

Closing the loop: a Shared Decision Making Pathway for Hybrid Closed Loop Systems

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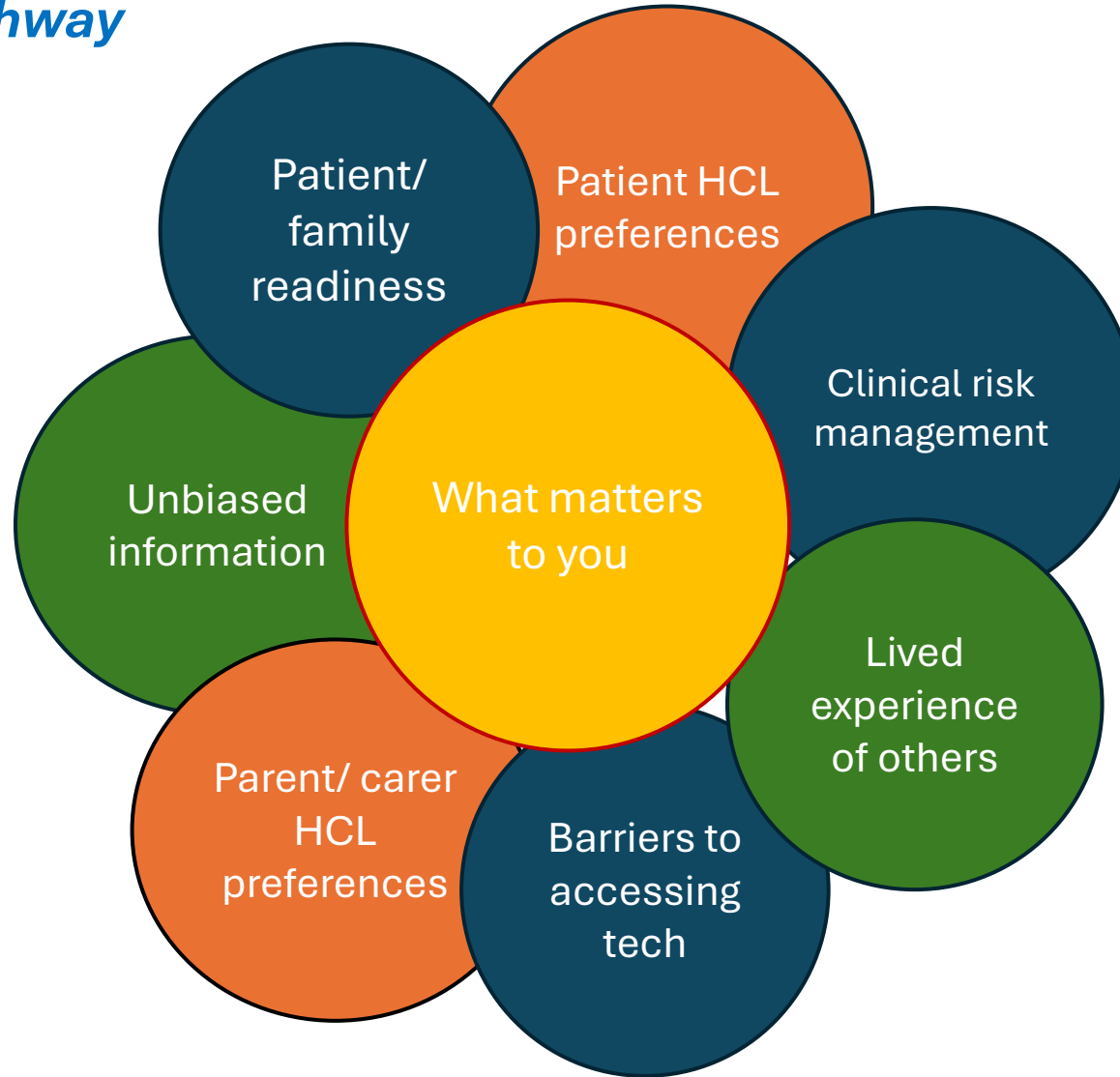
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May 2025

Introduction

Hopes for an HCL pathway



Introduction

Why is SDM important?

Results from patient/parent surveys completed before SDM was implemented:



*Only around **3 in 5** felt they were given a choice*



***1 in 5** on HCL would have made a different choice looking back*



***1 in 6** parents did not feel their child was involved in decision-making*



***1 in 5** did not feel they were able to weigh the different options*

Introduction

Our Aims

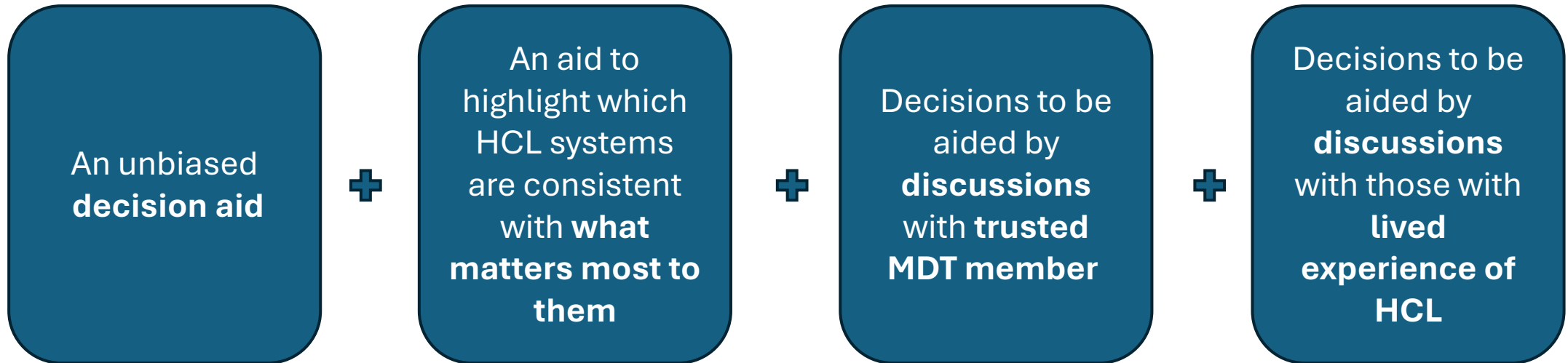
- 1) **Start well:** Getting patients and families the HCL system that best fits their needs and clinical requirements, using existing, limited resources
- 2) **Support:** Bringing patients, families and MDT voices into one space
- 3) **Optimising HCL:** to work in a way that supports patients' lifestyle and values throughout their time with their HCL system
- 4) **Clinical outcomes and risk:** controlling clinical risks from using HCL
- 5) **Streamlining workflow:** ensuring consistency of message across MDT and replacing reactive ad-hoc support with a proactive, structured pathway
- 6) **Access for all:** Give everyone the option of using HCL, including those with complex needs and at higher clinical risk

Designing a pathway

How to improve the experience of shared decision making in HCL: a co-designed pathway

Co-design from the start and throughout development.

Insights from focus groups with parents and YP, around what they wanted & needed – and how they wanted it delivered



Shared decision-making in HCL is ‘more than the facts’*

A values-based HCL decision aid needs to be embedded into a robust HCL pathway

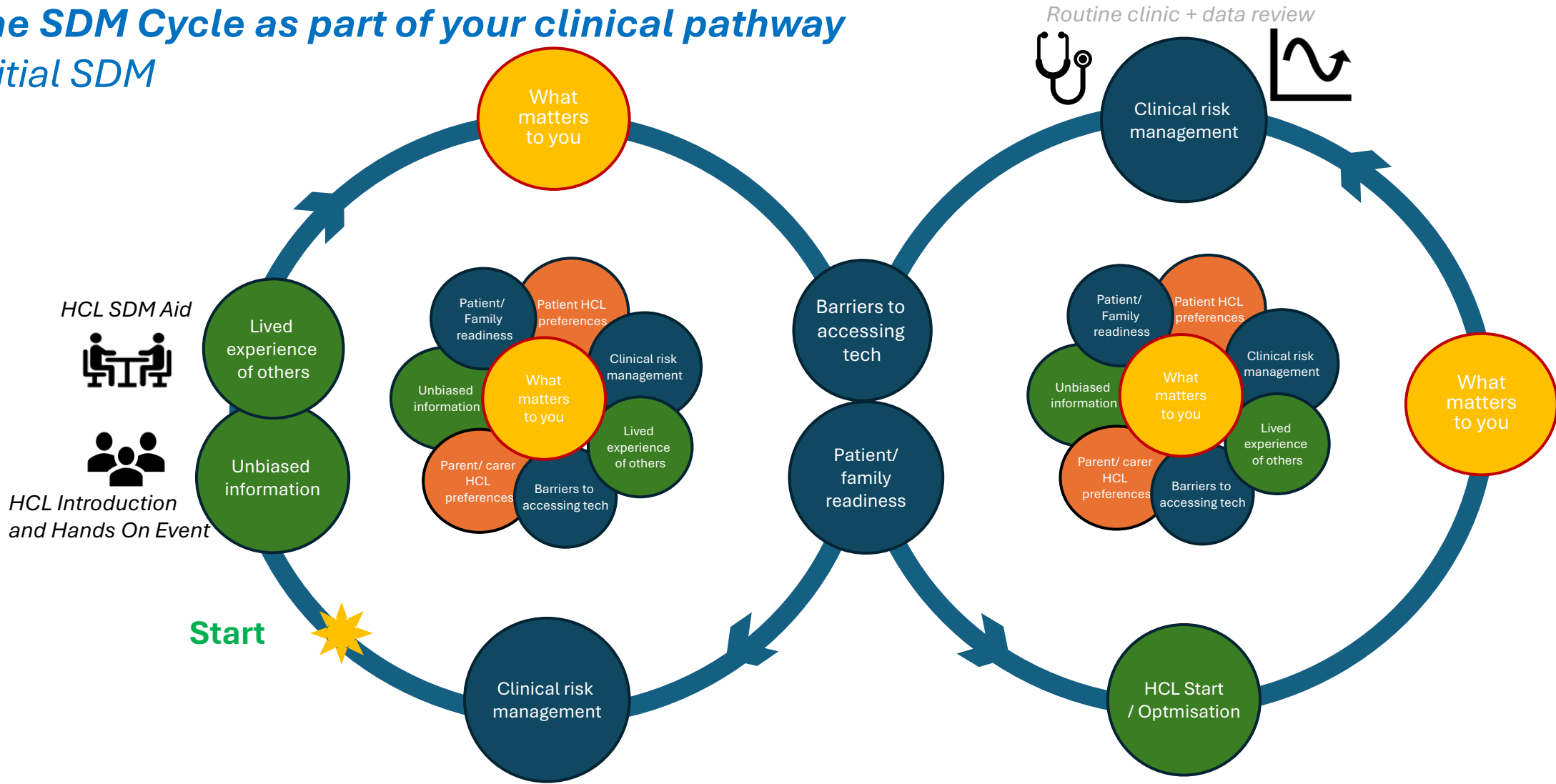
Connection with the team (as well as digital content) was highly valued

*E.g. The NHSE HCL SDM tool is great at relaying the facts and building some insight, but doesn’t cover this scope

Designing a pathway

The SDM Cycle as part of your clinical pathway

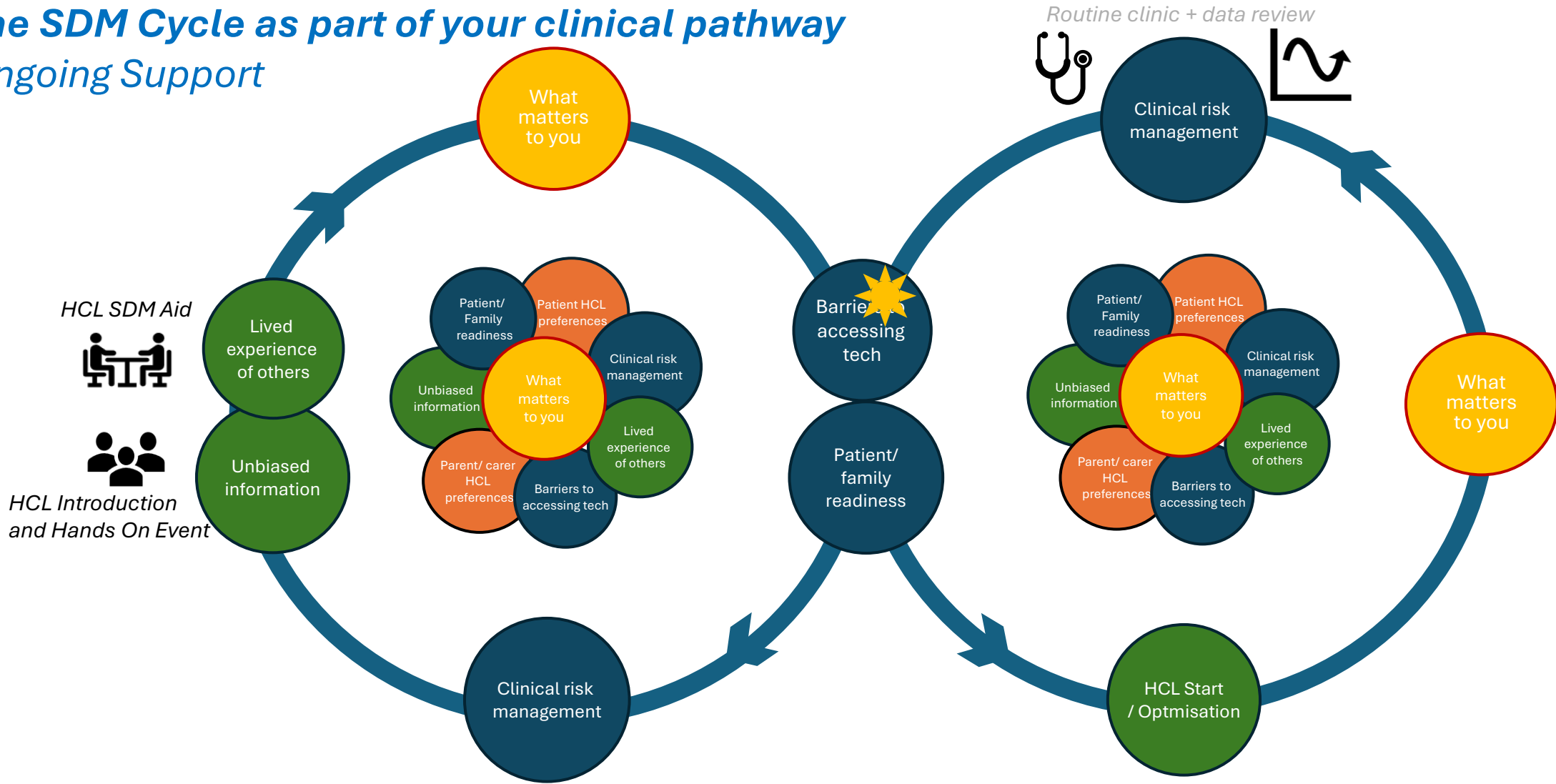
Initial SDM



Designing a pathway

The SDM Cycle as part of your clinical pathway

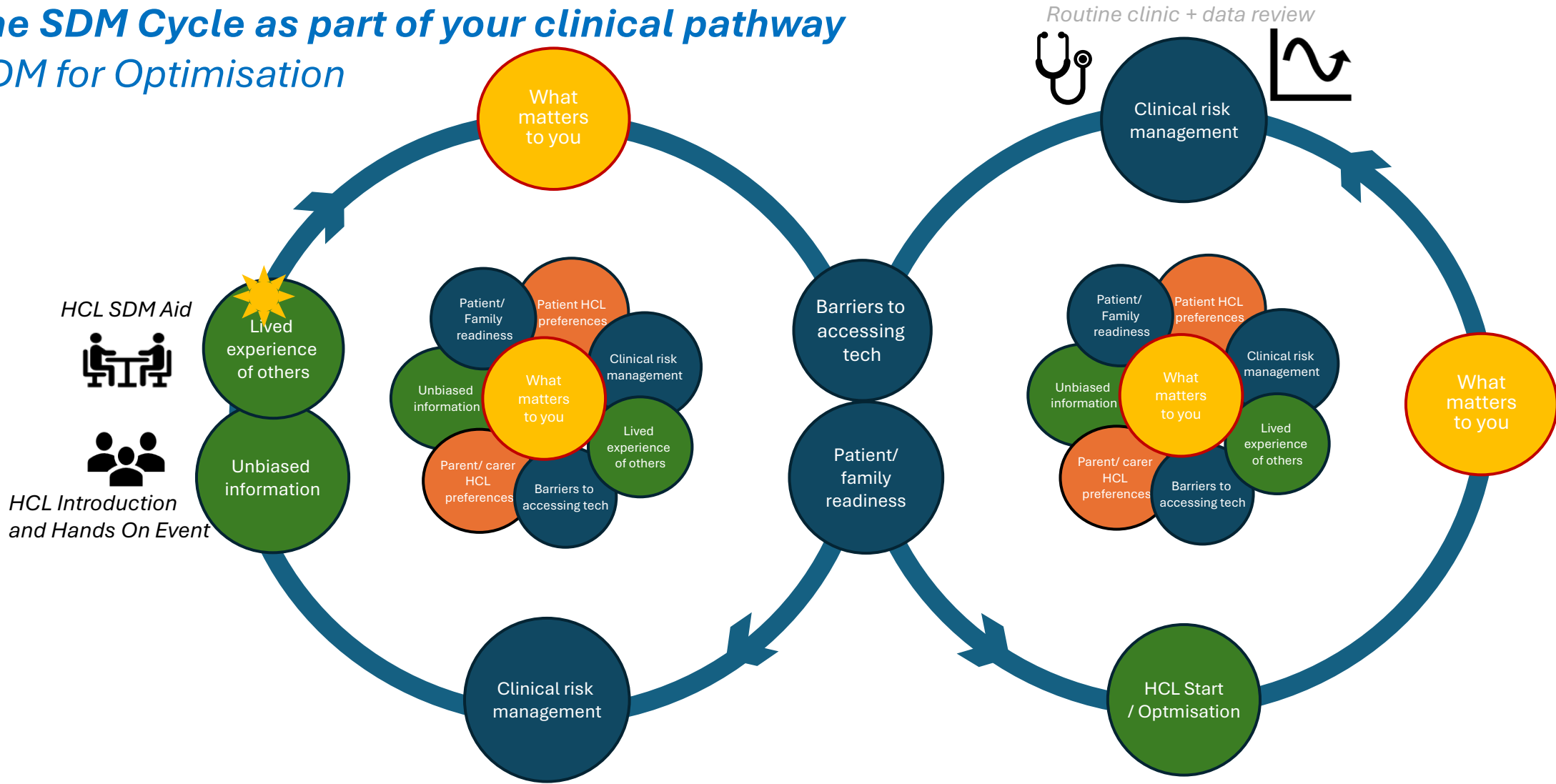
Ongoing Support



Designing a pathway

The SDM Cycle as part of your clinical pathway

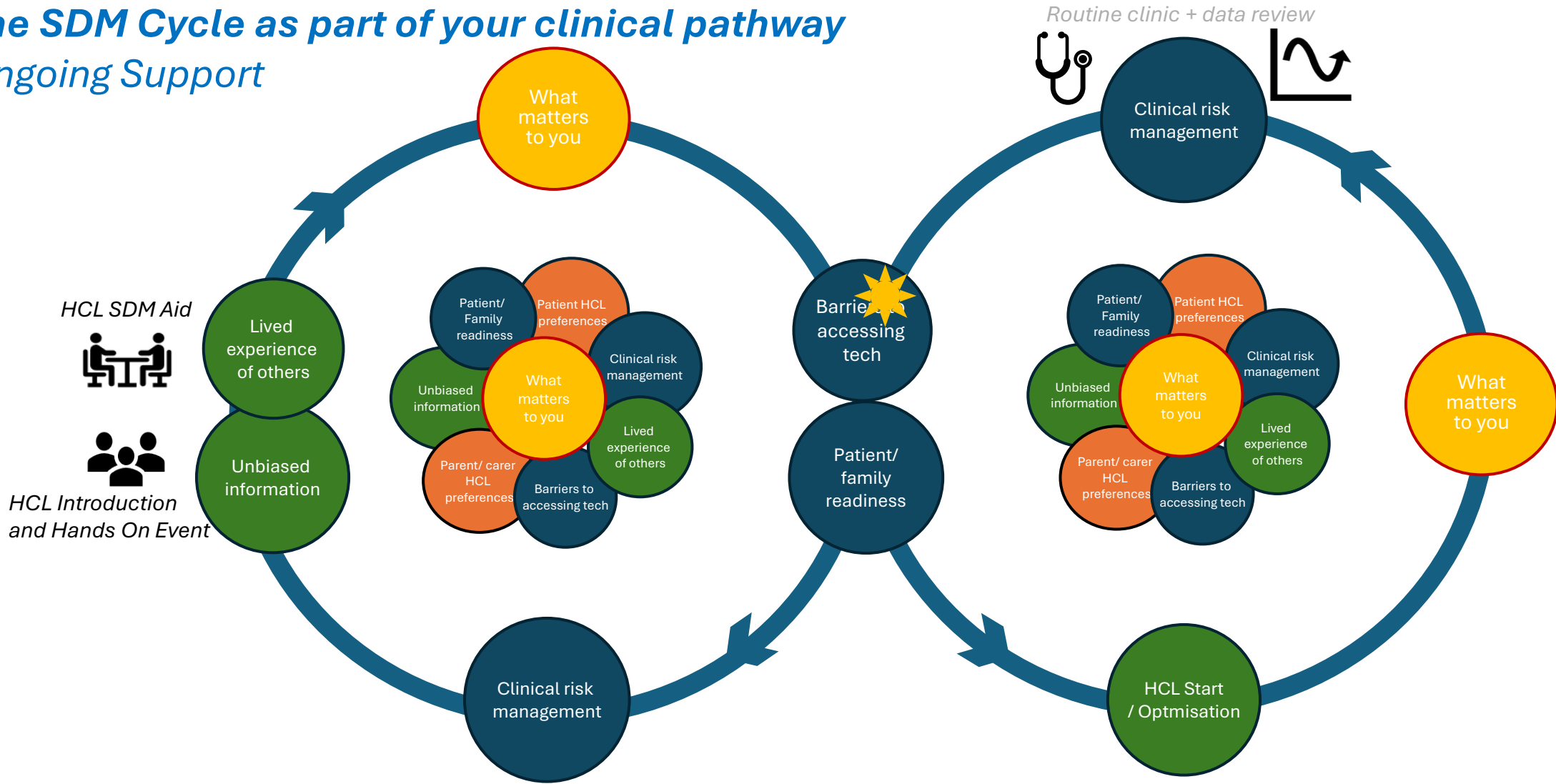
SDM for Optimisation



Designing a pathway

The SDM Cycle as part of your clinical pathway

Ongoing Support



Designing a pathway

HCL Introduction and Hands On Event



- Introduced in April 2024- Integral component of HCL Pathway, mandatory attendance *
- Run quarterly.
- 2 hours – weekday evening.
- MDT approach.
- Presentations/Interactive discussions
- Concepts of Shared decision making and Care Pathways introduced.
- Not run as a 'Showcase'
- Industry do not attend.
- **Expert patients/experiences shared**
- **HCLs 'hands on'/Resources/Discussion with MDT/Expert Patients**
- Group Q&A, Timelines, Expectations MDT/Families. Next Steps.

*** awareness of potential need for bespoke approach for some families (equitable access)**

Designing a pathway

Face to face SDM: Decision aid



SOUTHAMPTON
Children's Hospital

Hybrid Closed-Loop Systems

An aid for making shared decisions

Click or tap the logo to start

1 Introduction

2 How does HCL help?

3 Your Values

4 Your Options

5 Your Decision

Useful Links

Introduction

What is hybrid closed-loop (HCL) technology?
Hybrid closed-loop technology involves three things. Click or tap on each one below to find out more.
Or you can click the arrow on the bottom right to skip to the next section.

Insulin pump

Continuous glucose monitor (CGM)

Controller device or smartphone

← →

1 Introduction

2 How does HCL help?

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4 Your Options

5 Your Decision

Useful Links

Your options

Click or tap on an option to find out more.

T: Slim with Control-IQ

Ypsomed with CampAPS Fx

Medtronic 780G

Omnipod 5

Dana i with CampAPS Fx

Pen injections

← →

1 Introduction

2 How does HCL help?

3 Your Values

4 Your Options

5 Your Decision

Useful Links

How does HCL help?

Click or tap on each point below to see how HCL affected it.

HbA1c

Time in range

Hypoglycaemia

Fear of hypos

Quality of sleep

Time Point	HbA1c (mmol/mol)	HbA1c (%)
Before HCL	62	7.8%
After 6 months on HCL	55	7.2%
National recommended target	48	6.5%

Six months after starting HCL, HbA1c dropped by 7 mmol/mol (0.6%) on average.

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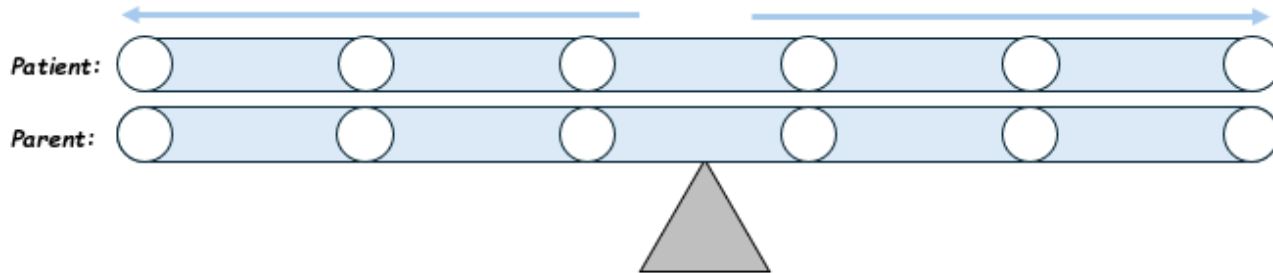
Designing a pathway

Face to face SDM: What matters to me

All HCL systems need some input (or adjustments) from you and your clinical team to work as best as they could. Some systems require more adjustments than other. Sometimes, you might have to make a **trade-off** between the 'best' glucose levels possible, and the number of adjustments you need to make.

Q1. Along this line, place a tick in the circle closest to how you feel.

- I want the **best** glucose level possible
- I can use a system that needs **a lot of adjustments** from me
- I'm happy with a **very good** glucose level
- I prefer a system that **doesn't need many adjustments** from me



- Capturing patient and parent perspectives during use of the SDM aid
- Improving access by simplifying text and using images where possible

Q5. I regularly swim for sessions that last over 1½ to 2 hours.

Yes No

Q6. When I am swimming, I prefer:

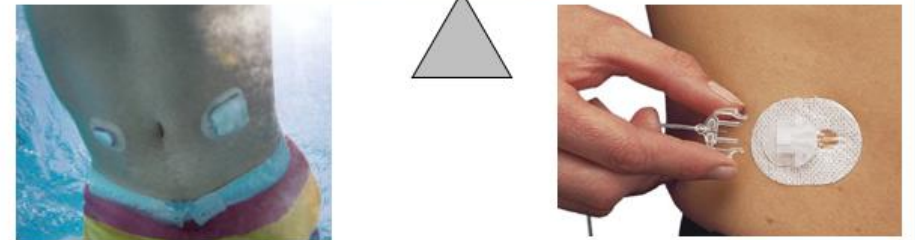
Having a waterproof pump that stays on my body
 (Note: the pump can stay in water for maximum 30 minutes)

Taking the pump off, then putting it back on when I am done
 (Note: the pump can be taken off for maximum 1-1½ hours)

←-----→

Patient: ○ ○ ○ ○ ○ ○ ○


Parent: ○ ○ ○ ○ ○ ○ ○



Designing a pathway


Face to face SDM: Decision aid











Your options

Preferences and personal lifestyle



Points important to me / my family	Pen injections	T: Slim	Omnipod 5	Ypsomed with CampAPS Fx	Dana i with CampAPS Fx	Medtronic 780G
Shape						
Real-time remote data	Dexcom/Libre + phone	Dexcom only + phone	Dexcom/Libre + phone	Dexcom/Libre + Phone	Dexcom only + Phone	Phone
Mobile phone / controller is not needed	Needed for bolus calculator					
Small and discreet						
Choice of cannula			Tubeless. 1 cannula			
Helps with lows and highs						
Lots of user input possible						
Split/extended bolus				'Add Meal' function	'Add Meal' function	
Sports Mode		'Exercise Mode'	'Activity Mode'	'Ease-off'	'Ease-off'	'Temp Target'
Can be removed for high contact sports			Can't be removed			
Waterproof / swimming		Ok in rain	Max 1 hour	Ok, but recommend removing	Ok, but recommend removing	Ok, but recommend removing

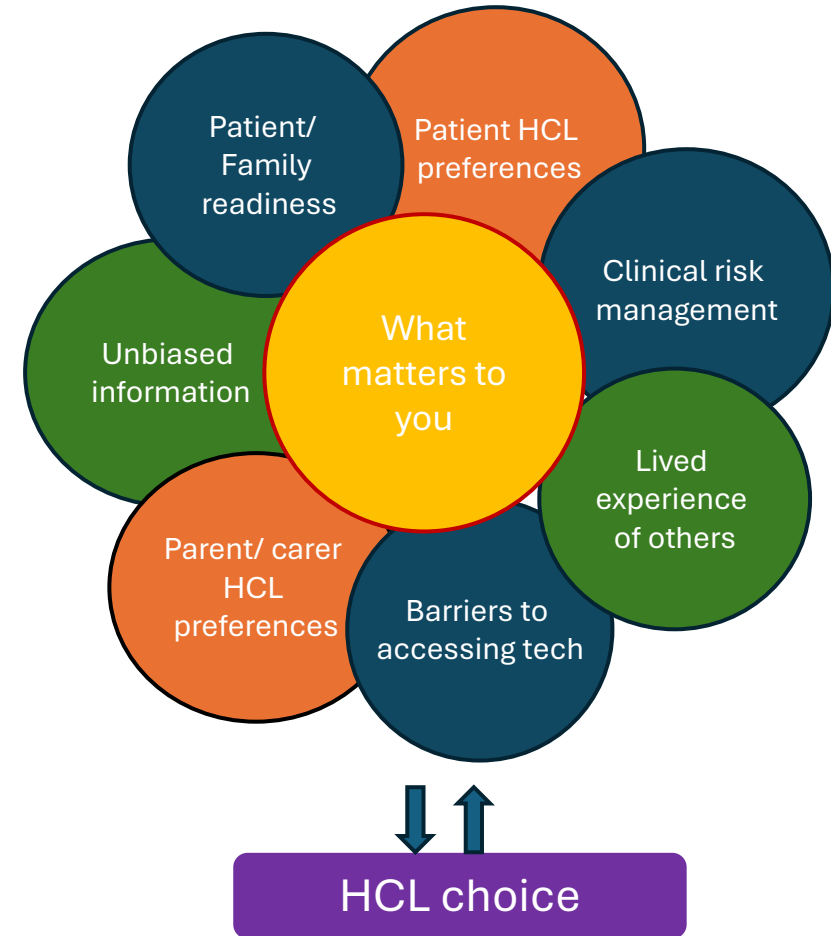
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Designing a pathway

Integrating preferences with readiness and risk

Co-design emphasised the importance of connection and collaboration together with MDT.

MDT need a collaborative way to identify **clinical risk, barriers** and **patient readiness for HCL** whilst balancing this against patient preferences and values.



Designing a pathway

Integrating preferences with readiness and risk

- ***How we have these conversations matters.***
 - Shared conversations about **values, risk** and **readiness**.
 - Communication with patients/families has the potential to support the development of intrinsic motivation for self management.



Self-determination theory (Ryan & Deci, 2000).

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55,68-78.

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Designing a pathway

The SHARE consultation:

Shared decision making in HCL and Readiness Integrating preferences with readiness and risk

The SHARE consultation aims to promote:

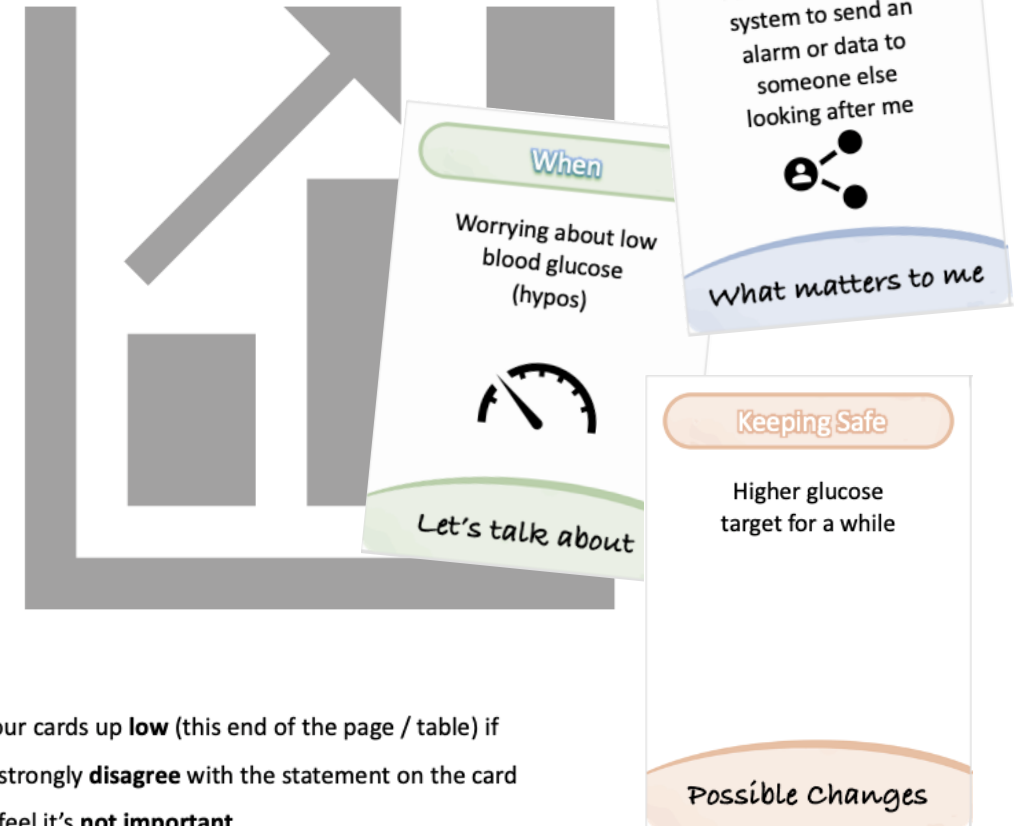
- feeling understood and *connected* with the team in this decision
- *autonomy* for patients and families
- co-identification of areas for *competency* development (education)

Integrates patient and family values (***What Matters to You***) with risk and readiness

- *Beyond* a questionnaire
- Cards provide hands-on collaboration between patient, family and MDT on topics of risk of risk and readiness.
- Improving link to Clinical Risk Management

Place your cards up **high** (this end of the page / table) if

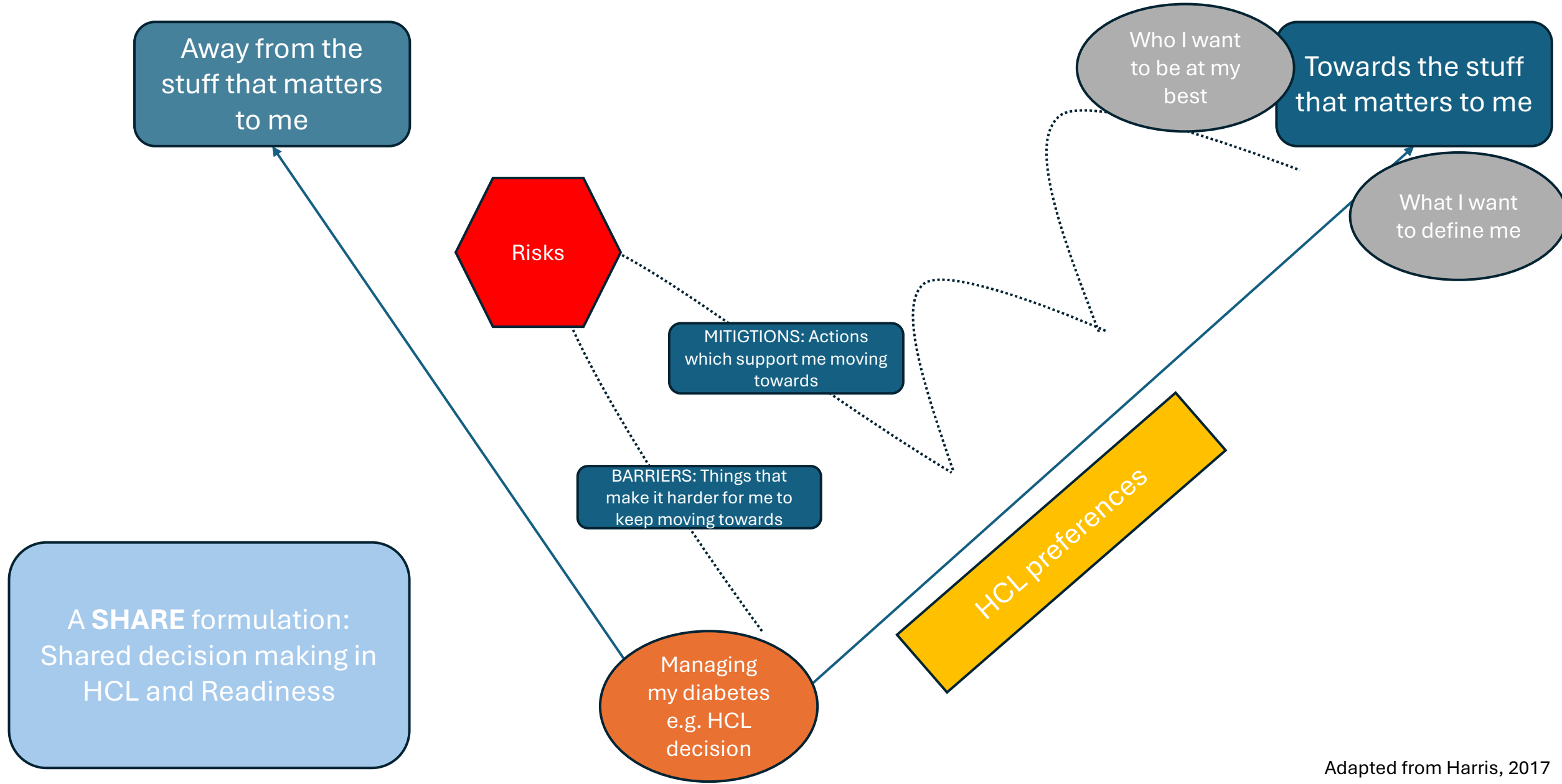
- You strongly **agree** with the statement on the card
- You feel it's **important**
- You feel it's an **issue** for you



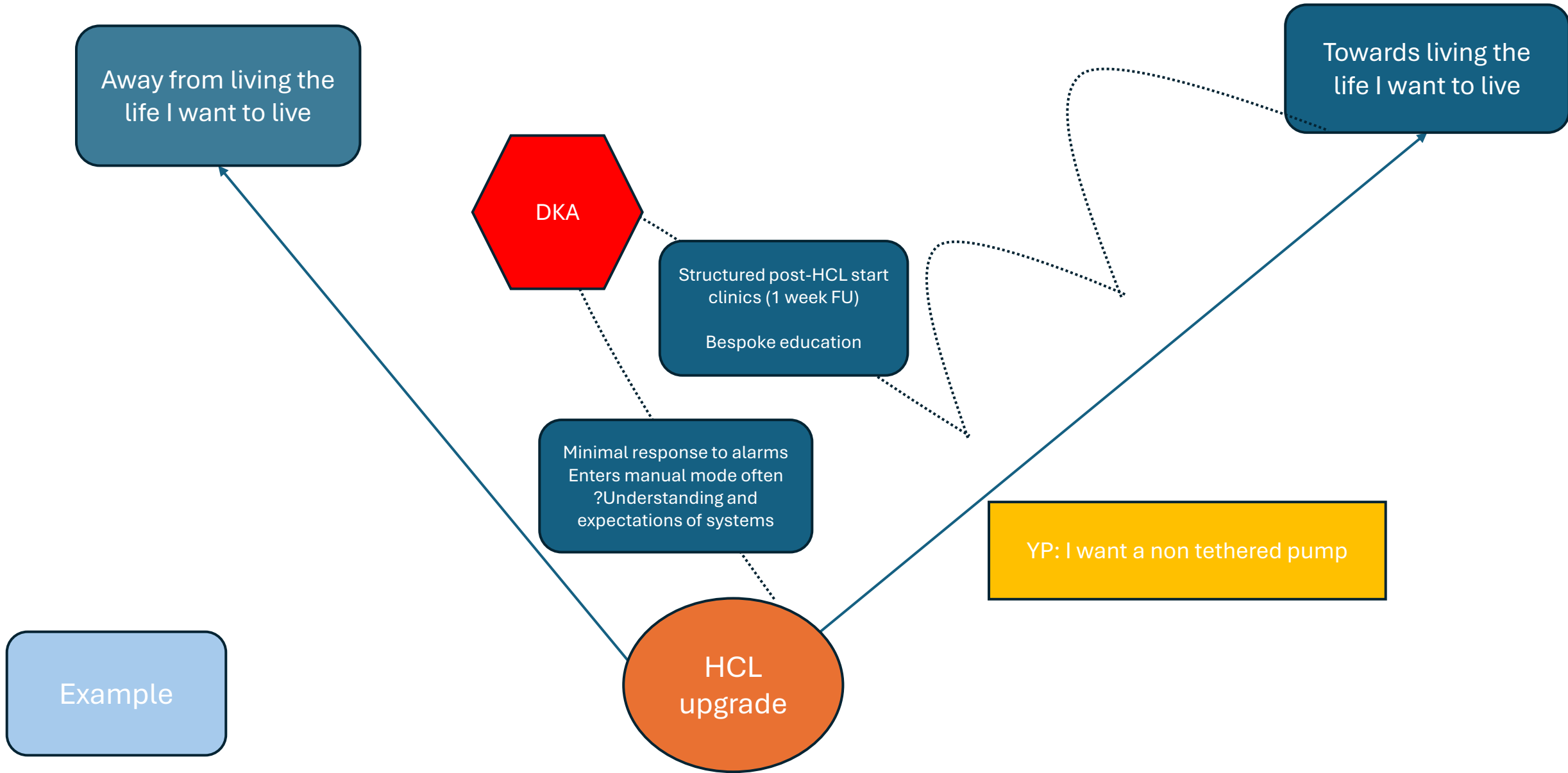
Place your cards up **low** (this end of the page / table) if

- You strongly **disagree** with the statement on the card
- You feel it's **not important**
- You feel it's **not an issue** for you

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Adapted from Harris, 2017



Designing a pathway

Expectations and timeline

- HCL Pathway discussions introduced during Newly Diagnosed Care Pathway (consistent messages embedded).
- Journey is dynamic. Clinics/home visit.
- All steps mandatory for both naïve & upgrade families (page 1).
- Naïve/upgrades to new HCL follow page 2.

Children's Hospital

Hybrid Closed Loop (HCL) System Pathway

This document belongs to

This sheet will help you track your progress along the pathway to starting your new pump and Hybrid Closed Loop (HCL) system. Write down the date as you complete each step and bring this sheet along with you to all appointments.

Step

- HCL waiting list:**
You will be added to the waiting list. Your keyworker will keep you updated on the timescale ('wait').
- HCL information evening:**
Attend a 2-hour information evening at Southampton hospital to know more about HCL.
Takes place every 3 months.
- CGM education:**
Complete a CGM education programme (1-2 sessions).
Waiting time: 2 weeks to 4 months.
If you need to change to a different CGM to be compatible with your new pump, you will need to redo the education for this specific CGM.
- Shared decision-making:**
Your keyworker will discuss your individual family's needs, and you can make a decision. After this, you will be invited to either an HCL group start or a 1:1 start.
Waiting time: 3-6 months.
- Pump ordering:**
The pump you chose will be ordered and delivered to your home address.
Takes place 7-14 days before your HCL start.
- Pre-course preparation:**
You will receive information via email regarding pre-course content. This includes learning, onboarding, contract, sick day rules and a new insulin prescription.
- HCL start and education session:**
Attend a 3-hour group start/education session at UHS (maximum of 4 families at a time). This is led by company representatives and the diabetes specialist nurse team.

Date Completed

Upgrading from your previous HCL?
Start from Step 4

Date I started my HCL System

Congratulations, you have now started using your new HCL system! Now turn the page over for your follow up education and support.

Children's Hospital

Hybrid Closed Loop (HCL) System Pathway

This document belongs to

Now that you have started your new HCL system, you will need to complete ongoing education and follow up clinics. This will help you make the best out of your new system and ensure you can use it safely in all situations.

Step

0-10 Days – Remote support:
You will receive remote support by your diabetes team via telephone, email, or text.

1-2 Weeks – First follow up in clinic
This clinic will be to provide a refresher on safety and sick day rules, then to make adjustments to your HCL settings as needed.

6-8 Weeks – Second follow up in clinic
This clinic will help you understand your own data, how to review them, and how to make decisions based on these.

3-6 Months – Advanced education session
This session will focus on more advanced features of your HCL system, as well as tailoring education to your needs (for example, using HCL in sports).

Throughout the first 6 months, you will also continue to receive ongoing remote support and education to build your knowledge and skills, including advanced modes and troubleshooting.

This process will begin again after 3-3½ years. At that point, you will get to look again at your options for a new HCL system if you would like.

Date Completed

Upgrading from your previous HCL?
Start from Step 4

Date when I will review my options again (around 3½ years from your HCL start date)

Southampton Childrens Hospital. Version 1, 2024

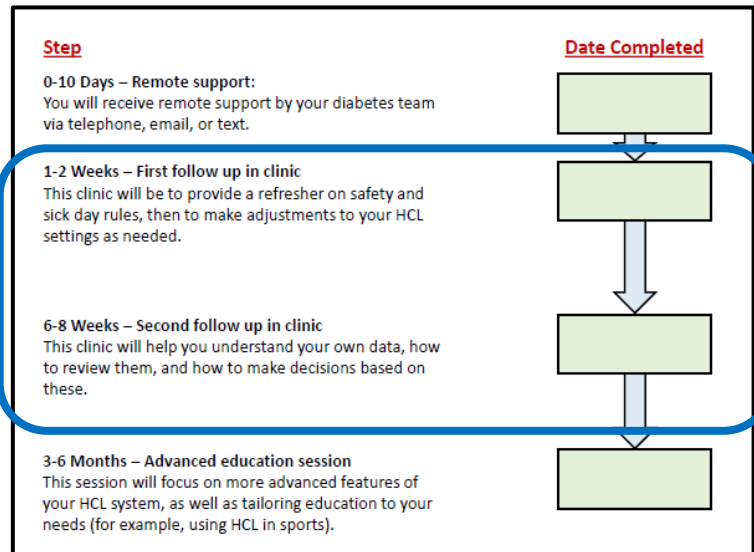
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Designing a pathway

Post HCL start clinics



- 1-2 weeks FU
- 6-8 weeks FU
- Proforma: essentials, hypo/hyperglycaemia, settings



Essentials

- Issues in 1st week
- Connected to Glooko & able to download appropriately
- Essentials to carry with you
- Charging pump / controller
- Set changes
 - Patient / parent able to demonstrate / talk through set change
 - When to do a routine set change

High & low blood sugars

- Hypo treatment
- Ketone rules
 - When to check for ketones
 - What ketone levels are significant
- Pen insulins
 - Bolus (fast insulin) insulin
 - Basal (long acting) insulin
- When to do pen injections
- How to calculate a pen correction dose
- How much basal insulin if pump fails
- Contact numbers

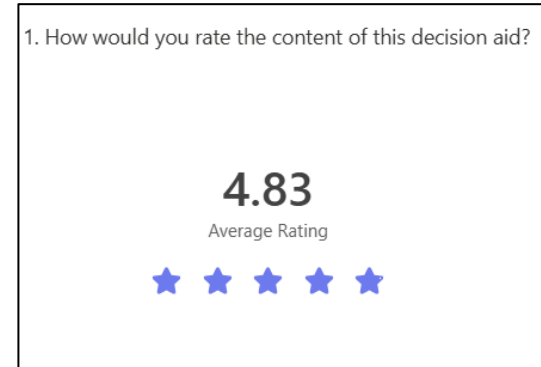
Settings

- Closed loop
 - Switch closed loop on / off
 - How to recognise pump is in closed loop
- How to set / change date & time
- Sleep mode
- Review settings together
 - Basal settings
 - Bolus settings
 - Carb ratios
 - Correction factor
- Changing pump settings
- Alarms and Alerts
 - Check alarm settings
 - How to activate / deactivate
 - Which alarms cannot be switched off
 - Managing alarms
- Total daily dose

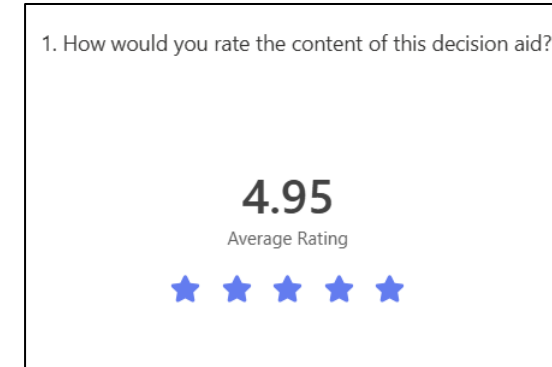
Outcomes

1. Post-session feedback

Cohort 1 (n=30)



Cohort 2 (n=19) [Ongoing]



2. Reconsidering choices

From cohort 1 to cohort 2: Decision making changed
Changes to values 'What matters to me'

Cohort 1 **17%** of CYP reconsidered initial choice after SDM

Cohort 2 **60%** of CYP reconsidered initial choice after SDM

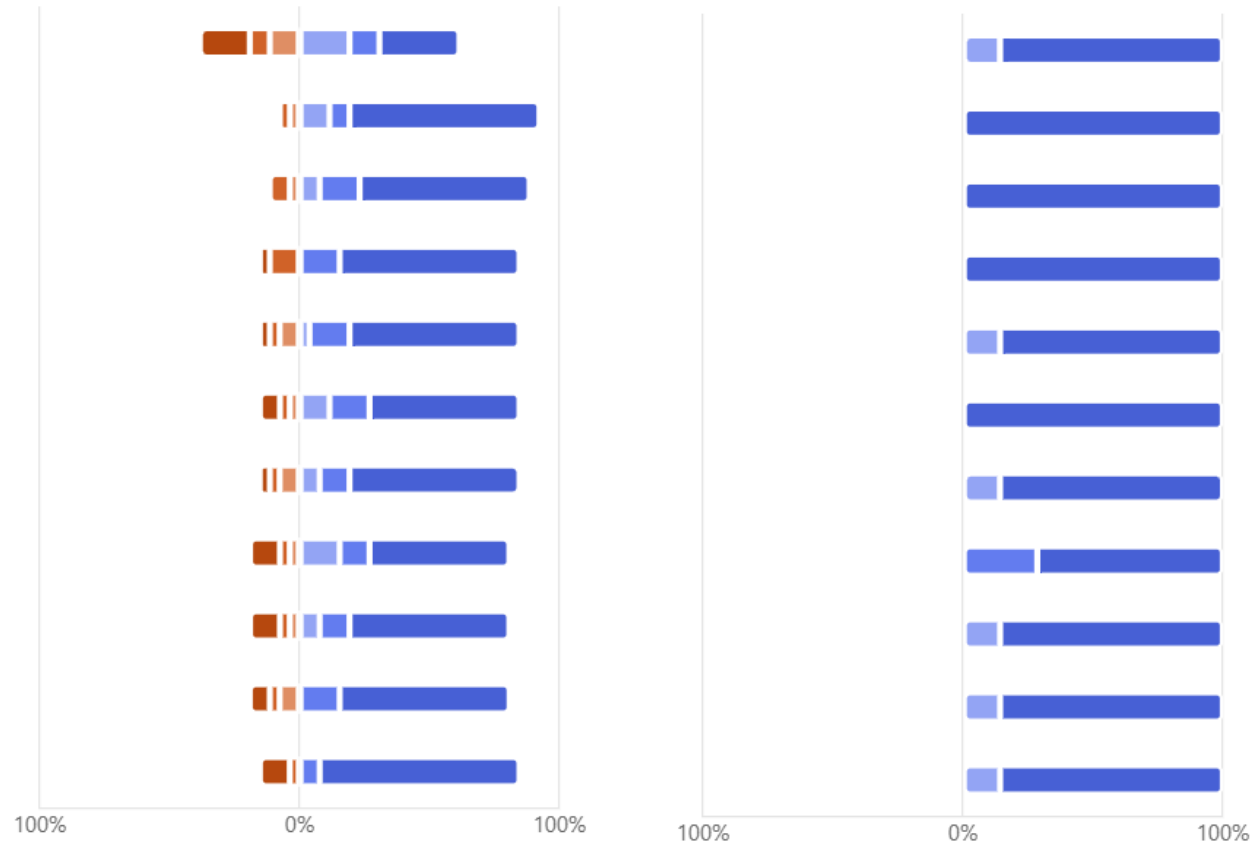
Outcomes

3. SDM-Q-9

- The diabetes team made it clear that a decision needed to be made.
- The diabetes team told us that there are different options for managing diabetes.
- The diabetes team explained the advantages and disadvantages of the management options (e.g. different HCL systems, pens...)
- The diabetes team helped me understand all the information.
- The diabetes team helped my child to understand the relevant information (where age appropriate)
- The diabetes team asked me which management option I prefer for my child.
- The diabetes team asked my child which management option they prefer.
- Together with the diabetes team we thoroughly weighed the different management options.
- Together with the diabetes team we selected a management option.
- Together with the diabetes team we reached an agreement on how to proceed
- The diabetes team have encouraged and supported me to involve my child in this decision-making process at each step.

Pre-SDM (n=26)

Post-SDM Cohort 1 (n=7)
[Ongoing]



● Completely Disagree
 ● Strongly Disagree
 ● Somewhat Disagree
 ● Somewhat Agree
 ● Strongly Agree
 ● Completely Agree

Outcomes

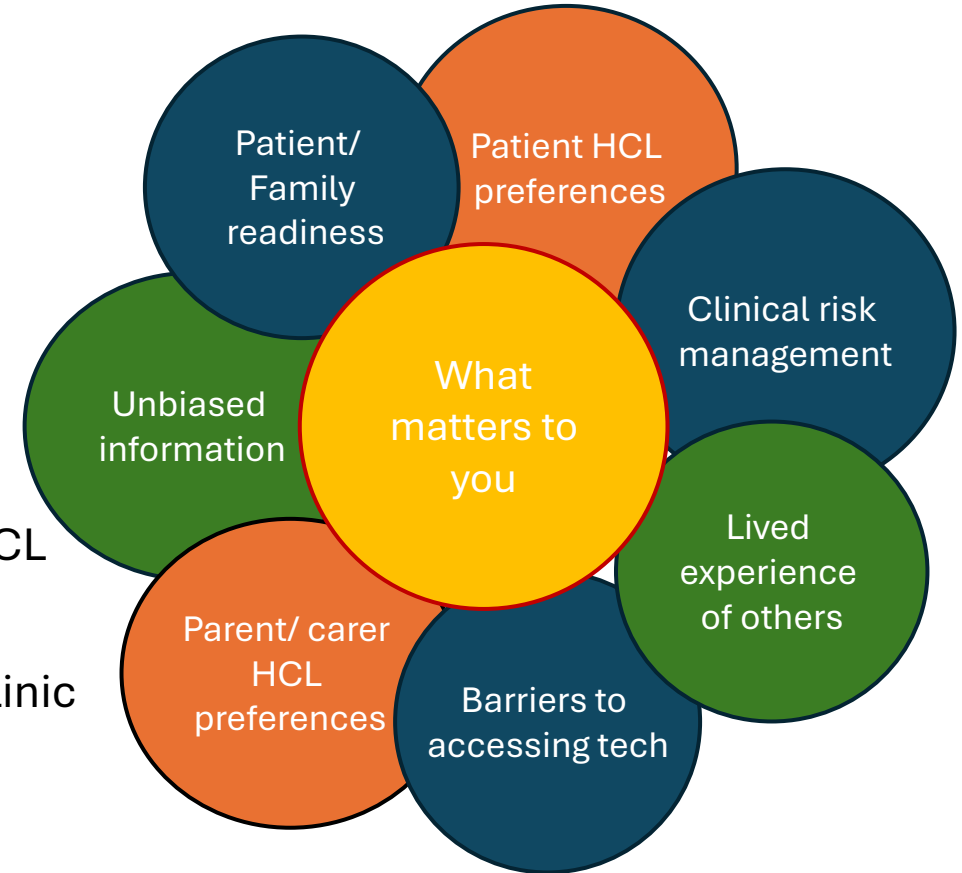
4. *Clinical outcomes*

Future work: does a structured shared decision-making + follow-up pathway produce clinical benefits?

- HbA1c, glycaemic outcomes
- Frequency of emergency admissions
- Frequency of contact to nurse keyworkers / out of hours advice
- Engagement with diabetes self-care
- Overall benefits to the health economy?

Hopes for our SDM Pathway

- Generating space for more effective communication across all stakeholders
- Maximising and sustaining safe and effective use of HCL technologies
- Extend capacity (for training and delivery) nationally, including capturing improvements and even wider range of voices
- Seeking funding to publish online tools as part of an integrated package, keeping pathway intact and up-to-date
- Contributing to improving health outcomes needed to sustain HCL funding beyond 2029
- Embed before next generation of closed loop systems arrive in clinic



Thank you!

Please feel free to contact us at joanne.summerton@uhs.nhs.uk