

Towards Health Data Autonomy: Bridging Consumer Wearable Data and Clinical Big Data for Holistic Healthcare

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Abstract—The rapid proliferation of health data from consumer wearables and clinical encounters has created vast but underutilised information streams. Wearables such as Fitbits, Garmins, and Apple Watches generate continuous physiological and behavioural data, yet these remain siloed within proprietary platforms and are only partially accessible to users in the form of summary metrics. Clinical health data, conversely, are collected episodically and often restricted to the search for specific biomarkers, with limited reuse for retrospective or holistic analysis. Both streams exemplify “big but wasted” data that fail to realise their potential for personalised, preventive, and autonomy-driven healthcare. This narrative review synthesises current evidence on the limitations of wearable and clinical health data practices, and considers how applying FAIR data principles (Findable, Accessible, Interoperable, Reusable) to the personal health data space, alongside data ownership mechanisms, interoperability standards, and digital twin frameworks, could unlock their combined value. By integrating these perspectives, we outline a pathway towards patient-centred infrastructures in which health data are not only generated but meaningfully repurposed to inform long-term health trajectories, clinical decision-making, and population-level research. We also discuss the significant technical, legal, and equity-related challenges that any such framework must overcome, and we are explicit throughout about which elements of this framework are established practice and which remain aspirational.

Keywords—Health data autonomy, wearables, FAIR principles, interoperability, digital twins, data governance.

I. INTRODUCTION

Health data today is generated at a scale unimaginable a decade ago. Two streams dominate: continuous wearable output, and episodic but validated clinical records. Each is routinely siloed and disconnected from the other. In this review “health data autonomy” is our own term for the health domain, adapted from the broader concept of “data autonomy” in digital governance [1], denoting a framework that grants individuals meaningful control over their own health information. We argue this can bridge both streams, while being candid about what is established practice and what remains proposal. Sections II and III characterise wearable and clinical data; Section IV examines the missed opportunities from keeping them separate; Sections V-VII develop the framework, apply it, survey its challenges, and Section VIII concludes.

Consumer wearables capture continuous physiological and behavioural data, yet this remains locked in vendor-specific ecosystems, rarely validated to medical-grade standards. Clinical data is the opposite: precise and validated, but episodic, fragmented across providers, and often discarded once its diagnostic purpose is served [2], [3], [4]. Recent advances in multimodal foundation models suggest a further evolution in digital health, moving beyond task-specific algorithms towards general-purpose models capable of jointly learning from electronic health records, physiological signals, medical imaging, genomics, and other health modalities. Such models offer the prospect of unified representations of an individual’s health across diverse data sources, but their effectiveness depends fundamentally on interoperable, longitudinal, and high-quality data infrastructures.

In this context, health data autonomy becomes not only a governance objective but also an enabling prerequisite for the next generation of AI-enabled healthcare.

The result is a missed opportunity for holistic, preventive care, in which high-frequency wearable signals could contextualise clinical diagnostics and clinical benchmarks could validate consumer-derived signals [3].

A. Defining health data autonomy

Health data autonomy is the principle that individuals should have meaningful control over the collection, access, and reuse of their personal health information, so that data serve data subjects, not only institutional or commercial interests. The underlying “data autonomy” concept, as a governance principle against the misuse of personal data, is due to Gstrein [1], developed for smart cities and digital infrastructure; we extend it to health. The health-specific term itself is our own formulation, not drawn from a prior health-specific source, and we want that authorship unambiguous. Health data autonomy overlaps with but is not synonymous with adjacent concepts. Personal health records give patients a record of their data but rarely portability or governance over its reuse [5]. Self-sovereign identity and decentralised-identifier approaches give patients cryptographic control over credentials and access but limited deployment specifically for continuous wearable streams [6]. Data cooperatives pool member data under collective governance rather than individual control with role-based access for healthcare. Citizen data sovereignty, proposed specifically for wearable and wellness data, is closest in spirit to the framework discussed on this paper but has been argued primarily as a consent mechanism for research reuse rather than as a

bridge to clinical integration. [7].

Health data autonomy, as we use it, is distinguished by its explicit focus on reconciling wearable and clinical streams under patient control, rather than governing either in isolation.

We align health data autonomy operationally with the FAIR principles [8]: data retrievable, usable across systems without loss of fidelity, and retainable in value beyond any single encounter, supported by governance that preserves consent, transparency and equity [4]. It is worth being precise that FAIR is a data-management standard, not a legal ownership or control mechanism; it constrains how data can be structured and exchanged. Reconciling the wearable and clinical streams so both can be integrated and reused is the task addressed in the rest of this review.

B. Aim, scope, and structure of this review

This narrative review draws on PubMed, Scopus, and Google Scholar searches (September 2025–July 2026; ~500 sources) using terms including "health data autonomy," "wearable health data," "clinical big data," "FAIR principles health," "EHR interoperability," "digital twin healthcare," complemented by grey literature and targeted searches for post-2025 developments. The search was thematic rather than organised around predefined subquestions, prioritising evidence illustrating core arguments over exhaustive subfield coverage. This carries the limitations of any narrative review: selection was not independently duplicated, no formal risk-of-bias appraisal was applied, and reliance on English-language databases and our own thematic judgment means relevant work may have been missed. The evidence that follows should be read as illustrative rather than exhaustive.

II. DATA PRACTICES FROM WEARABLES

Apple, Fitbit, and Garmin dominate the wearable market, with Oura and Whoop serving sleep- and recovery-focused niches [9], [10]; Meta has more recently demonstrated a wrist-based EMG interface for gesture-based interaction [11], broadening the category. Across platforms, wearables commonly measure heart rate and heart rate variability (HRV), sleep duration and stage, step counts and activity, VO2 max, SpO2 and breathing rate, and stress or readiness indices, with select models adding skin temperature, ECG-based rhythm notification, and manual health logging. These streams hold potential for long-term monitoring but remain largely confined within vendor ecosystems.

A. Accuracy and structural limitations

Germini et al. [12], synthesising 65 studies of wrist-worn trackers, found step counts and heart rate the most reliably measured outcomes, while energy expenditure was consistently least accurate, with errors regularly exceeding 30%. Fuller et al. [13] similarly found heart rate accuracy declining at higher exercise intensity and in users with higher BMI or darker skin tones. A 2026 population-level analysis of Apple's FDA-cleared hypertension notification

feature illustrates the same pattern in a clinically validated context: an alert raised the probability of true hypertension from 45% to 81% in adults over 60, but from only 14% to 47% in adults under 30, and its absence was markedly less reassuring in older and higher-prevalence demographic groups [14].

Device-level validation against polysomnography confirms this unevenness in sleep-specific wearables. On the Wearanize+ dataset, Zmax EEG sleep staging agreed with PSG only moderately (YASA versus Dreamto, mean kappa 0.45 versus 0.37) with persistent N2/N3 confusion [15]; band power and spindle detection matched PSG features only after per-subject calibration [13]; and the Empatica E4 showed strong heart rate concordance ($r = 0.861\text{--}0.986$) but more variable skin temperature concordance ($r = 0.762\text{--}0.956$) [17]. Data also sit in proprietary apps with only aggregated summaries exposed to users [9], [10], and most devices lack HER interoperability [18].

Continuous monitoring of heart rate, HRV, sleep, and activity enables early detection of deviations that may precede clinical events, including atrial fibrillation flags and burnout-predictive fatigue patterns [19], [20]. A recent pilot study [18] ($n = 79$) found significant correlations between wearable use and quality-of-life domains ($r = 0.33\text{--}0.41$), though the small, cross-sectional, self-selected sample makes this hypothesis-generating rather than confirmatory. This potential also remains constrained by reliance on summary metrics rather than raw data [22]. Most wearables operate within proprietary ecosystems that cannot be seamlessly transferred into EHRs or research databases [18], and differing formats, APIs, and update cycles jeopardise reproducibility even where exchange is feasible [4]. Standards such as HL7 FHIR exist to overcome this [23], but adoption remains slow and fragmented [24]. We regard convergence on common standards as a prerequisite for health data autonomy, not merely an aspiration.

III. DATA PRACTICES FROM CLINICAL HEALTH DATA

A. Nature of clinical data

EHRs encompass laboratory results, imaging, medication records, and coded diagnoses and procedures [25], alongside unstructured notes and continuous vital signs in acute settings [26], [27]. Production is immense: over 14 billion laboratory tests annually in the US [25] and 1.1 billion in NHS England [29]. Analysed longitudinally, this could inform individual management, population health, and predictive analytics [4]. Much clinical data is tied to a single diagnostic or billing purpose and archived without longitudinal reuse [3]. EHRs capture snapshots rather than continuous records, and fragmentation across providers produces duplicated tests and inconsistent care [30].

Patients rarely have seamless record access, and what

access exists is seldom interoperable with wearable data [31]; clinicians face data overload and weak decision support [26]. Once a test has served its immediate purpose it is rarely revisited, preventing identification of broader patterns such as early multimorbidity markers [2], [3]. Heterogeneous EHR platforms and institution reluctance to share produce fragmented records [27], and GDPR's consent requirements, while vital for privacy, complicate secondary use [32]. Any autonomy-centred framework must engage these constraints directly.

B. Potential: longitudinal trajectories, network modelling, population health

Linking encounters over time would let clinicians track disease progression and detect early warning signs [27]. At population level, integrated datasets support network modelling of comorbidity clusters and outcome prediction [33], [25], [34], shifting clinical data from a narrow diagnostic record to a strategic resource.

IV. CONVERGENCE & MISSED OPPORTUNITIES

A. parallel paradox: both datasets are "big" but underused

EHRs provide structured but episodic snapshots [30]; wearables provide fine-grained real-time data without clinical validation [9]. Wearable data lacks clinical grounding; clinical data lacks continuity. Their convergence is where the value lies. Continuous pre-operative activity and sleep tracking can inform risk stratification, and post-operative monitoring can bridge the gap to follow-up: in CABG patients, wrist-worn trackers detected physiological deviations up to a week before hospitalisation for decompensation [36], a hospital-reported pilot found Fitbit-derived models predicted paediatric appendectomy complications up to three days before formal diagnosis [37]. At consumer scale, the launch of OpenAI Health in the U.S. illustrates growing commercial interest in patient-facing integration of wearable and clinical data rather than constituting evidence that such integration has solved interoperability challenges [38].

B. Long-term risks of non-integration

Fragmented streams leave patients unable to exercise meaningful control over their information [39], and wearable data may be commercially exploited without informing care [40]. The absence of patient access is not itself a safeguard against commercialisation: data locked in vendor ecosystems is already commercially exploited, and easier access could in principle also mean easier commercial access. What access and interoperability add is the possibility of governance, a mechanism through which patients can see, contest, and redirect data use, an open design problem rather than a guarantee. Clinicians are meanwhile deprived of ecologically valid metrics, and over time only digitally literate or affluent patients may be able to synthesise their own data, entrenching inequality [41].

V. HEALTH DATA AUTONOMY FRAMEWORK

This framework draws together established technical and legal building blocks in a new configuration; it has not been implemented as an integrated system, and several components face open questions addressed in Section VII.

A. Principles

Health data autonomy centres on individual control, framing the patient as an active steward rather than a passive data subject, shifting authority from institutions to individuals [42]. The FAIR principles supply both conceptual anchor and practical scaffold, articulating a dual mandate of patient agency and technical and ethical safeguards.

B. Technical enablers

Data ownership and portability, through personal health records and patient-controlled data vaults [43], is the first enabler; cross-platform integration via standards such as HL7 FHIR is the second [23]. AI, machine learning, and digital twins can maximise value once data are accessible [43], but do not themselves resolve governance and access problems. Federated learning remains primarily a privacy-preserving training mechanism [35]; its potential for personal empowerment or micro-monetisation is largely undemonstrated. Blockchain-based provenance recording [44] faces real complexity, energy cost, and scalability constraints for continuous physiological data. These enablers are structural prerequisites, not solutions in themselves.

C. Ethical and social dimensions

Trust is foundational: patients must feel their data are handled securely and transparently [45], and transparent consent and accountability are preconditions, not optional enhancements, though current law does not yet make this easy at the pace wearable data collection requires (Section VII-B). Health literacy determines whether access translates into meaningful engagement [46], and the digital divide risks making autonomy a privilege of the advantaged unless policy ensures inclusive access and guards against commercial monopolisation [47], [32].

Several operational mechanisms remain unresolved by this framework: how consent is withdrawn retroactively, how access is delegated to caregivers or transferred in emergencies, how erroneous wearable data is corrected once integrated into clinical records, and accountability when automated recommendations drawing on both streams are wrong. We flag these as necessary components of any implementation rather than problems this review solves.

Table 1. Components in health data autonomy ecosystem

Example	Maturity	Evidence basis	Responsible actor
Individual control (V-A)	Principle, undeployed	Riso et al. [39]	Patient, regulator
Data vaults	Established,	Ruhi & Chugh	Patient, vendor

<i>(V-B)</i>	Fragmented	[5]	
HL7 FHIR/ openEHR (V-B)	Established, inconsistent	Mandel et al. [23]	Standard bodies, EHR vendors
Federated learning (V-B)	Research-stage	Rieke et al. [35]	Institutions
Blockchain provenance (V-B)	Early stage, unscaled	Agbo et al. [44]	Technical implementers
Digital Twins (VI-C)	Narrow deployment	Twin health [60]	Commercial platforms

VI. HYPOTHETICAL SCENARIOS: APPLYING THE FRAMEWORK

These scenarios are deliberately hypothetical, combining existing evidence with extrapolation.

A. Scenario 1: Wearable big data autonomy

Consumers would move from descriptive summaries to integrated predictive signals of stress, fatigue, or recovery from combined HRV, resting heart rate, activity, and SpO2 data [48]. Multimodal wearable data has captured deviations in pregnancies that did not progress to term [49] and HRV changes near preterm birth [50], with deviation-detection algorithms maturing [51], [52]. A recent multimodal sleep foundation model trained on over 585,000 hours of clinical polysomnography, rather than wearable data, predicted 130-disease risk from a single night's recording with strong discrimination [C-index ≥ 0.75] [53]; its authors note that extending this approach to wearable-derived signals, which lack full brain activity and differ in sampling rate and noise, would require retraining and independent revalidation. That gap between clinical-grade and consumer-grade signal fidelity is the same gap that keeps a general-purpose consumer forecasting product hypothetical.

B. Scenario 2: Clinical big data autonomy

AI-integrated EHR, genomic, and immunological profiles have improved therapy tailoring in autoimmune rheumatic disease [52]; graph-based machine learning connecting EHRs to a biomedical knowledge graph has linked clinical phenotypes with molecular endotypes in atopic dermatitis [55], alongside parallel work on genomic-EHR integration [56] and cardiovascular genomic interoperability [57]. Autonomy here means patients accessing these integrated views rather than isolated results and it concerns governance over who controls access, reuse, and downstream decision-making.

C. Scenario 3: Integration via digital twins and autonomy-driven infrastructures

Digital twins, dynamically updated computational replicas, could in principle simulate disease trajectories and test interventions virtually [43], with autonomy as the governance layer determining how wearable and clinical data are combined.

The iASiS project offers a precedent for heterogeneous data fusion [56], and generative AI modelling disease

progression from large-scale EHRs [59] suggests growing feasibility. Narrow, single-condition digital twins are beginning to reach commercial deployment, such as an industry-reported metabolic digital twin combining lab results, continuous glucose monitoring, and activity data to guide GLP-1 therapy management [60], but no general-purpose health digital twin of the kind described here has been deployed at scale.

VII. CHALLENGES

A. Technical challenges

Harmonised data standards remain absent across sources: digital pathology alone still contends with proprietary, vendor-specific whole-slide image formats that limit interoperability despite DICOM's availability as a vendor-neutral alternative [61], outsourced lab tests use divergent coding, and wearables are not medical-grade instruments [13]. Proprietary APIs reinforce silos, and adoption of HL7 FHIR and openEHR remains inconsistent [23]. In the United States, regulatory pressure toward standardisation has intensified over the past two years: CMS's Interoperability and Prior Authorization rule began enforcing FHIR-based API and decision-timeline requirements for major payers from January 2026, and ONC's HTI-5 proposed rule would streamline EHR certification around API-based interoperability [62][63].

B. Legal and ethical challenges

GDPR imposes real constraints on secondary use, depending on the applicable Article 6/9 lawful basis, this may require explicit consent, a public-interest justification, or another recognised legal ground [32]. It is difficult to see how these protections, which exist to guard against continuous surveillance of personal data, can be reconciled with continuous wearable data sharing without substantial new governance infrastructure; we regard this as the largest open question the framework faces, unresolved by any enabler in Section V-B. Static consent models fail to reflect data that accrues continuously, and dynamic consent remains unevenly implemented [64]. The European Health Data Space Regulation has recently moved from policy initiative to binding law, in force since March 2025, with secondary-use provisions phasing in through 2027 to 2029 [65], [66], a genuine step toward the needed governance, though one that governs structured clinical data and does not reach consumer wearable data held by commercial vendors.

Beyond data governance, the emergence of the European Union Artificial Intelligence Act [67] introduces a complementary regulatory layer governing how AI systems themselves are developed and deployed. While the EHDS focuses on enabling secure access to health data and the GDPR regulates its processing, the AI Act establishes a risk-based framework for AI systems, with many medical AI applications classified as high-risk and therefore subject to requirements for data quality, transparency, human oversight, risk management, and post-market monitoring.

As health data autonomy evolves from a data-sharing concept into an AI-enabled ecosystem incorporating predictive models, compliance will increasingly require alignment across all three regulatory frameworks rather than treating data governance and AI governance as separate challenges.

C. Social and equity challenges

Access to smartphones, broadband, and wearables is unequally distributed [46], and subscription-based devices create socioeconomic stratification in who benefits from continuous monitoring. Datasets skewed toward affluent, digitally literate populations risk producing biased models that fail to generalise [68]. Without deliberate effort, autonomy-driven infrastructures risk reproducing rather than reducing existing disparities.

VIII. CONCLUSIONS

More health data is generated today than at any prior point in history, yet its potential to transform care remains only partially realised: wearables provide continuous insight, clinical systems hold validated records, and neither is adequately connected to the other or accessible to the patients who generated it. This review has argued that health data autonomy, grounded in individual control, FAIR principles, and interoperable governance, can serve as that bridge. We have tried to be explicit about what is evidenced and what is proposed: wearable accuracy limitations, clinical data fragmentation, and existing interoperability standards are well documented; the combined framework, and the digital twin, federated learning, and blockchain enablers discussed in Section V, are not. Achieving this vision requires convergence on common data standards, honest engagement with the hurdles GDPR and consent frameworks pose (only beginning to be addressed by the EHDS for clinical, not wearable, data), investment in equity and digital literacy, and realistic assessment of what these technologies can and cannot currently deliver.

Autonomy is not a technical upgrade but a cultural realignment requiring sustained, multidisciplinary commitment. The clinical payoff is concrete: patient-controlled longitudinal data would substantially reduce information fragmentation and improve continuity of care.

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