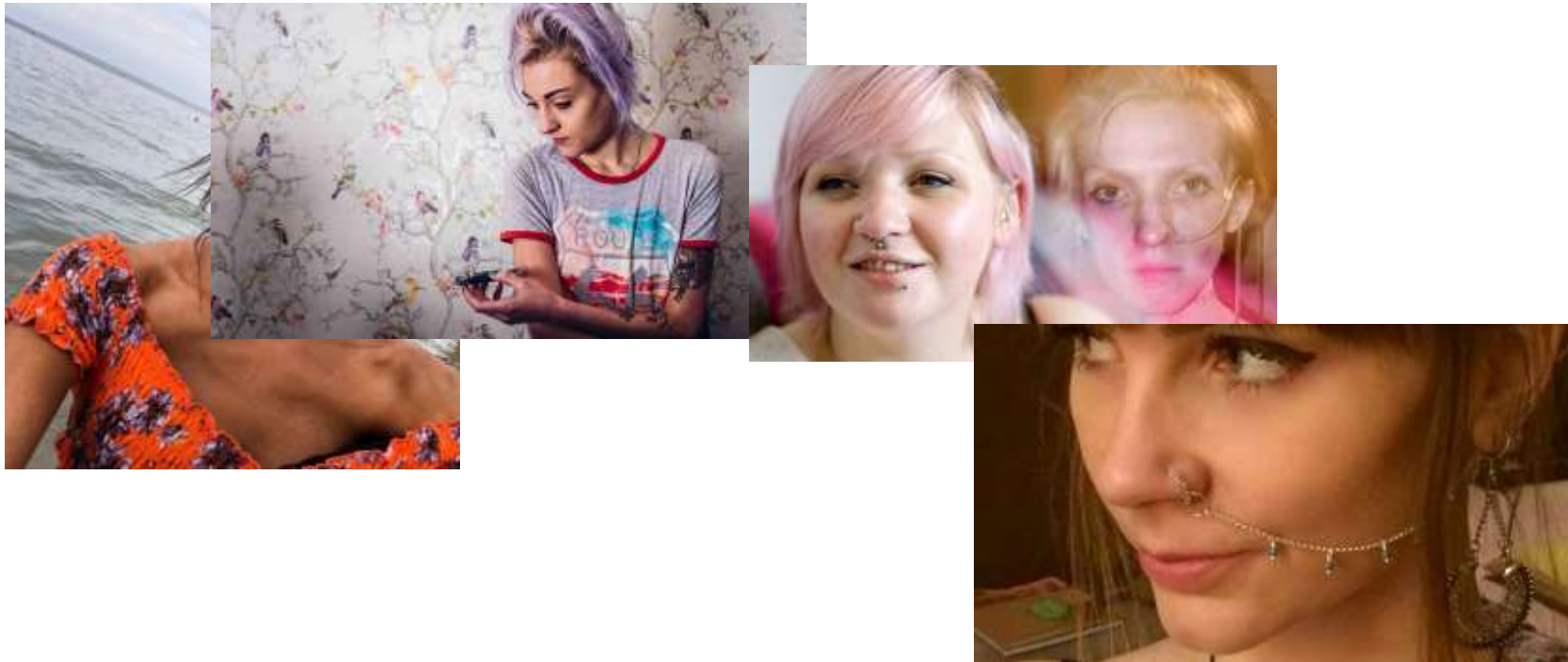
Dr Sophie Harris

Overview

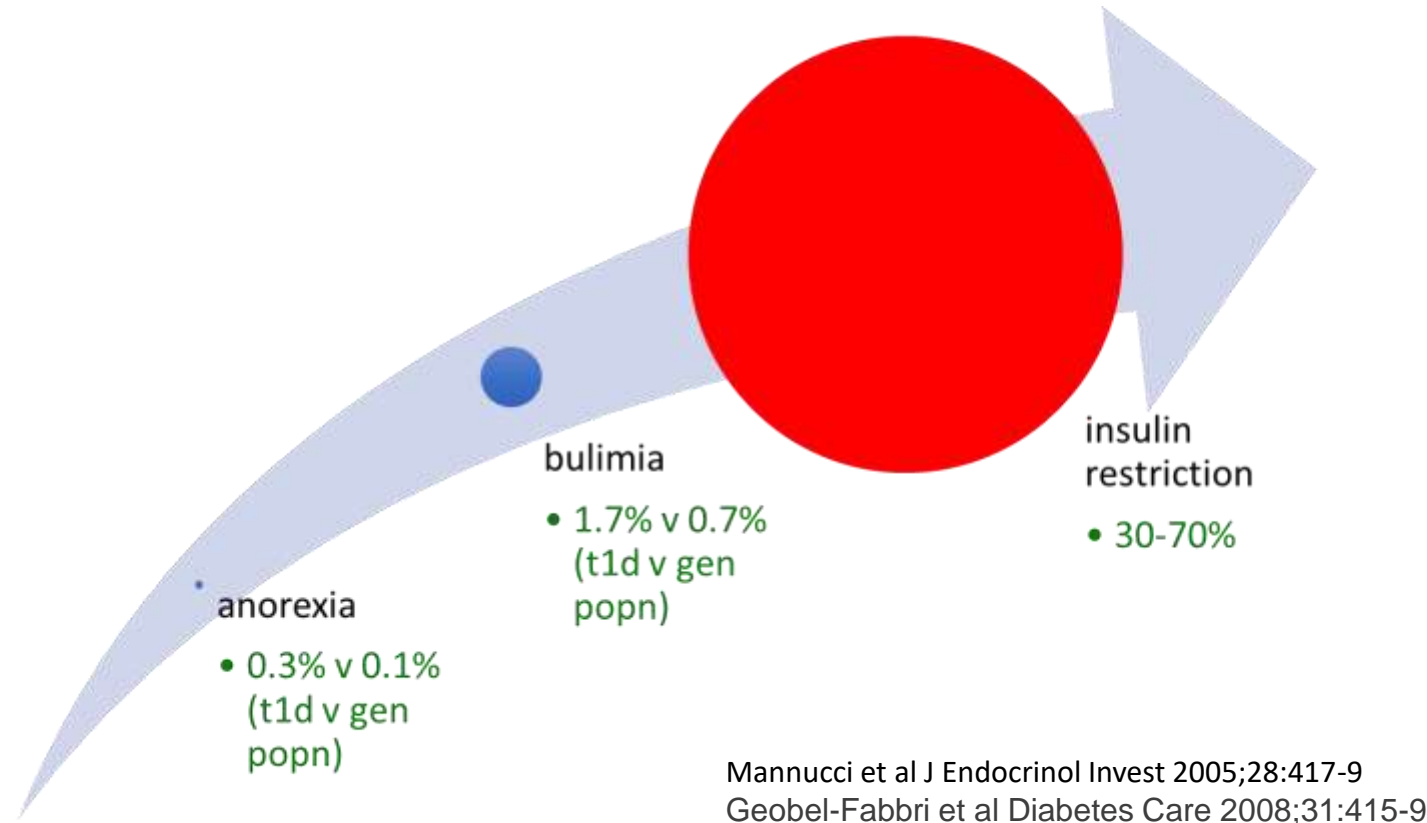
- Context
- KHP Definition of T1DE
- Hub & Partner model
- Model of care
- Example case load

Eating disorders in type 1 diabetes (T1D)

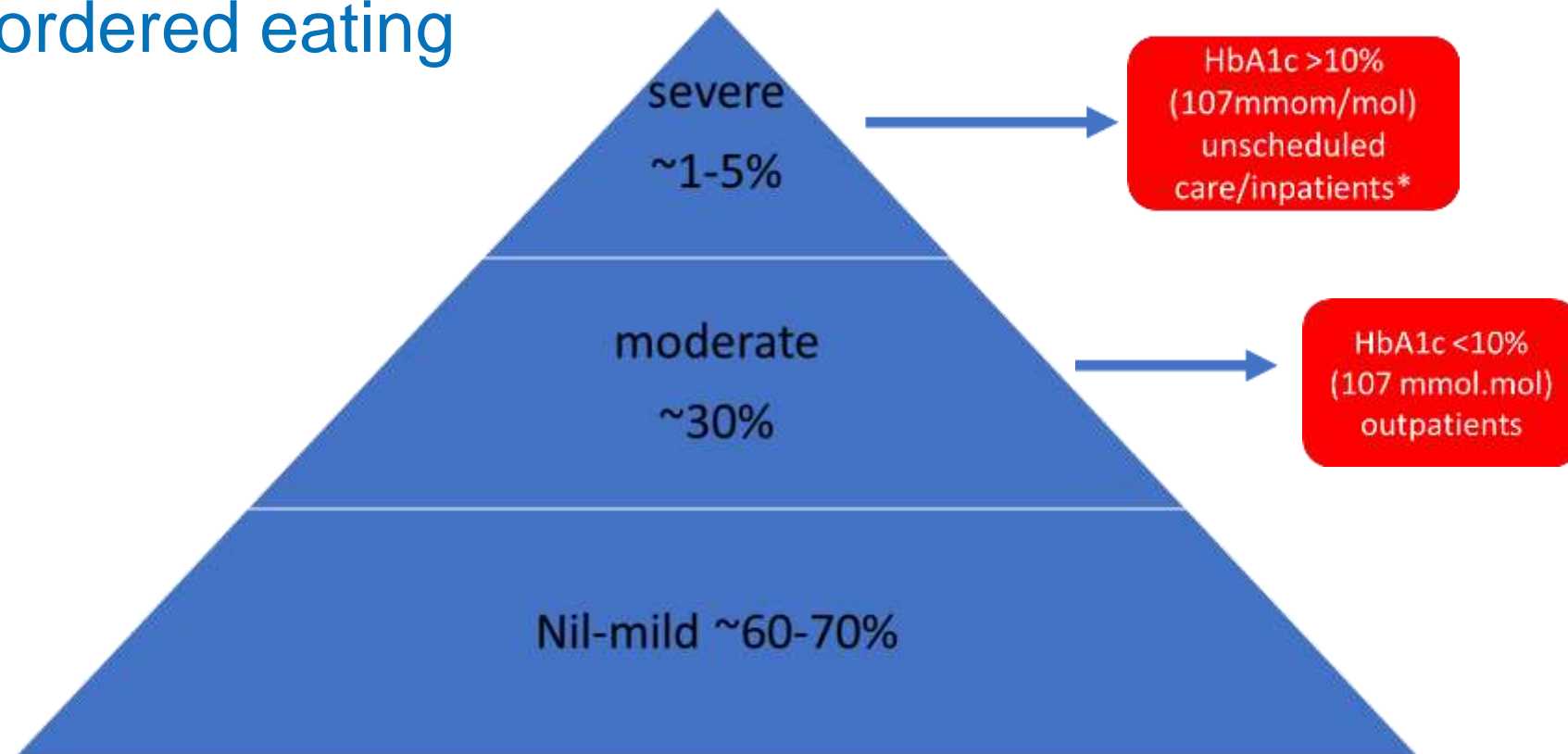
Disordered eating, diabulimia... increased awareness at patient, clinical and organisational levels of a serious life threatening mental-physical co-morbidity



The epidemiology of eating disorders in T1D



A theoretical pyramid model of severity of T1D and disordered eating



¹ Goebel-Fabri et al, Diabetes Care 2008; ² Polonsky WH et al, Diabetes Care 1994; ³ Bachle C et al. Plos One 2015;

⁴ Jones JM et al, BMJ 2000; ⁵ Scheuing N et al Diabetes Care 2014 *exception those with anorexic behaviours

King's Health Partners definition of type 1 diabetes and disordered eating

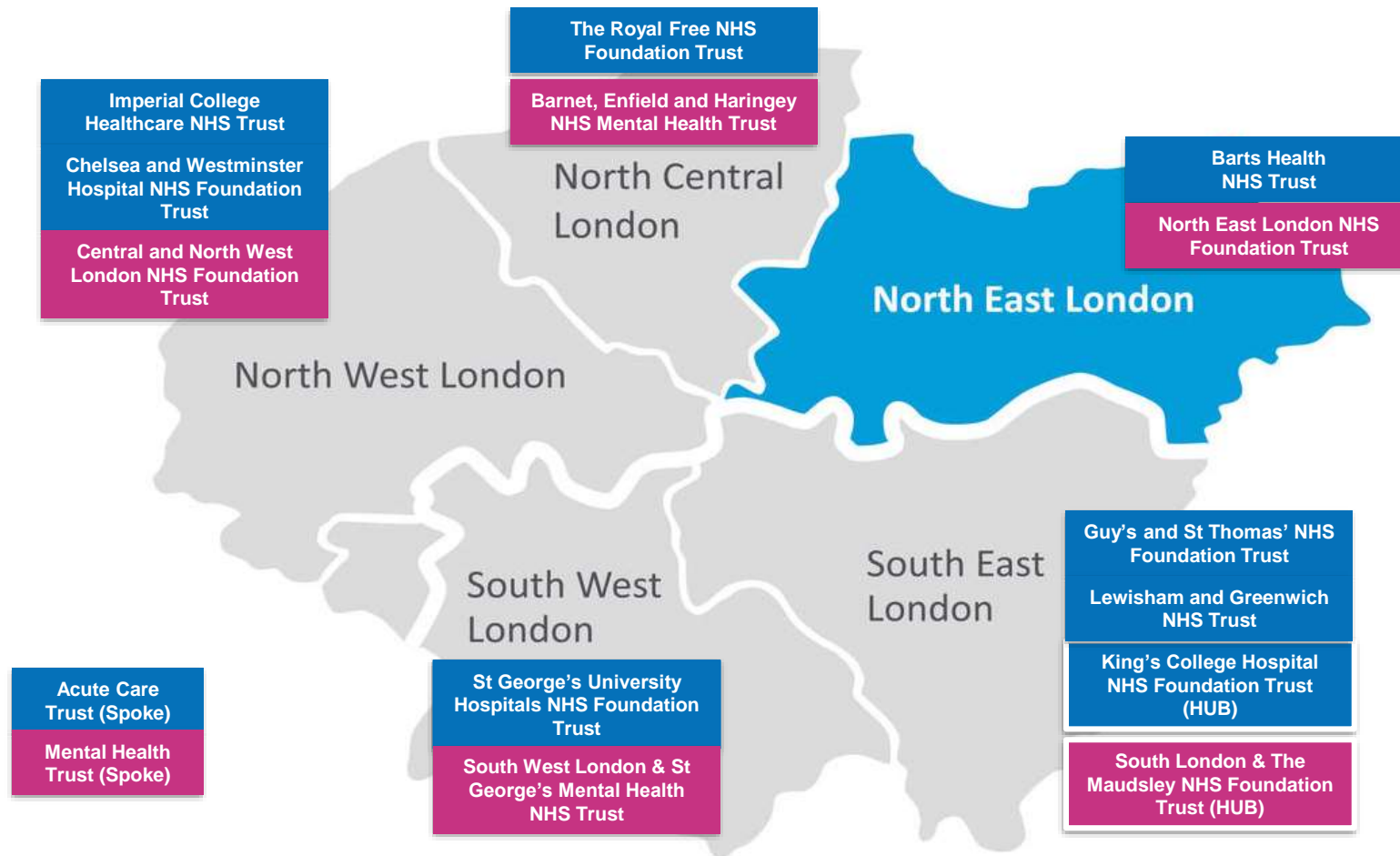
Core criteria

1. Type 1 diabetes
2. Pervasive fear of insulin as weight gaining
3. Omission of insulin to control weight

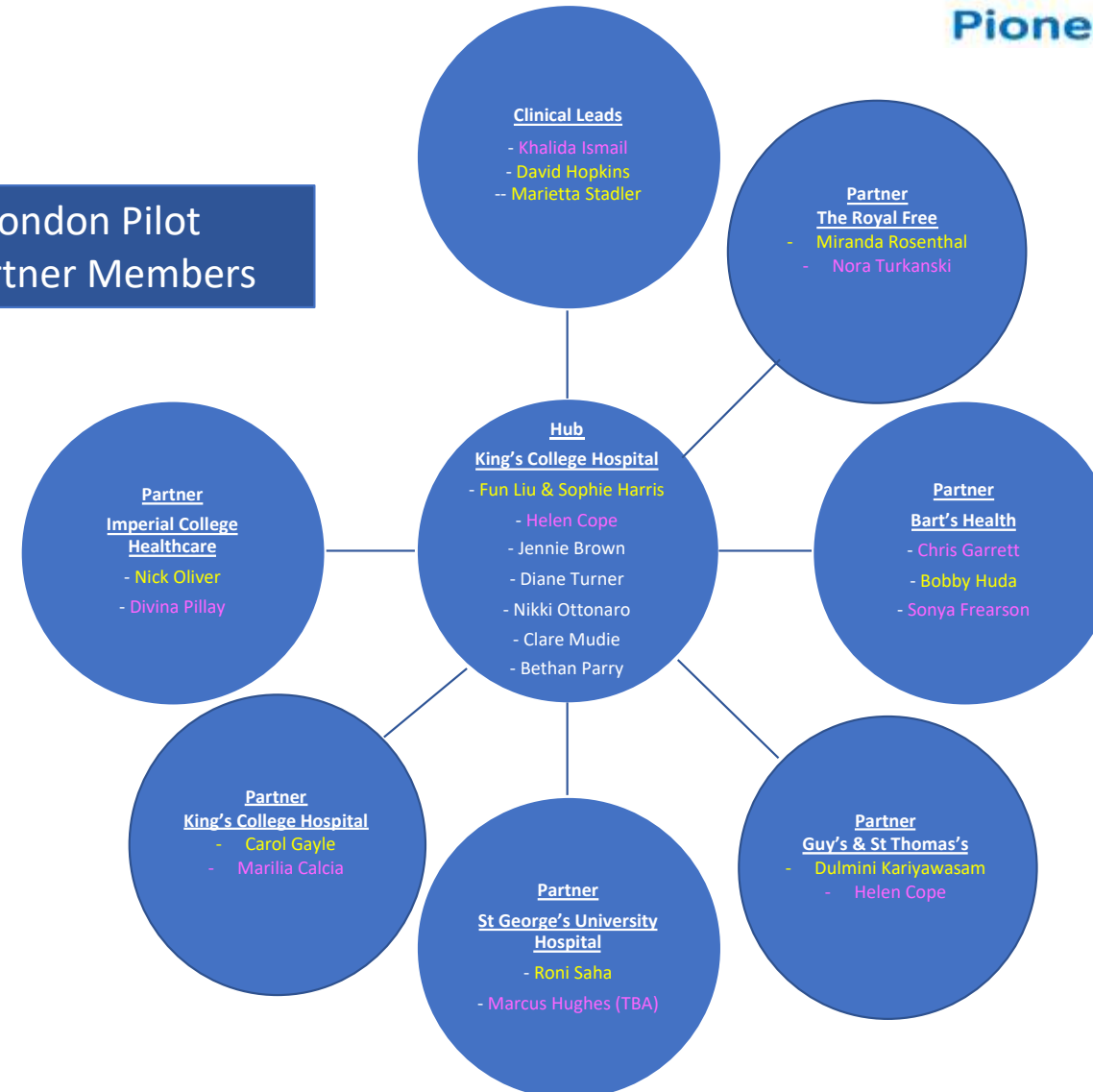
Severity indicators

- HbA1c $\geq 10\%$ for at least the past 12 months
- recurrent DKA defined as >1 admission for DKA in past 2 years
- Recurrent hypoglycaemia
- BMI ≤ 15 kg/m²

Map of Hub & Partner Sites across London

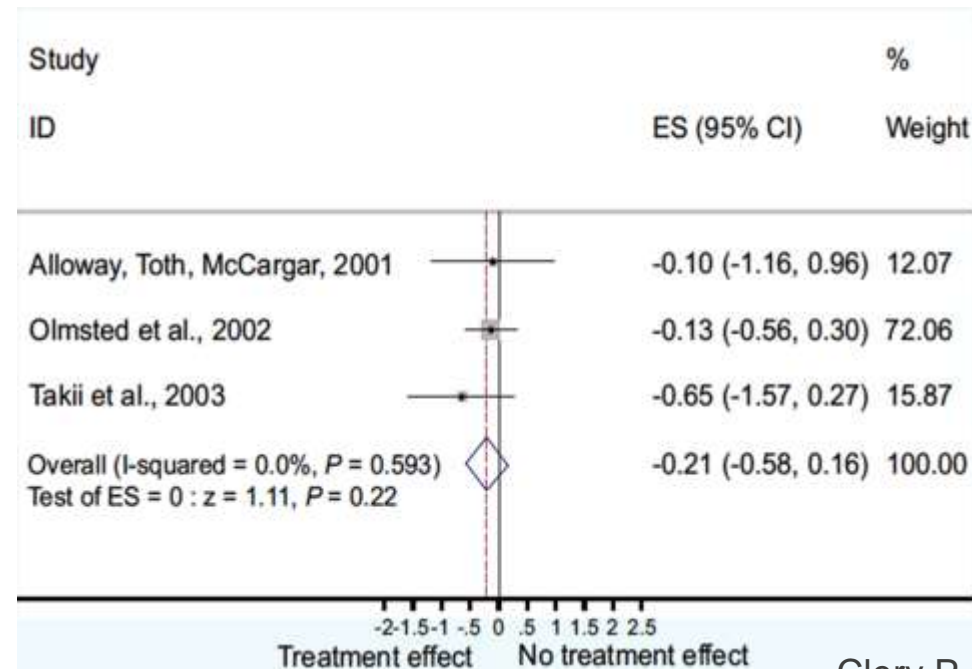


**T1DE London Pilot
Hub & Partner Members**



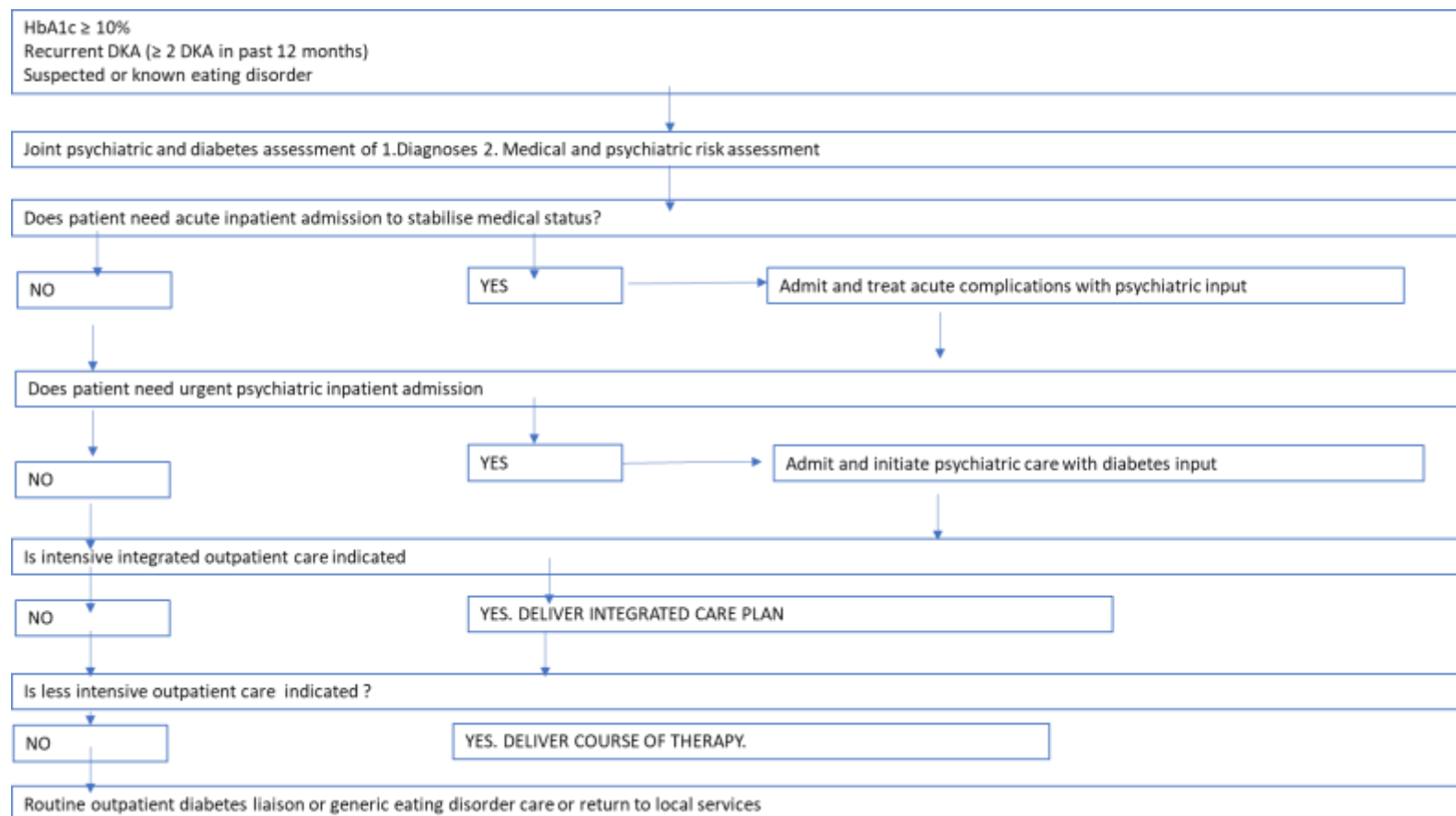
At present no evidence for effective interventions for T1D for eating disorder to improve glycaemic control

Treatment effect size of intervention on HbA1c

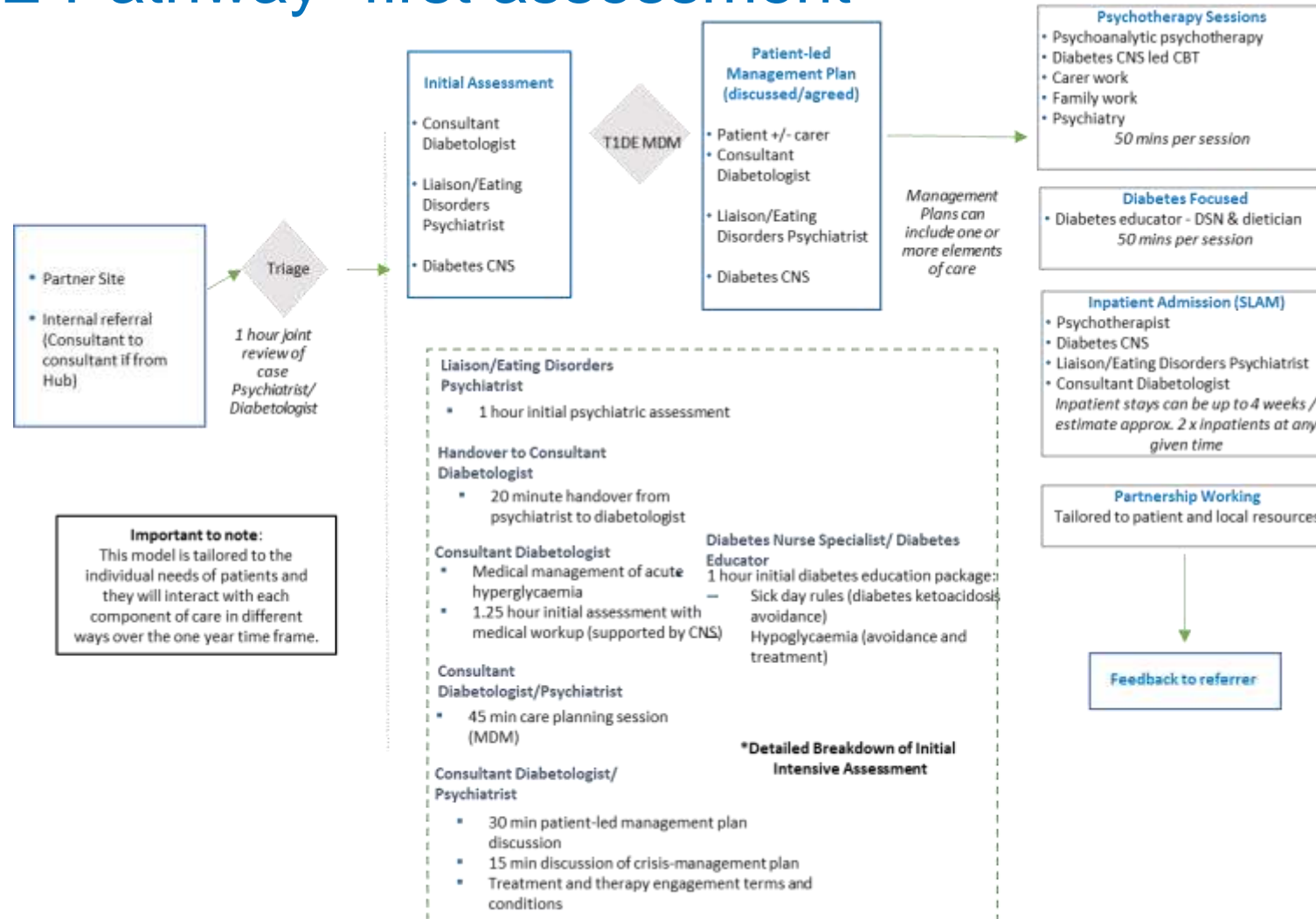


Clery P et al. Diabetic Medicine 2017

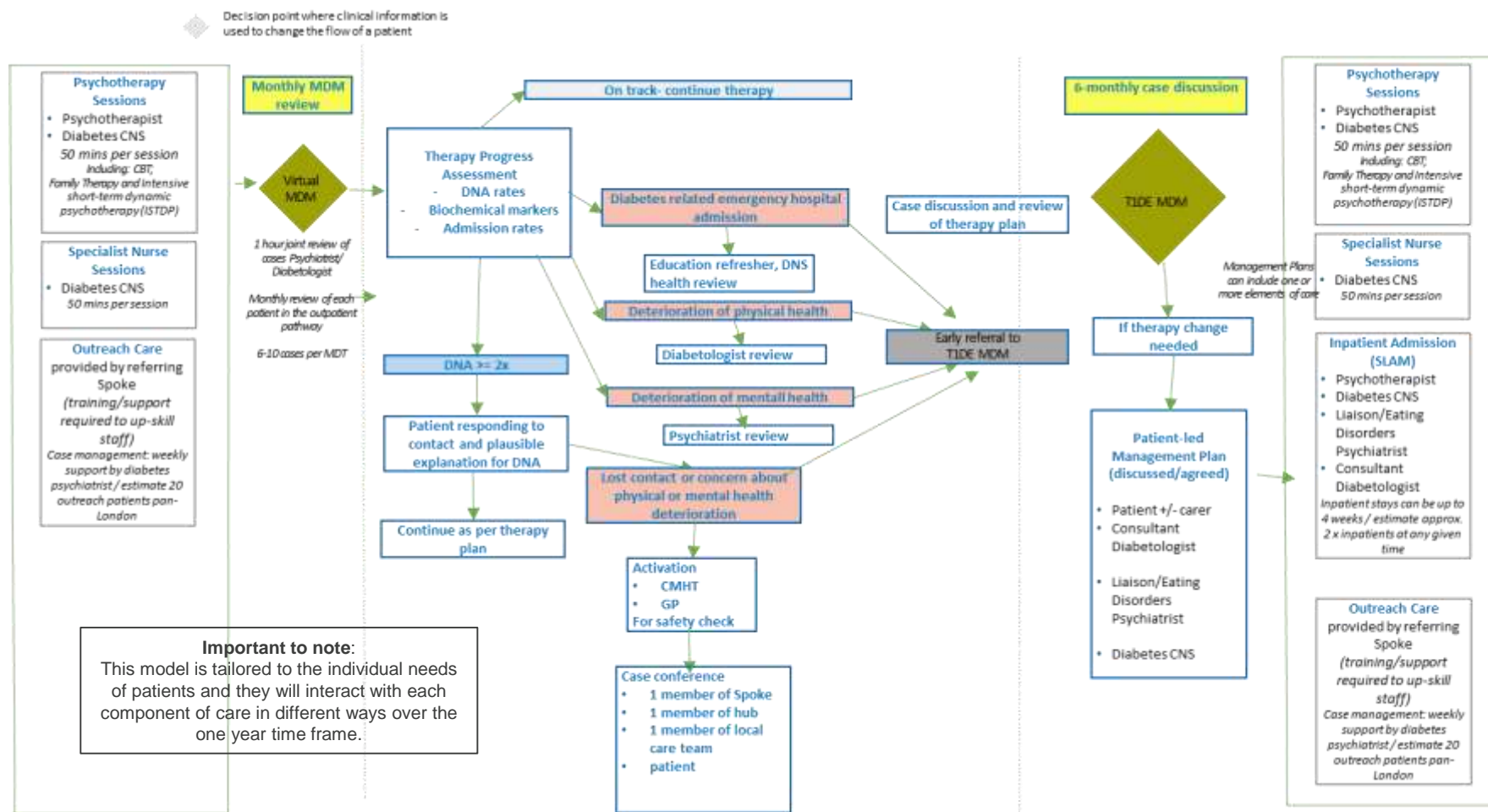
Treatment Decision Flow Chart



T1DE Pathway- first assessment



T1DE Pathway- outpatient



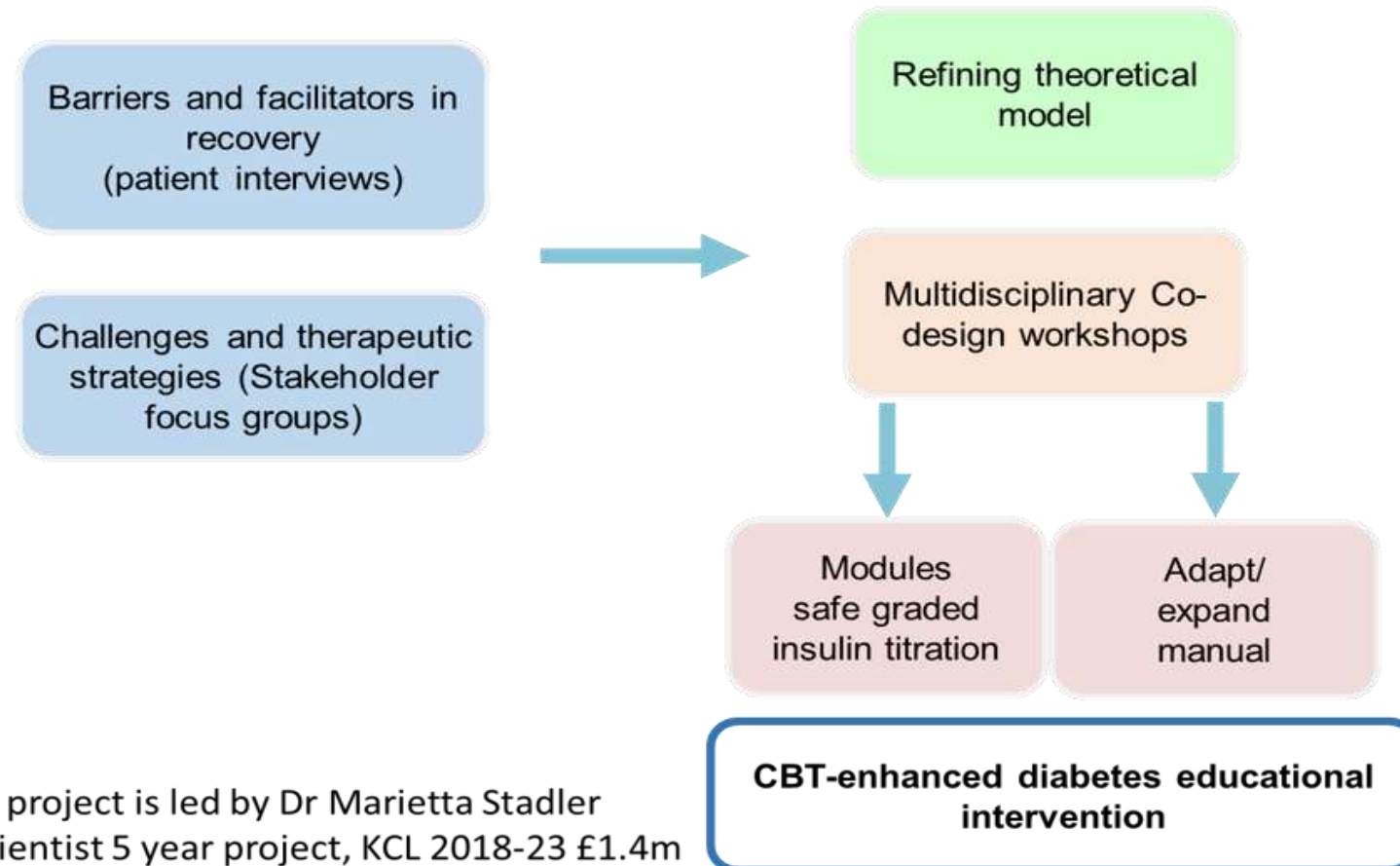
Key components of King's integrated model

- Referral criteria for severe T1D eating disorder
- Assessment: joint psychiatric and diabetes assessment
- Integrated psychiatric and diabetes report and care plan
- Interventions can include:
 - psychotropics
 - safer management of diabetes
 - graded titration of insulin dose
 - psychoanalytical psychotherapy
 - inpatient psychiatric unit to bring routine
 - cognitive behaviour therapy skills with diabetes care
 - medical investigations
 - family and carers
 - DNA management
 - Quarterly patient led care reviews +/- local teams
- Discharge: Feedback loop to referring team

T1DE service 7/2018- 9/2019 severe spectrum service users with >6 months service use

	Age (diabetes duration)	DKA admissions /year at baseline	HbA1c first visit	diabetes late complications	Admission ED unit	Hba1c latest %	DKA admissions since T1DE clinic
Hub							
1	25 (6)	1	16.1	0	2018 (5 weeks)	17.0	2
2		0		Autonomic NP	0		?
3		none	12.0	DRP	0	8.2%	0
4	20 (2)	monthly	15.0	0	2017, 2018	12.0%	4
5	18 (6)	3	13.0			12.0%	
Spoke- Diabetes							
6	30 (17)	0	14.3	Severe DRP, NP	Aged 19	7.5%	0
7 (RoyalFree)	42 (32)	1	12.5	Severe DRP Nephropathy Autonomic NP, MCI	0		4
8 (RF)	22 (6)	1	12.6		0		0
9 (KCH)	22 (16)	0	13.8		Offered/refused	12.4	1
10 (KCH)	27 (6)	5	11.8		considered	2	2
Spoke- ED unit							
11 (Bethlem)	28 (1)	0	6.5%	Severe hypoglycaemia x 40 call outs	2018/19		0
12 (St George's)	18 (11)	0	7.4%		Anorexia nervosa		0

Research programme for mild to moderate Safe management of people with Type 1 diabetes and EAting Disorder studY (STEADY)





KING'S HEALTH PARTNERS DIABETES, ENDOCRINOLOGY, OBESITY

Pioneering better health for all

For more information:
King's Health Partners
Ground Floor, Counting House
Guy's Hospital
London SE1 9RT

 0207 188 2892

 kingshealthpartners@kcl.ac.uk

 www.kingshealthpartners.org

 @kingshealth

 King's Health Partners

