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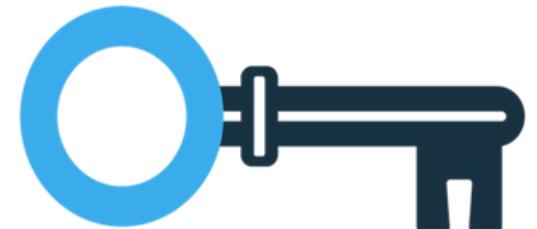
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Developing a Diabetes Data Rights Charter

HDR UK Midlands Annual Conference
12th September 2025

Dr Louise Hatherall
University of Birmingham



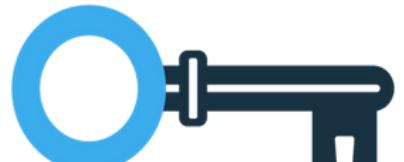
Diabetes Data
Rights

Outline

- What is ‘diabetes data’?
- Why do we need a Charter?
- Existing data rights mechanisms
- The Charter
- The Principles
- Next Steps

What is Diabetes Data?

- Technologies such as continuous glucose monitors, insulin pumps
- December 2023: NICE recommended Hybrid closed loop systems for managing type 1 diabetes
- Significant volumes of data - e.g., points generated every 1 - 5 mins



Why do we need a Charter?

- Despite the centrality of this data for the care and long-term outcomes of people with diabetes – they neither have **full access to**, nor **control over**, their diabetes data.
- Reputational & legal implications for industry
- Slowed innovation for people with diabetes

Aren't existing data protection laws enough?

Promising Provisions

- UK/EU GDPR - health as special category data, requiring explicit consent to processing.
- UK/EU GDPR - Right of data access; Right of data portability

Limited In Practice

- 'Explicit' consent to dense, technical terms & conditions
- Limits to enforceability & geographic reach

Draft Charter



A Charter “to articulate a set of principles that key stakeholders should consider to enable PwD to, safely and securely, exercise control over their diabetes data in a manner which meets their personal needs and values.”

EASD 2024

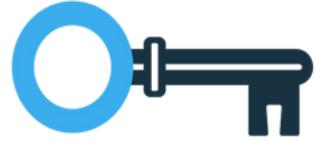
Thriveabetes
2024

D-Data
(San
Diego) 2024

ATTD 2025

Virtual
Roundtable
(1) 2025

Virtual
Roundtable
(2) 2025



Data Access: Real-time, safe, securely, when necessary, access to data on their devices, in a format useable for PwD.



Privacy and Security: Data is stored & transferred privately & securely.



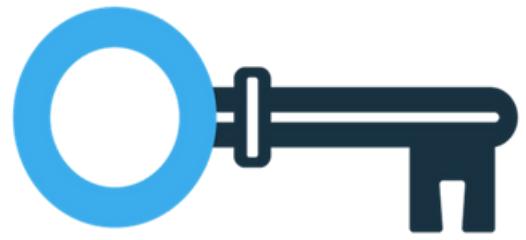
Data Benefits: Prioritising needs & interests of PwD when determining how diabetes data is collected, formatted, stored & used.



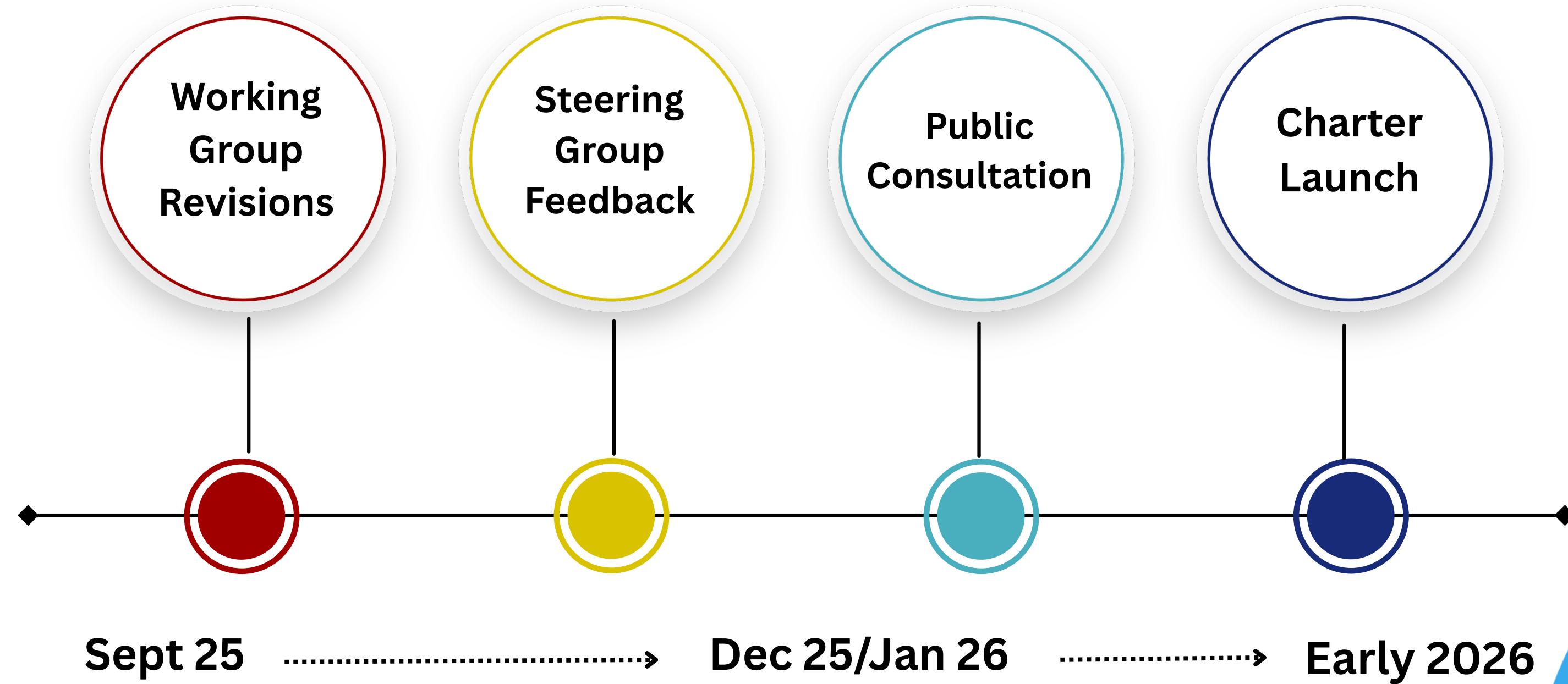
Transparency and Accountability: What diabetes data is held & how is this data used & shared?



Choice & Control: Meaningful consent for data sharing (With whom? What purpose?)



Diabetes Data Rights





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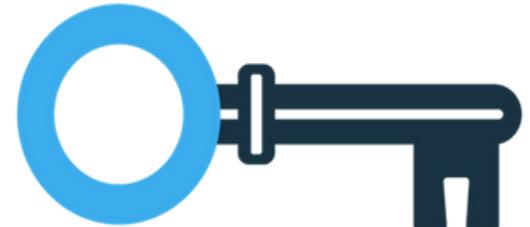
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Thank you!

Dr Louise Hatherall

On behalf of the Diabetes Data Rights Team



**Diabetes Data
Rights**