Patient centricity and the promise of data

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Patient centricity and the promise of data – two themes, four perspectives

What patients want
- Minimise disease and monitoring burden
- Support research & be supported by latest clinical research results
- Data protection

What payers/ systems expect
- No incremental monitoring burden
- Evidence for efficacy and efficiency on relevant endpoints

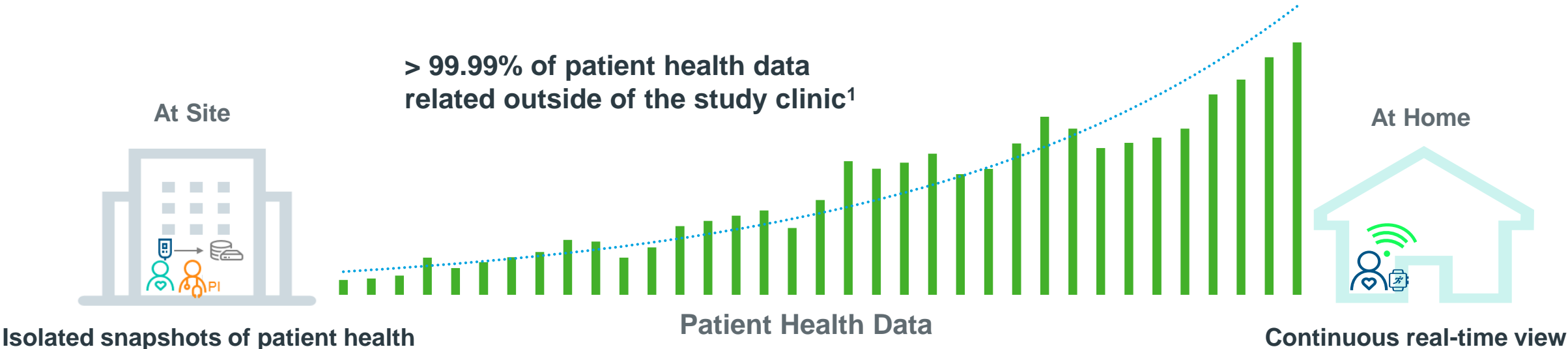**What HCPs require**
- Low monitoring burden
- Credible evidence

What Pharma Industry understands
- More relevant data for less investment

Take something that used to be a patient-reported outcome — now I can simply track it using a wearable, ... **increasing my datasets and reducing the number of patients** I need in order to get significance, thereby shrinking my trial and making it **less expensive and faster to conduct** – *SVP, Sanofi*

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Clearly, current clinical research approach takes a narrow view on classical health data which limits its relevance to the patients

At Site

> 99.99% of patient health data related outside of the study clinic[1]

At Home

Isolated snapshots of patient health

Patient Health Data

Continuous real-time view

- The exponential growth of healthcare data offers both **an opportunity to incorporate** this wealth of data into the clinical study processes, and **a challenge, given the disparate sources** where a patient's healthcare data may be contained

- Successful integration of new patient health data sources will allow a new view on trial endpoints

1: https://ehrintelligence.com/news/why-moving-beyond-the-ehr-is-needed-for-population-health/

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Four key data science innovations that help make data more patient-centric

1 **Enrich**
datasets and overcome the limitations of 1ary/ 2ary data

2 **Connect**
real time data feeds from the patient with recorded healthcare data
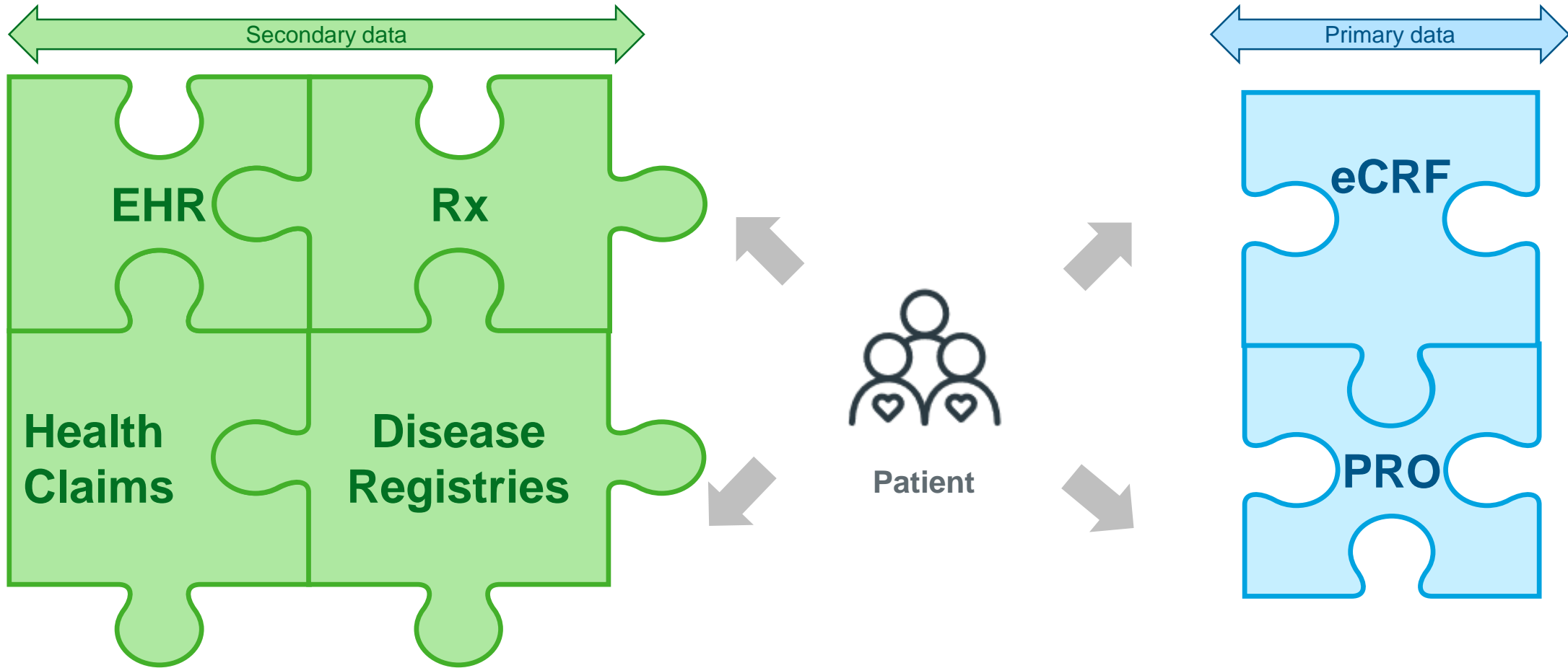
3 **Link**
genomic data with healthcare information

4 **Aggregate**
data in federated data models

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The distinction between secondary and primary data research – should we care

Secondary data

EHR **Rx**

Health Claims **Disease Registries**

Patient

Primary data

eCRF

PRO

Enriched Studies:
Data extracted from each source is linked at the **Patient Level**
using unique identifiers and combined into **one comprehensive** data set

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Connected health technologies enable better clinical research

Aggregated view of patient data

WEARABLES

MEDICAL DEVICES

VOICE

CONNECTED DEVICES

Patient

PROs

APPS

CONTEXTUAL DATA

SOCIAL MEDIA
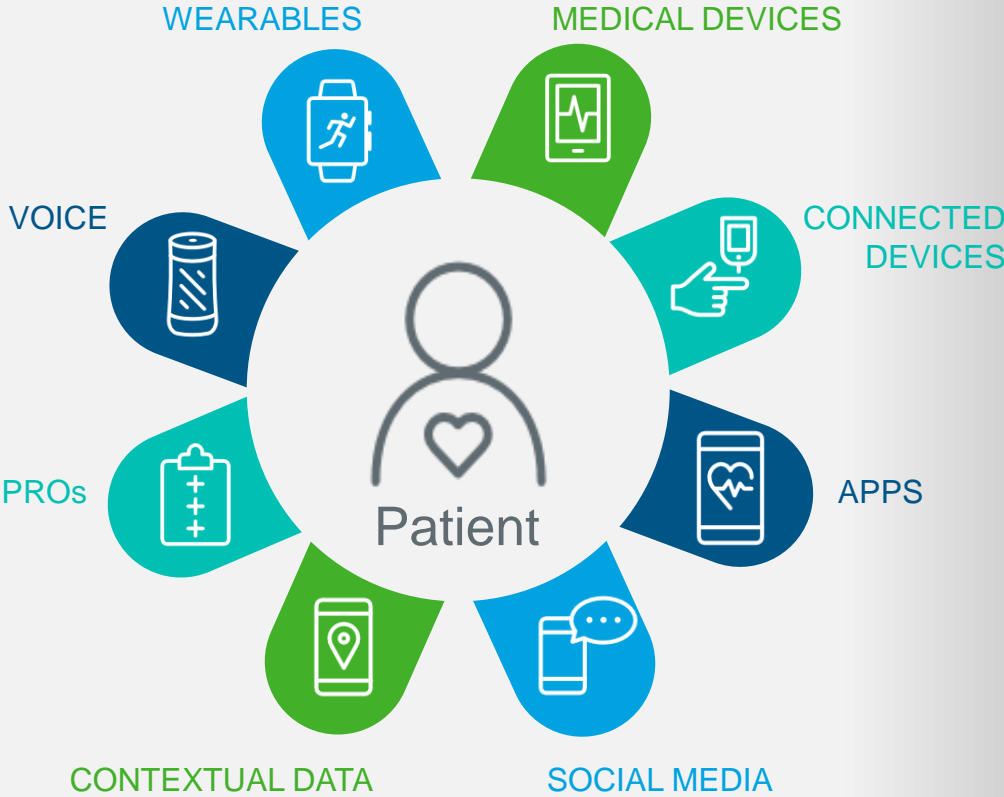
Optimising clinical research

- Patient centric designs
- Smaller study size
- Faster timelines

Enabling bigger choice of better treatments

- Novel endpoints
- Digital biomarkers
- Digital therapeutics

Enabling a new model for better care delivery

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Today, connected devices can serve evidence generation in several therapeutic areas

CGM = Continuous Glucose Monitoring, ECG/ EKG = Electrocardiogram, Ox = Oximetry, EEG = Electroencephalogram

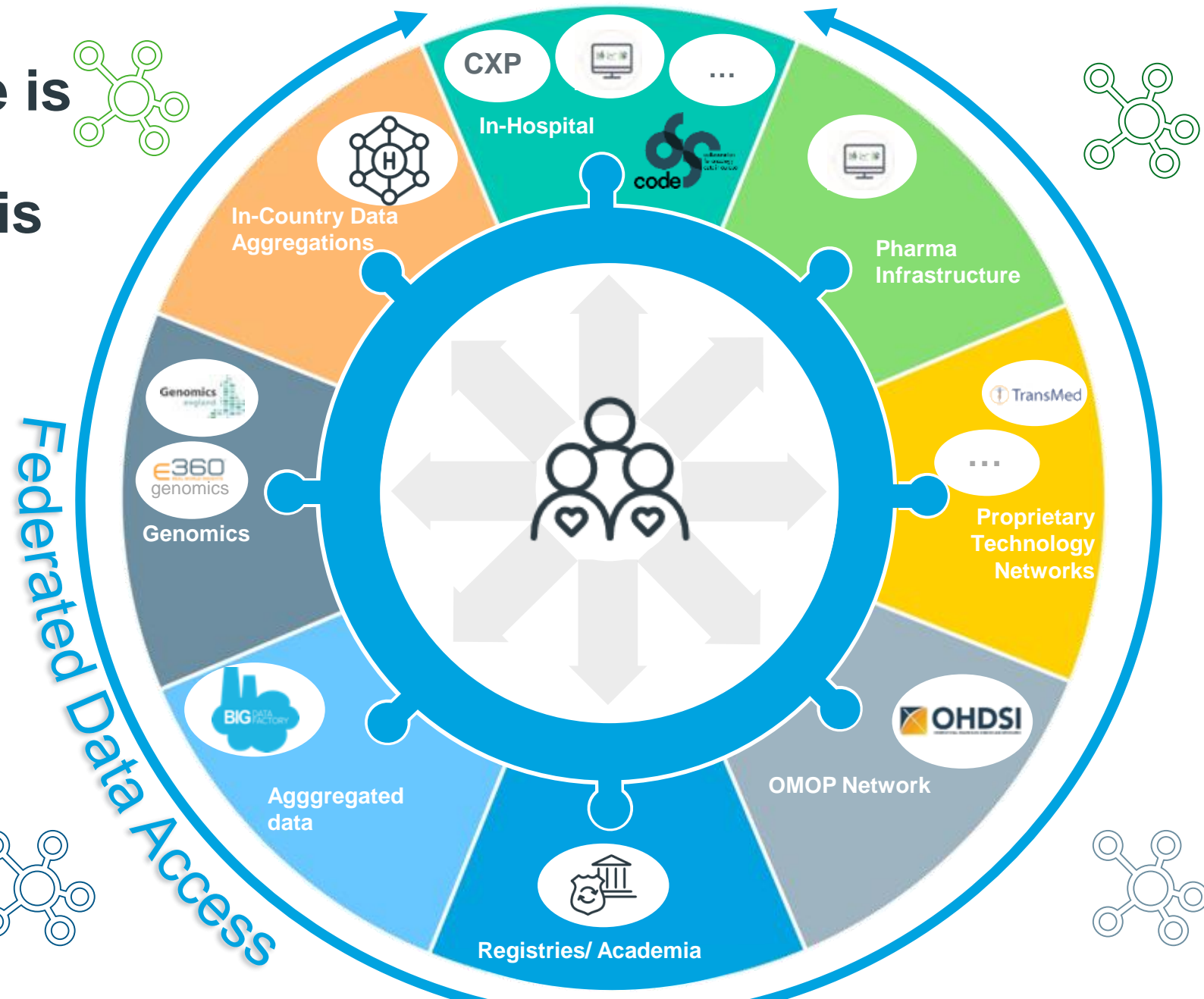|	Meta-bolic	CNS				CVOT	ONC	Respiratory	
		MS	Depression	Parkinson's	Pain			COPD	IPE
CGM	X								
Actigraphy	X	X	X	X	X			X	X
ECG/EKG						X			
Spirometry						X		X	X
Blood Pressure	X			X		X		X	X
Weight	X	X	X		X		X		
Vital/Heart Rate					X	X	X	X	X
Pulse Ox (SpO2)								X	X
EEG		X	X	X					
Tremor Detection		X		X					

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To make genomics data work it needs to be linked across silos with Real World longitudinal patient health data

Search specific mutations across multi-tumour types & multiple genomic databases

Aggregate results

Real World Data Insights
- Demographics
- Patient characterisation
- Treatment Patterns
- Outcomes

Mutation based patient profiles & characterisation

Example: Patient characterisation and demographics of patients with HER2 point mutations

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A current challenge in data science is that information is distributed across silos

Federated Data Access

- In-Hospital — CXP ... code
- Pharma Infrastructure
- Proprietary Technology Networks — TransMed ...
- OMOP Network — OHDSI
- Registries/ Academia
- Aggregated data — BIG DATA FACTORY
- Genomics — Genomics england, e360 genomics
- In-Country Data Aggregations

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Key takeaways

1 **Patient data** is essential to achieve **patient centricity** and base patient-relevant decisions on sound evidence – but there are gaps that prevent widespread use

2 **Enriched studies, connected health, and genomics** can bridge the gaps; federated data models allow navigation of heterogeneous data sets.
To keep focus on patient centricity - keep the patient's need in mind

3 These new approaches will challenge **current evidence methodologies and processes** in many pharma companies, calling for an entrepreneurial and sharing mindset and new strategies of stakeholder engagement

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Thank you

For information about the Personalised Healthcare Collaborative, please visit:
https://futureproofinghealthcare.com