



Knowledge Exchange Seminar Series (KESS)

...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland



Diabetes education for adults with learning disabilities: addressing the inequalities

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What is a LD?

- Difficulty in learning (based upon IQ)
- Difficulty in social functioning
- Varying levels of LD (APA, 2002)
- Identified as a hard to reach population and difficult to recruit (Taggart et al., 2013)



Health Inequalities: Mortality

Lower life
expectancy

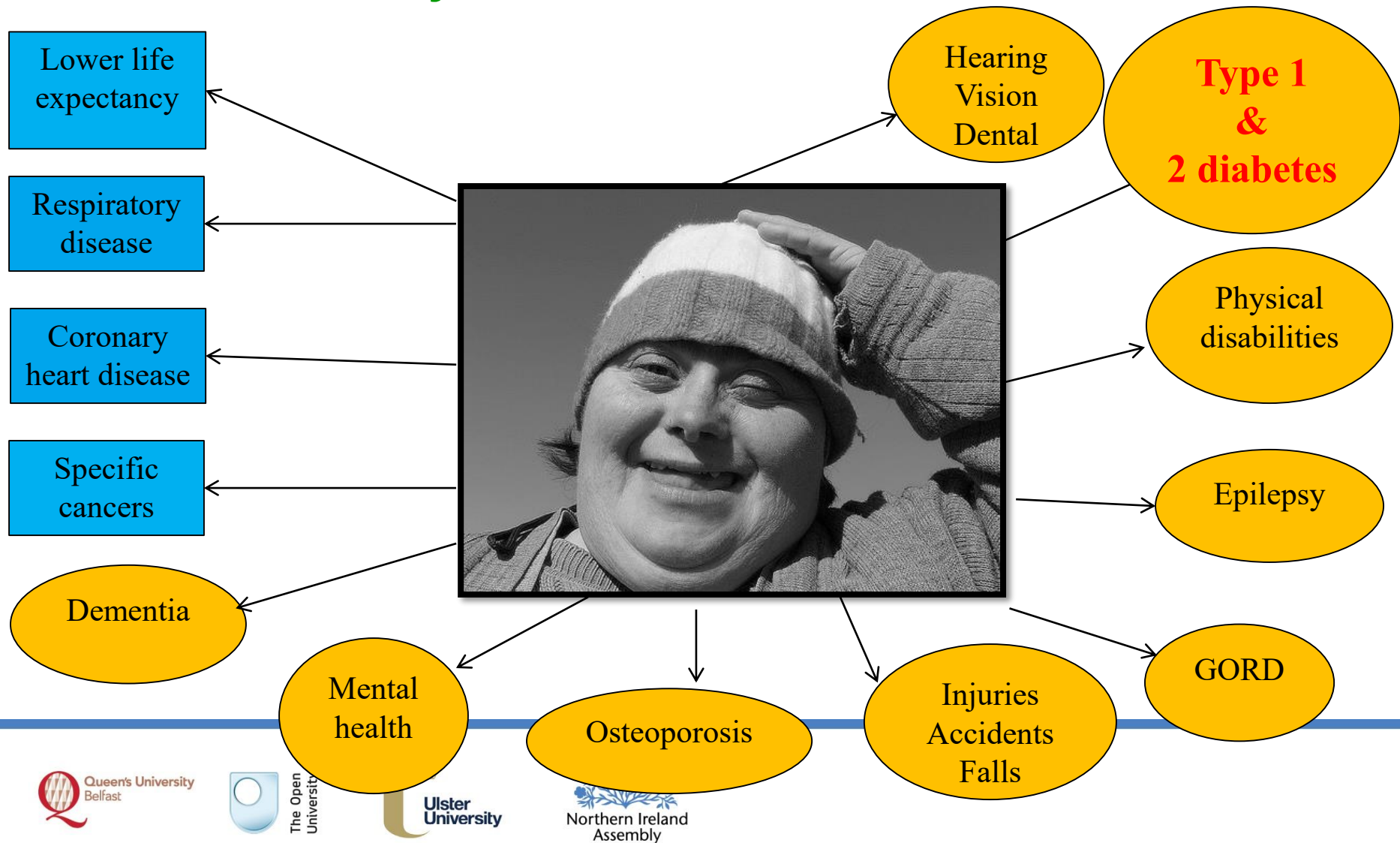
Respiratory
disease

Coronary
heart disease

Specific
cancers



Health Inequalities: Secondary Health Conditions



Prevalence of Diabetes in People with LD

- Evenhuis et al. (1997) in Holland reported a **17%** prevalence rate of T2D, Lindsay (2006) in England reported a **5 fold increase** of developing diabetes, and Shireman et al. (2010) and Lunsky et al. (2011) in Canada have reported that people with LD are **4 to 5 times** more likely to develop T2D (16%-20%)
- Taggart et al. (2013) in N. Ireland found 67.2% had T2D and 32.8% had T1D, of whom 23% of people with Down Syndrome had T1D
- McCarron et al. (2015) in Ireland proactively screened for diabetes in over 850 adults with LD aged 40yrs and found an **11%** prevalence rate
- Balogh et al. (2015) using administrative data in Canada, reported that **disparities** in prevalence of diabetes between those with and without LD were most notable among women and younger adults
- In two recent **systematic reviews** prevalence figures were found to vary from 3%-18% depending on the **sample and screening: 8.3%** (McVilly et al., 2014; MacRea et al., 2015)

Risk Factors of Diabetes in People with LD

- People with LD are more likely to develop T1D: **genetics** (DS, Pradi-Willi syndrome, ASD(!) (Merrick & Morad, 2010, Shireman et al., 2010, McVilly et al., 2014; Balogh et al., 2015)
- People with LD are more likely to develop T2D: **genetics and lifestyle** (diet, restricted physical activity, sedentary behaviour, medication, obesity) (Taggart et al., 2013, 2014, McVilly et al., 2014; Balogh et al., 2015)
- A recent population-based cross-sectional analysis study further added weight that **multi-morbidities**, including diabetes, are more common in adults with LD and **occur at an earlier age**, thereby making the management of this condition more complex (Cooper et al., 2015)



Impact of Diabetes and People with LD

- Holmstrom & Rosenqvist (2005) examined people with LD misunderstandings about T2D, finding **confusion about the cause, anatomy and physiology; complications; signs of hypoglycaemia and lifestyle management (exercise, dietary)**
- Dysch et al. (2011) in England interviewed 4 adults with diabetes using IPA, and found:
 - That participants demonstrated some knowledge of the language surrounding diabetes, **but considerable confusion and uncertainty** about their illness
 - The impact of diabetes was described in terms of physical, emotional and social consequences, and participants spoke of diabetes in the context of **co-existing health problems**
- Balogh et al. (2015) reported that in terms of hospitalizations for diabetes-related ambulatory care-sensitive conditions, people with LD were **2.6 times more likely to be hospitalized**
- There is a paucity of research about the impact of diabetes on this population

Management of Diabetes in People with LD

- Diabetes UK (2008) interviewed 38 people with LD and their healthcare staff & diabetes staff, they reported (**Lack of appropriate information, Poor healthcare and Overall poor diagnosis**)
- Taggart et al. (2013) reported that individuals with LD who were found to have **poor glycaemic control**, were statistically more likely to have T1D and be younger, live with parents or independently and be obese.
- Results also illustrate that the UK **national standards for good diabetes management were only partially being met** (Shireman et al., 2010; Taggart et al., 2013; Balgoh et al., 2015)
- Tripp et al. (2015) in New Zealand interviewed LD staff, and reported that there was an identified need for initial and ongoing **diabetes education for staff, family carers and the people with LD**; in collaboration with diabetes and disability services needing to build confidence and **promote self-management practices**.

Diabetes Structured Education

- People with LD and T2D are not routinely offered structured education to self-manage their condition (Slowie et al., 2010; Taggart et al., 2014) despite this being identified by NICE guidelines (2003, 2011) as 'best practice'
- The need for structured education programmes for T2D internationally has been given a high priority on many Government health care agendas (NICE, 2004; DoH, 2005)
- One specific UK national programme, **DESMOND** (Diabetes Self-Management for Ongoing and Newly Diagnosed) has been shown to be a robust and effective programme for those with T2D (Gillett et al., 2010)
- However, this structured education programme developed to improve the biomedical, psychosocial, and self-management strategies for the general population with T2D has not been targeted at adults with LD



DESMOND

**DESMOND stands for 'Diabetes Education
and Self Management for Ongoing and Newly Diagnosed'**

More simply...

- It's a way of finding out more about Type 2 diabetes
- It's a resource to help you to manage the changes diabetes will bring to your life (self-manage)
- It's an opportunity to meet and share experiences with others
- DESMOND is a family of education modules
- NICE Guidelines (2003)



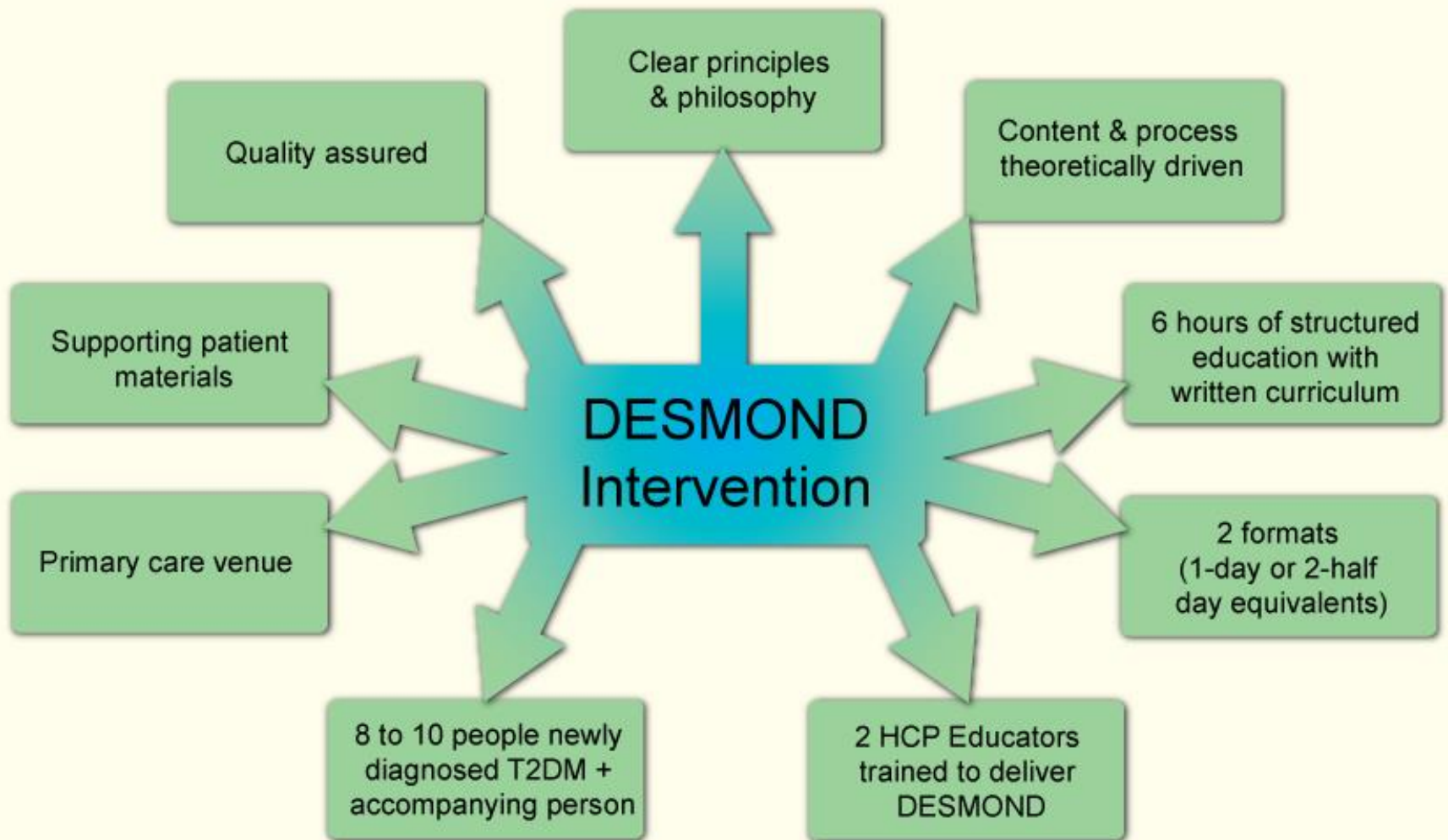
What is DESMOND?

There are currently 4 DESMOND education modules available

- DESMOND Newly Diagnosed
- DESMOND Foundation- (for those who have established diabetes)
- DESMOND BME- course delivered in Gujarati, Punjabi, Urdu and Bengali
- DESMOND Walking Away from Diabetes
- A new 5th module: DESMOND-ID



DESMOND



Diabetes and People with LD: the challenges

- Level of LD (borderline, mild, moderate and severe / profound)
- Cognitive deficits / processing information / re-call / re-appraisals of beliefs and behaviours
- Communications difficulties / comprehension / acquiescence
- Low levels of literacy skills and different learning skills
- Engagement with family and paid carers / or lack of this
- Variation in supports provided to monitor Hb1Ac, aid with managing a healthy diet, exercising / becoming less sedentary, medication compliance, eye examinations, foot care, etc.

Adapting DESMOND for adults with LD

- A 2 iteration process delivered to 13 adults with LD and T2D and their family/paid carers
- 6 weeks, 2 ½ hrs per week (additional week for carers)
- Focus group with adults with LD, carers, three independent observers and educators: all sessions video taped in 1st iteration
- Meetings held to review observations and feedback, and refine the resources and curriculum
- **DESMOND-ID developed**
- 1 x LDN and 1 x DSN trained as educators



Adapting DESMOND for adults with LD

- Time
- Core concepts simplified



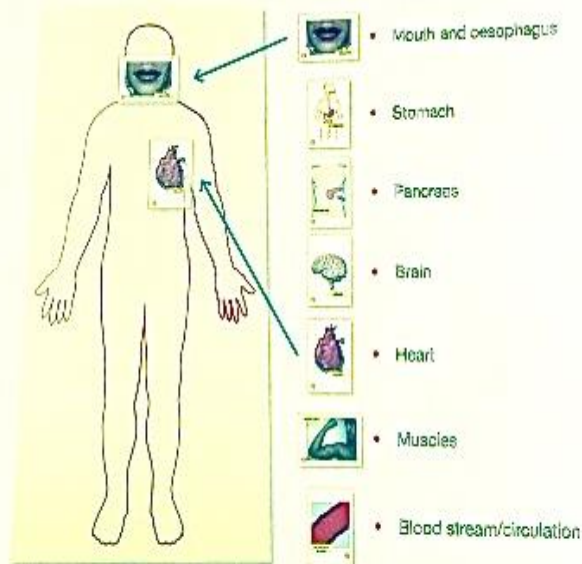
Intellectual
Disabilities

Adapting DESMOND for adults with LD

Desmond

Intellectual
Disabilities

- Time
- Core concepts simplified
- Pictorial representations (visual, photos, pictures, symbols)



What is this organ/body part?

Participants may not understand the term organ. Provide an example – the stomach is a body part.



Session Plan

Before the session begins place all the Risk Factor posters on the wall where participants can see them

BLOOD SUGAR	BLOOD FAT	BLOOD PRESSURE
ACTIVITY	ACTIVITY	ACTIVITY
FEELING	FEELING	FEELING
WEIGHT	WEIGHT	WEIGHT
CHOLESTEROL	CHOLESTEROL	CHOLESTEROL
DIET	DIET	DIET
?	?	?

FEELING SAD	BODY SHAPE	SMOKING
ACTIVITY	ACTIVITY	ACTIVITY
FEELING	FEELING	FEELING
WEIGHT	WEIGHT	WEIGHT
CHOLESTEROL	CHOLESTEROL	CHOLESTEROL
DIET	DIET	DIET
?	?	?

Invite participants to take out their Being Active Diary which they were given at the first session and inform participants that you will be looking at these in a little while.

Adapting DESMOND for adults with LD

- Time
- Core concepts simplified
- Pictorial representations (visual, photos, pictures, symbols)
- Repetitious learning / interactive sessions
- Development of skills / developing 'self-efficacy'
- Support for carers (education of carers)
- Health action plans / goal setting
- Celebration and fun



Intellectual
Disabilities



DAY 1	DAY 2	DAY 3	DAY 4	DAY 5	DAY 6
Welcome and introduction (25 mins)	Welcome back (20 mins)	Welcome back (20 mins)	Welcome back (20 mins)	Welcome back (20 mins)	Welcome back (20 mins)
My story with diabetes (part 1) (15 mins)	My story with diabetes (part 2) (15 mins)	Knowing what your blood sugar levels mean (35 mins)	Heart and circulation problems: what can I do to keep healthy (part 1) (40 mins)	Food and fats (35 mins)	Diabetes health action plan: what will I work on? (35 mins)
My body and diabetes (20mins)	What diabetes does to your body? (25 mins)	Break (15 mins)	Break (15 mins)	Break (15 mins)	Break (15 mins)
Break (15 mins)	Break (15 mins)	Being active (40 mins)	Other diabetes health problems: what can I do to keep healthy (part 2) (35 mins)	Making healthier food choices (40 mins)	Keeping my plan going (35 mins)
What is diabetes? (35mins)	Food and blood sugar (35 mins)	What did I learn today? (10 mins)	What did I learn today? (10 mins)	What did I learn today? (10 mins)	Important questions and celebration of achievement (15 mins)
What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	
2 hours	2 hours	2 hours	2 hours	2 hours	2 hours

Feasibility of DESMOND-ID

Eligibility criterion, 66 adults with LD across the three countries met the criterion, of these 39 agreed to participate in the study (consenting rate of 59%).

Attendance rate was excellent with 10 participants (53%) attending all 6 sessions and the remainder attending 4 – 5 sessions.

Only one participant withdrew from the intervention due to a deterioration in health and one person was lost to follow up due to mental health problems.

In terms of carer attendance, ten (83%) attended all sessions, one (8.3%) attended 5 sessions, one (8.3%) attended 3 sessions and one carer (8.3%) attended 2 sessions.



Results of DESMOND-ID Feasibility study

Variables	Intervention Group		Control Group	
	Baseline	Follow-up	Baseline	Follow-up
HbA1c mmol/mol (SD)	67.19 (23.91)	57.39 (18.75)	61.67 (15.36)	65.47 (17.13)
BMI	30.67 (4.97)	30.4 (4.51)	37.3 (6.33)	37.57 (6.33)
Systolic blood pressure, mmHg	127.64 (11.06)	133.71 (6.87)	132 (15.6)	136 (19.2)
Diastolic blood pressure, mmHg	75.5 (5.43)	79.28 (4.60)	75.1 (10.6)	81.1 (6.98)

Impact of the study

Better
management/control
of T2D

Improved health
promotion for this
population

Improved quality of
life for the person
with LD and their
carers

Reduction in
emergency hospital
admissions

Reduced burden on
health care costs

Challenges in managing diabetes in people with LD

- **Identification and screening** of diabetes in this population (registered with a GP, 'hidden invisible population', annual health checks) (McConkey et al., 2015)
- **Prevention and health promotion:** diet/nutrition, sedentary lifestyle, medication, obesity, identified at 'risk' of developing T2D, etc. (Taggart & Cousins, 2014)
- Good management of diabetes: **Whose responsibility is it?** (Taggart et al., 2013, 2014; Brown et al., 2017)
- **Better co-ordination** between LD and diabetes professionals (Taggart et al., 2014; Brown et al., 2017)
- **Creating opportunities** for people with LD to actively engage in diabetes prevention, screening, education and management (Emerson & Hatton, 2014, Taggart & Hatton, 2014)

Thanks for listening

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Northern Ireland
Assembly



The Open
University



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