National Joint Registry

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The NJR experience as a model for further implementation of a central MD registry in the UK. Benefits of a common language for the NJR RIAP agreement

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Outcomes and Registries Programme (ORP) origins

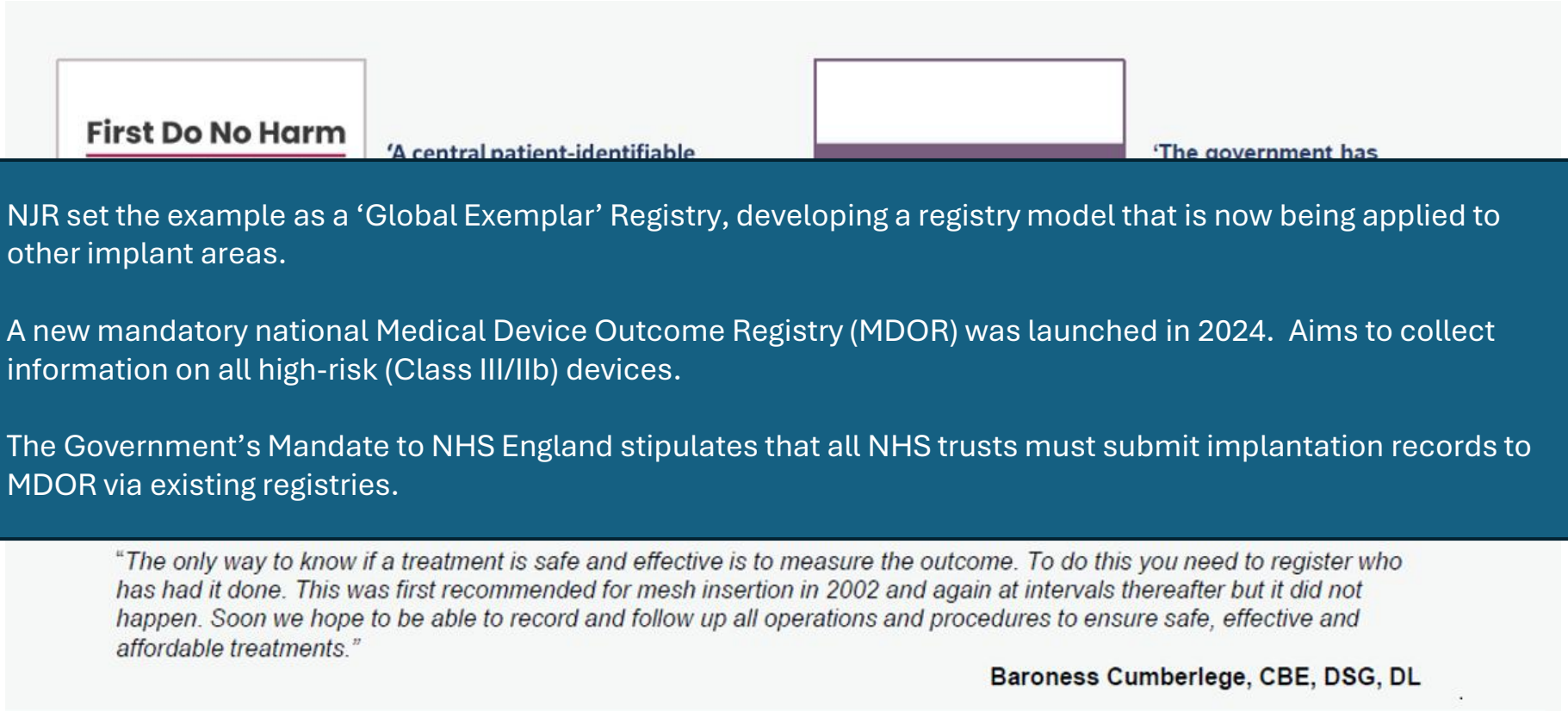
'A central patient-identifiable database should be created by collecting key details of the implantation of all devices at the time of the operation. This can then be linked to medical device outcome registries to research and audit the outcomes both in terms of the device safety and patient reported outcomes'

'The government has committed "in principle" to creating a public repository of consultants' practice details that sets out their practising privileges and key performance data, including how many times they have performed a particular procedure and how recently'

"The only way to know if a treatment is safe and effective is to measure the outcome. To do this you need to register who has had it done. This was first recommended for mesh insertion in 2002 and again at intervals thereafter but it did not happen. Soon we hope to be able to record and follow up all operations and procedures to ensure safe, effective and affordable treatments."

Baroness Cumberlege, CBE, DSG, DL

Outcomes and Registries Programme (ORP) origins (cont.)



NJR set the example as a 'Global Exemplar' Registry, developing a registry model that is now being applied to other implant areas.

A new mandatory national Medical Device Outcome Registry (MDOR) was launched in 2024. Aims to collect information on all high-risk (Class III/IIb) devices.

The Government's Mandate to NHS England stipulates that all NHS trusts must submit implantation records to MDOR via existing registries.

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This programme is aiming to replicate standards set by the NJR as follows:

- Deliver a **sustainable** registry platform and technical approach that meets diverse clinical needs.
- Provision of **high-quality data and insights** to aid decision making.
- Empower clinicians and patients with better access to **outcomes data.**
- Deliver **secure, trusted and resilient technology** foundations to enable transformation.
- Enable **consistent onboarding** of registries through a flexible approach.
- Where appropriate, to **consolidate** similar registries and/or collections to reduce burden whilst maximizing utility and value.
- Adoption of national **standards.**
- Support continuous learning, improvement, and **innovation.**
- Offer a **robust support package** for data submitters (noting different levels of digital maturity).
- Demonstrate improvements to **patient safety**, transparency and clinical outcomes.

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When successful, the programme will enable multiple benefits across health and care

By providing a data and analytics service and infrastructure, the following opportunities could be realized:

a) **Improved patient care and outcomes** through better surveillance, quality improvement, research and innovation.

b) **Higher quality data and analyses** through the adoption of common data standards to enable linkage, consistency and analytics to support quality improvement.

c) **Increased transparency and public awareness** of data assets, uses and outputs through the transparent sharing of benchmarked information, research information and routine reporting in line with Outcomes & Registries Directions.

d) **Release clinical time and focus** (within registries) to focus upon clinical leadership, strategy and improvement – by engaging data professionals to lead on technical challenges around infrastructure, legal permissions, linkage, processing, access, etc.

e) **Reduction in data collection burden** and enable more ready access of linked data assets through centralized processing, linkage and onwards sharing.

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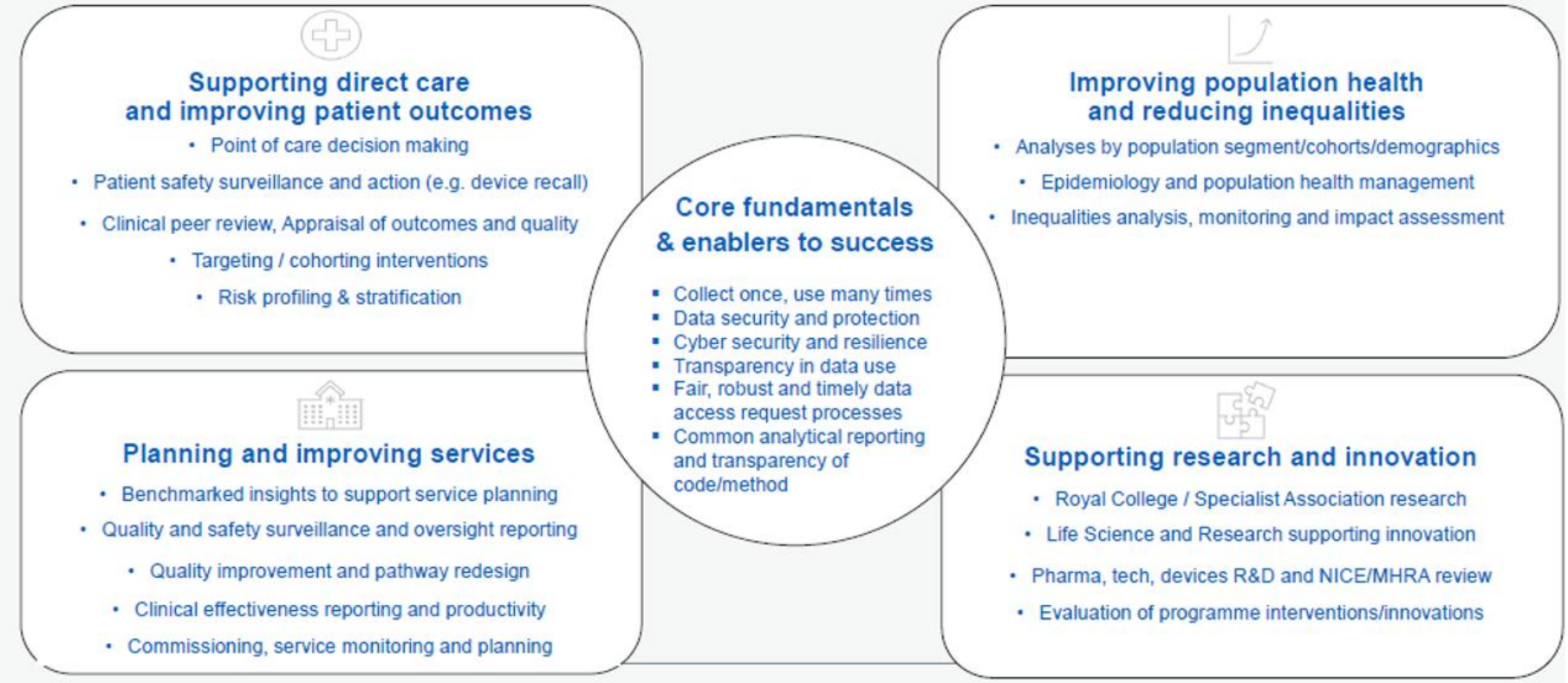
There are a broad variety of uses-cases for different clinical audit & registry data



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Benefits of a ‘Common Language’

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Global Picture – Orthopaedic Registries

- Registries have been established globally that highlight the benefits– including the NJR.
- Some orthopaedic registries are over 20 years old, with data cited many times in high quality publications.
- Registry data are routinely used to meet regulatory compliance.
- Registries have been shown to improve standards and shape best-practice.
- This has led to increased development of registries around the world.

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Benefits of International Alignment

There are clear benefits in aligning data across international registries:

- Establish standards to create a ‘common language’.
- Provides the basis for enhanced assessment of the effectiveness of treatment using real world data.
- Create a diversified pool of data for research.
- International collaboration and research
- Enables validation of analysis across international boundaries.

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