KEY POINTS

Freeing Personal Health Data: Balancing Systems Integration, Service Improvement and Privacy Risks

The US Centers for Medicare & Medicaid Services (CMS) launched the Health Tech Ecosystem on 30 July 2025, giving patients the ability to share medical and wellness data across providers, insurers and technology companies.

The initiative aims to advance prevention, early detection and a more responsive health system. Critics, however, warn that the platform could expose sensitive patient information to misuse or commercial exploitation by technology firms, highlighting gaps in data privacy oversight and consent transparency.

Globally, this initiative is building on a legacy of frameworks developed beyond US borders, that have been gradually reshaping different aspects of digital health data access. The European Health Data Space (EHDS) entered into force on 26 March 2025, harmonising secure access and secondary use of data across the European Union. Singapore's National Electronic Health Record (NEHR), first introduced in 2011, has developed a centralised system linking public and private care. Australia's My Health Record, first launched as the 'Personally Controlled Electronic Health Record' on 1 July 2012, has since expanded into a national opt out programme.

These developments are opening opportunities for health products informed by real time data. However, clear communication and responsible use remains essential to maintaining public trust.

The Systems Challenge: Breaking Down Silos

Fragmented health data is a significant barrier to value-based care. Separate provider networks, incompatible technology and restrictive rules lead to duplication, poor coordination and missed opportunities for prevention.

Interoperable flows can provide:

- **Holistic insights** by combining clinical, lifestyle and wearable data.
- **Continuity of care** across borders and providers, addressing gaps for mobile populations.
- **Population health management** through real time analytics to identify risks earlier.

Implications for Insurers: Integrated data supports stronger chronic care management, reduced hospital costs and evidence-based design of sustainable insurance products.

Enhancing Customer Service and Delivery

The free movement of health data has potential to improve service quality:

- **Proactive engagement** through personalised alerts and digital coaching.
- **Reduced friction** as records follow patients between systems.

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- **Improved chronic care** with multi-disciplinary teams accessing longitudinal data.

Implications for Insurers: Enhanced experiences can strengthen differentiation. Seamless data-enabled services may appeal to younger and more mobile members who expect personalised care.

Risks: Privacy, Exploitation and Monetisation

The same flows that improve care introduce vulnerabilities. Wellness applications and technology firms often sit outside healthcare privacy frameworks, exposing sensitive data to commercial use, targeted advertising or opaque brokering. Even anonymised datasets may be re-identified when combined with genomic or socioeconomic information.

Public trust can be eroded if data is perceived as influencing underwriting or pricing decisions. State access for surveillance or profiling also raises concerns.

Implications for Insurers: Clear boundaries between service innovation and commercial decision making are increasingly important. Visible safeguards and independent verification may help sustain confidence.

The Central Tension

Policy makers face a structural dilemma. Greater movement of data can make healthcare more efficient, personalised and continuous. At the same time, these flows create risks of misuse and commercial exploitation.

If not resolved, this tension risks either constraining innovation through excessive caution or undermining trust through perceived misuse.

Towards a Compromise Solution

1. **Regulatory Guardrails with Broad Scope**
   Legal protections that extend across all entities handling health-related data provide consistency. The EHDS illustrates the value of prohibiting secondary use for marketing, underwriting or other non-clinical purposes.

Implications for Insurers: Designing services within these limits can reinforce reputational strength and align with public expectations.

2. **Independent Oversight and Accountability**
   Independent authorities with the power to audit and sanction misuse strengthen governance.

Implications for Insurers: Engagement with oversight bodies offers insurers an opportunity to shape workable rules while demonstrating commitment to transparency.

3. **Patient Empowerment and Data Portability**

Mechanisms that allow individuals to control what is shared, with whom and for how long are central to acceptance. Dashboards, access logs and portability rights foster trust.

Implications for Insurers: Supporting such empowerment encourages member loyalty and creates scope for opt-in personalised services.

Conclusion

The move towards freeing personal health data is reshaping health systems worldwide. The United States, the European Union, Singapore and Australia have each created frameworks to reduce fragmentation, support prevention and enable mobility of care.

For insurers, the opportunities include new prevention-focused services, improved customer experience and more sustainable approaches to chronic care. At the same time, transparent governance and respect for patient control are essential to maintaining public confidence.

A balanced approach is emerging; robust regulation, effective oversight and genuine patient empowerment. By adopting this balance, insurers and health systems can unlock the promise of integrated wellness while protecting the trust that underpins the digital health future.

Key Resources:

Read more on health data regulations impacting health insurers:
The European Health Data Space
Join our network to interact and share best practice with other members: ***Data and Emerging Technology Member Network***

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