



Legal and Ethical Frameworks for AI-Powered Disease Surveillance Systems: A Scoping Review

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Abstract

Background: Artificial intelligence (AI)-enabled disease surveillance systems have become increasingly prominent in public health, particularly during recent global health emergencies. While these technologies offer potential benefits for early outbreak detection and response, their widespread deployment raises complex ethical and legal questions that remain insufficiently synthesised.

Objective: This scoping review aimed to map the existing legal and ethical frameworks governing AI-powered disease surveillance systems, identify dominant themes across jurisdictions, and highlight gaps relevant to policy and governance.

Methods: A qualitative scoping review was conducted following the Arksey and O'Malley framework and reported in accordance with the PRISMA-ScR guidelines. Searches were performed across major biomedical and legal databases, supplemented by authoritative policy and regulatory documents. The included sources were synthesised using thematic analysis to capture recurring ethical and legal concerns.

Results: The reviewed literature demonstrated substantial heterogeneity in governance approaches across regions. Privacy and data protection emerged as the most frequently discussed ethical concerns, alongside challenges related to informed consent, accountability, transparency, and equity. Legal frameworks varied widely, with comprehensive data protection regimes in some jurisdictions contrasted by fragmented or outdated regulatory structures elsewhere. Across settings, a consistent gap was observed between high-level ethical principles and their operationalisation in enforceable governance mechanisms.

Conclusions: AI-powered disease surveillance is governed by diverse and evolving legal and ethical frameworks, yet significant governance gaps persist. Addressing these gaps through context-sensitive, enforceable, and equity-oriented regulatory approaches will be essential to ensure responsible and trustworthy use of AI in public health surveillance.

Keywords: Artificial Intelligence, Ethics, Public Health Surveillance, Privacy

Introduction

Disease surveillance is a foundational function of public health systems, enabling early outbreak detection, monitoring of disease trends, and timely implementation of control measures.¹ Artificial intelligence (AI), machine learning, and data-driven analytics have increasingly enhanced these surveillance capacities by enabling the rapid integration and analysis of large, heterogeneous datasets.² During recent global health emergencies, particularly the COVID-19 pandemic, AI-powered surveillance tools were widely deployed to support outbreak detection, contact tracing, real-time dashboards, and predictive modelling, highlighting their growing role in public health preparedness and response.³⁻⁵

AI-powered disease surveillance refers to the application of algorithmic techniques, including machine learning, natural language processing, and predictive analytics, to population-level health data in order to improve epidemiological monitoring and decision-making.⁶ These systems frequently integrate data from electronic health records, laboratory reporting platforms, mobile devices, mobility datasets, and digital media sources to generate near-real-time insights.⁷ While such approaches offer advantages in efficiency, scalability, and predictive capability, their deployment at a population scale introduces complex ethical and legal challenges related to data governance, individual rights, transparency, accountability, and equity.^{8,9}

The ethical and legal implications of AI in healthcare have been increasingly examined, with principles such as autonomy, beneficence, non-maleficence, justice, transparency, and accountability frequently cited as foundational to responsible AI use.¹⁰⁻¹² Legal analyses have similarly focused on data protection, consent, liability, and regulatory oversight.¹³



However, when AI technologies are applied specifically to public health surveillance, these concerns are amplified by the scale of data collection, the often implicit or mandatory nature of participation, and the risk of long-term or secondary use of data beyond the original public health purpose.¹⁴⁻¹⁶ Existing reviews have predominantly focused on AI ethics in clinical and healthcare settings, where decision-making occurs at the individual patient level. In contrast, AI-powered disease surveillance operates at a population level, involving large-scale data aggregation, mandatory or implicit participation, and state-led interventions, thereby introducing distinct governance challenges that remain insufficiently synthesised.¹⁷

Governance of AI-powered disease surveillance further extends beyond conventional academic literature to include statutory law, regulatory instruments, and “soft-law” mechanisms such as ethical guidelines and policy frameworks.¹⁸ Evidence in this domain remains fragmented across disciplines and jurisdictions, with limited synthesis of how ethical principles and legal requirements are operationalised in practice.¹⁹ This fragmentation is particularly evident in low- and middle-income settings, where regulatory infrastructures may lag behind rapid technological adoption.²⁰

Given the breadth, heterogeneity, and evolving nature of this evidence base, a scoping review represents an appropriate methodological approach to systematically map existing legal and ethical frameworks governing AI-powered disease surveillance.²¹ Accordingly, this scoping review aims to synthesise peer-reviewed and policy-oriented literature to identify dominant themes, regulatory approaches, and governance gaps across global contexts, thereby informing future research, policy development, and responsible implementation of AI-enabled public health surveillance systems.

Despite the increasing deployment of AI-powered disease surveillance systems, there remains a lack of synthesised evidence on how legal and ethical frameworks are operationalised across jurisdictions. This review addresses this gap by systematically mapping existing governance approaches and identifying inconsistencies between high-level principles and their real-world implementation. Accordingly, the objectives of this scoping review are to:

1. Map the key ethical principles associated with AI-powered disease surveillance systems.
2. Examine the legal and regulatory frameworks governing these systems across jurisdictions.
3. Identify gaps and inconsistencies between ethical principles and their implementation in practice.

Material and methods

Study Design

This scoping review was conducted following the methodological framework proposed by Arksey and O’Malley and the refinements suggested by Levac et al., and reported in accordance with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines.^{22,23} The scoping review design was chosen because the evidence on AI-powered disease surveillance is heterogeneous and cross-disciplinary, spanning peer-reviewed research, legal scholarship, policy documents, and ethical guidelines, rather than focusing on specific interventions or outcomes.

Research Questions

The review was guided by broad, exploratory research questions aimed at mapping the existing landscape rather than testing hypotheses. Specifically, the review sought to:

1. Identify the ethical principles most commonly discussed in relation to AI-powered disease surveillance systems (for example, privacy, autonomy, transparency, fairness, accountability, and equity).
2. Examine the legal and regulatory frameworks that govern these systems across different jurisdictions (for example, data protection laws, public-health emergency powers, and AI-specific regulations).
3. Explore how ethical and legal approaches are implemented in practice and where gaps or inconsistencies exist between high-level principles and concrete governance mechanisms.



Information Sources and Database Selection

Comprehensive searching was performed to capture literature across public health, law, ethics, and computer science domains. Following the Population–Concept–Context (PCC) framework, the search strategy was developed in collaboration with a health-sciences librarian to ensure coverage of relevant terms and compatibility with database indexing systems.

The primary databases searched were:

- MEDLINE (via PubMed) – for biomedical and public-health literature
- Scopus – for multidisciplinary coverage, including computer science and social sciences
- Web of Science Core Collection – for high-impact journals and citation-tracking
- HeinOnline – for legal scholarship, statutes, and regulatory commentary
- Google Scholar – for supplementary grey literature, including institutional reports and preprints

For grey literature, targeted searches were conducted in authoritative sources such as:

- World Health Organization (WHO) reports and guidance
- European Commission digital-health and AI-related documents
- National public-health and data-protection agencies (for example, CDC, UK Health Security Agency, and national data-protection authorities)

The initial search strategy was trialled iteratively, with search terms adjusted to balance sensitivity and specificity across databases. The final search was conducted in February 2025, and no additional updates were performed beyond this point.

A combination of title, abstract, and key words were used in the searches conducted while taking into consideration the functionality of the database. Key words (i.e. MeSH terms in MEDLINE) were used with regard free-text words to ensure data sensitivity and specificity.

On the other hand, a more structured approach was applied for grey literature, where targeted searches of institutional websites were included along with the screening of the first 100-200 results that appeared on Google Scholar and were sorted by their relevance. The approach followed ensured that there was an adequate coverage of the data while maintaining its feasibility as well as consistency.

Search Strategy and Terms

The search strategy combined three core concept domains: population/context, concept/technology, and ethics/legal/governance. The following terms and combinations were used (with appropriate Medical Subject Headings [MeSH] and database-specific syntax where applicable):

- Population/Context:
 - “disease surveillance”, “public health surveillance”, “infectious disease surveillance”, “outbreak detection”, “pandemic preparedness”, “COVID-19”, “public health emergency”
- Concept/Technology:
 - “artificial intelligence”, “machine learning”, “deep learning”, “predictive analytics”, “digital surveillance”, “digital health”, “big data”
- Ethics/Law/Governance:
 - “ethics”, “ethical”, “governance”, “law”, “legal”, “regulation”, “regulatory”, “data protection”, “privacy”, “informed consent”, “accountability”, “liability”, “human rights”

Searches were limited to publications in English and from 2015 onwards, to reflect the rapid growth of AI and digital surveillance in public health, particularly in the context of recent global health emergencies.



Eligibility (Inclusion and Exclusion) Criteria

Eligibility was defined a priori using a formal inclusion and exclusion scheme. Studies and documents were included if they met all three criteria:

1. Population/Context

- Focused on AI-powered or digital technologies used for population-level infectious disease surveillance, outbreak detection, or pandemic preparedness (for example, mobile contact-tracing apps, digital symptom trackers, social-media-based surveillance, big-data early-warning systems, and predictive modelling platforms).
- Emphasis on public-health decision-making or population-level monitoring, rather than purely clinical, diagnostic, or hospital-based AI tools that do not contribute to broader surveillance systems.

2. Concept

- Explicitly discussed at least one ethical, legal, or governance aspect of such systems, including but not limited to:
 - Privacy, data protection, and confidentiality
 - Informed consent, autonomy, and participation
 - Equity, algorithmic bias, and digital exclusion
 - Accountability, liability, and responsibility for AI-related decisions
 - Transparency, explainability, and public trust
 - Data governance, secondary use, and long-term data retention
 - Human-rights considerations and regulatory oversight

3. Study type and language

- Peer-reviewed journal articles, empirical studies, systematic or scoping reviews, narrative reviews, and major policy or guidance documents (for example, from WHO, EU, national ministries, or data-protection agencies).
- Written in English, regardless of publication type or venue.

Exclusion criteria were applied systematically to ensure methodological clarity and focus:

- Studies that focused only on the technical performance of AI models (for example, predictive accuracy, algorithm design, or model validation) without explicit discussion of ethical, legal, or governance implications.
- Papers that addressed AI in clinical settings (e.g., diagnostics, prognostic tools, or hospital-level decision-support) without a clear linkage to population-level surveillance or public-health operations.
- Non-peer-reviewed blog posts, opinion pieces, and short news articles that lacked substantive analysis or citation of evidence.
- Documents that were not available in full text and could not be accessed through institutional subscriptions or reasonable open-access sources.

In addition, there were no geographical restrictions applied. Studies from all regions of the world were considered to have captured a variety of global variations in both legal and ethical frameworks. With regard to the purpose of this review, the AI-powered systems were defined as systems that take into account aspects of machine learning or data processing beyond principles of statistical methods. The studies addressed a number of surveillance and non-surveillance applications. Inclusion was derived from a context of whether the population-level formed a substantive component of the final analysis.

Study Selection and Screening Procedures

Prior to carrying out formal screening, reviewers independently screened a significant pilot sample to ensure that there is matching consistency and a shared understanding of both the inclusion and exclusion criteria of the study.



All identified records were imported into a reference-management software (e.g., EndNote or Zotero), and duplicates were removed automatically by the software and then checked manually. The screening process was conducted in two stages, with the involvement of two independent reviewers to enhance transparency and reduce bias.

1. Title-and-abstract screening

- Both reviewers independently screened all titles and abstracts against the inclusion and exclusion criteria.
- Full-text retrieval was ordered for any record that met at least one of the PCC criteria or for which eligibility was unclear.
- Disagreements at this stage were resolved through discussion, and where necessary, a third reviewer was consulted to reach consensus.
- A record of excluded studies with brief reasons for exclusion was maintained for transparency.

An informal assessment of inter-reviewer consistency was done during the screening process by regular comparison of inclusive decisions. A discussion and resolution of systematic discrepancies was conducted for the sole purpose of maintaining consistency throughout the application of criteria.

1. Full-text screening

- Potential full-text studies were then assessed by the same two reviewers, using the same inclusion/exclusion criteria.
- A simple checklist was used to capture:
 - Whether the study clearly described an AI- or digital-surveillance system
 - Whether an ethical, legal, or governance aspect was discussed
 - Whether the discussion was at population-level public-health surveillance
- Discrepancies were resolved through discussion, again with a third reviewer if disagreement persisted.

2. PRISMA-ScR flow diagram

- The selection process was summarised using a PRISMA-ScR-style flow diagram, which illustrates:
 - Number of records identified through database and grey-literature searches
 - Number of records after duplicate removal
 - Number of records excluded at abstract screening
 - Number of full-text articles assessed for eligibility
 - Number of studies finally included in the review
- The diagram and associated counts were reported in the Results section.

The documentation of all screening decisions and reasons for exclusion at the full text stage was done in a separate structured spreadsheet so as to ensure easier auditability and the transparency of the selection process.

Data Charting and Extraction

A standardised data-charting form was developed in Microsoft Excel, informed by the PCC framework and the review's research questions. The form was pilot-tested on a subset of 5–10 articles and then refined iteratively through team discussion.

For each included source, the following data were extracted:

- Bibliographic information: Author(s), year of publication, title, journal/publisher, country/region, and study type (e.g., empirical study, review, legal commentary, policy document).
- Population/context: Disease or public-health context (e.g., COVID-19, influenza, general pandemic preparedness, antimicrobial resistance, or emerging infectious diseases), level of analysis (local, national, regional, global).
- Technology and methods: Type of AI or digital surveillance technology used (e.g., mobile contact-tracing apps, social-media-based surveillance, big-data dashboards, predictive modelling platforms), data sources (e.g., electronic health records, laboratory data, mobility data, social-media data), and methodological approach (qualitative, quantitative, mixed).



- Ethical themes: Identified ethical issues, including privacy, consent, autonomy, equity, algorithmic bias, transparency, explainability, public trust, and surveillance overreach.
- Legal and governance aspects: Cited legal frameworks (e.g., GDPR, sector-specific data-protection laws, public-health statutes, emergency-powers legislation), regulatory bodies, and mechanisms of oversight or accountability.
- Proposed principles or frameworks: Any explicit ethical or legal frameworks, principles, or recommendations for the use of AI-powered disease surveillance systems (for example, transparency requirements, accountability mechanisms, or human-in-the-loop design principles).

Where the same article addressed multiple settings or technologies (e.g., both COVID-19 and broader pandemic preparedness), characteristics were recorded separately for each relevant context so that patterns could be mapped more accurately.

Data Synthesis

Synthesis followed a two-stage qualitative approach:

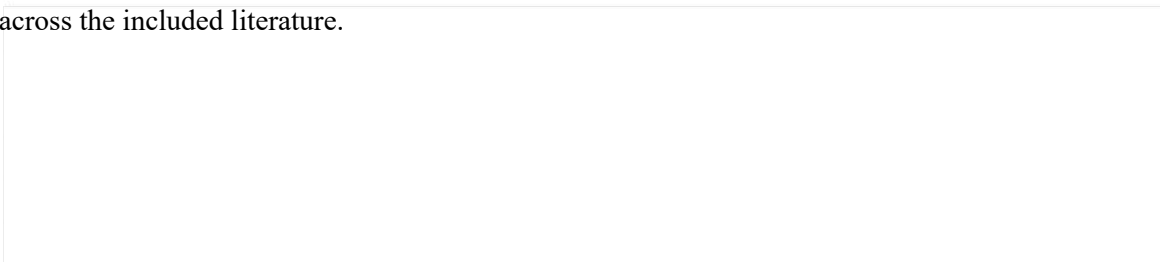
1. Descriptive (numerical and categorical) synthesis

- The included studies were summarised using descriptive statistics:
 - Distribution of studies by year, country or region, study type, and disease or public-health context.
 - Frequency of different AI and digital surveillance technologies (e.g., contact-tracing apps, social-media tools, predictive models, early-warning systems).
 - Preliminary mapping of recurring ethical and legal categories (e.g., privacy, consent, accountability, equity) across settings.
- These descriptive findings were presented in tabular and, where applicable, graphical form in the Results section.

2. Thematic analysis

- Qualitative thematic analysis was used to identify, analyse, and report patterns (themes) within the data, following the approach described by Braun and Clarke.
- The analysis process involved:
 - Familiarisation with the full set of included studies.
 - Initial coding of relevant text extracts related to ethical, legal, and governance issues.
 - Theme development through iterative grouping of codes into broader categories (e.g., privacy and data protection, accountability and liability, equity and algorithmic bias, transparency and explainability, public trust and engagement).
 - Review and refinement of themes by all members of the research team, including discussion of borderline cases and validation of theme definitions.
 - Themes were cross-checked against the original research questions to ensure that the synthesis accurately reflected the scope of the review.

The final synthesis integrated the descriptive overview with the qualitative thematic analysis, producing a structured account of how legal and ethical frameworks for AI-powered disease surveillance systems are conceptualised, implemented, and problematised across the included literature.





Ethical Considerations

As this study involved the secondary analysis of publicly available literature, no primary data collection from human participants was conducted. Therefore, formal ethics approval was not required, and the review was conducted in accordance with institutional guidelines for secondary research and scholarly review work.

Results

The final body of literature consisted predominantly of peer-reviewed articles and policy-oriented analyses published after 2020, reflecting the accelerated adoption of AI-enabled surveillance during and following the COVID-19 pandemic. The included studies comprised qualitative analyses, ethical commentaries, legal reviews, and selected empirical case studies examining national and regional surveillance initiatives. Most publications originated from high-income regions, particularly Europe and North America, although several adopted global or comparative perspectives.

A wide range of AI-powered surveillance technologies was reported, including mobile contact-tracing applications, digital symptom-tracking platforms, social media-based surveillance tools, big-data early-warning systems, and predictive modelling approaches for outbreak forecasting. COVID-19 was the most frequently examined disease context, followed by general pandemic preparedness and emerging infectious diseases. The study selection process is summarised using a PRISMA-ScR flow diagram.

Legal Frameworks Governing AI-Powered Disease Surveillance

Legal approaches to AI-powered disease surveillance varied substantially across jurisdictions. European studies emphasised the role of comprehensive data protection regimes, particularly the General Data Protection Regulation (GDPR), which imposes requirements related to data minimisation, purpose limitation, transparency, and safeguards against solely automated decision-making. In contrast, the United States was characterised by a fragmented regulatory landscape, combining sector-specific health privacy laws, public health statutes, and emergency powers, with limited AI-specific oversight.

For example, the European Union's General Data Protection Regulation (GDPR) provides explicit safeguards against solely automated decision-making and mandates principles such as data minimisation and purpose limitation. In contrast, the United States relies on sector-specific frameworks such as the Health Insurance Portability and Accountability Act (HIPAA), which does not fully address AI-driven surveillance. These differences illustrate the variability in regulatory preparedness for AI-enabled public health systems.

In several Asian contexts, legal frameworks prioritised state authority and public health efficiency, often permitting extensive data access during emergencies with fewer explicit protections for individual privacy. Across low- and middle-income regions, the literature frequently highlighted the absence of dedicated AI or digital surveillance legislation, reliance on outdated public health laws, and challenges related to enforcement capacity. Across jurisdictions, a consistent gap was identified in AI-specific legal provisions addressing algorithmic accountability, auditability, explainability, liability, and cross-border data flows.

Ethical Considerations

Privacy and data protection emerged as the most frequently discussed ethical concern. Many studies described tensions between public health objectives and individual rights, particularly during emergencies when consent standards and oversight mechanisms were weakened. Concerns regarding long-term data retention, secondary use of surveillance data, and function creep beyond the original public health purpose were recurrent.

Equity and inclusion were also prominent themes. Several studies highlighted risks of algorithmic bias arising from non-representative training datasets, potentially exacerbating existing health inequities. Digital divides, including unequal access to smartphones or digital infrastructure, were noted as limiting both the effectiveness and fairness of AI-based surveillance systems.



Transparency and explainability were closely linked to public trust. Opaque or proprietary AI models were viewed as particularly problematic in public health contexts, where legitimacy depends on accountability and public understanding. Ethical analyses emphasised the importance of explainable AI, clear communication strategies, and public engagement. Overall, the reviewed literature demonstrates substantial global heterogeneity in the ethical and legal governance of AI-powered disease surveillance. Despite increasing recognition of the public health potential of these systems, persistent gaps were identified across jurisdictions, particularly in relation to AI-specific regulation, accountability mechanisms, equity considerations, and public engagement.

Discussion

The findings of this review highlight a fundamental governance tension between the rapid technological expansion of AI-powered disease surveillance and the comparatively slow evolution of legal and ethical regulatory frameworks.¹⁰⁻¹² While ethical principles such as privacy, transparency, accountability, and equity are widely articulated across the literature, their translation into enforceable and operational governance mechanisms remains inconsistent across jurisdictions.^{17,19}

A central challenge identified across the literature is the structural tension between public health imperatives and individual rights. AI-driven surveillance systems rely on large-scale data collection, often under conditions where informed consent is limited or impractical. This reflects a broader governance dilemma in which utilitarian public health objectives may override rights-based protections, particularly during emergency contexts such as the COVID-19 pandemic.^{14,16} While such trade-offs may be justified in the short term, the absence of clear legal safeguards risks normalising expanded surveillance practices beyond emergency settings.

At the same time, some countries have taken a more government-driven approach, where stopping the spread of disease is the top priority, even if it means broader data access. These strategies can work well in controlling outbreaks, but they also come with risks. There's always the concern that once surveillance systems are in place, they might not be scaled back after the crisis ends. Without clear limits, what starts as a public health tool could slowly turn into something more permanent and harder to control.^{15,16}

The situation becomes even more complicated in low- and middle-income countries. In many of these settings, the legal systems weren't designed with AI in mind, so there's often a mismatch between modern technology and older laws.²⁰ This makes it harder to answer basic but important questions—like who is responsible if an AI system makes a mistake. On top of that, limited resources can make it difficult to properly monitor or regulate these systems. It's clear that solutions need to be tailored to local realities, rather than simply adopting models from wealthier countries.

Accountability emerges as a critical yet underdeveloped component of AI governance. The multi-actor nature of AI systems—encompassing governments, private technology developers, and data intermediaries—creates fragmented responsibility structures. Existing legal frameworks often lack clarity regarding liability for algorithmic decision-making, particularly in cases of error, bias, or harm. This suggests the need for more explicit governance models incorporating auditability, traceability, and defined accountability pathways.^{9,12}

Trust is also a major factor. For people to accept and support AI-based surveillance, they need to understand how it works and feel confident that it's being used fairly. When systems are too complex or operate like “black boxes,” it becomes difficult to build that trust. Clear communication and more understandable AI models can go a long way in helping people feel more comfortable with these technologies.^{9,12}



Fairness is another concern that can't be ignored. AI systems are only as good as the data they're trained on, and if that data isn't representative, the results won't be either. This can lead to certain groups being overlooked or misrepresented, which may worsen existing health inequalities. On top of that, not everyone has equal access to digital tools, which means some populations may be left out of these systems entirely.

Overall, what stands out is a gap between ideas and action. Concepts like fairness, transparency, and accountability are widely discussed, but there's still a lack of clear guidance on how to actually apply them in real-world settings.^{9,12,19} Bridging this gap will take more than just policies—it will require collaboration between researchers, policymakers, and technology developers to turn these principles into practical steps.

Another important point is that diseases—and the data used to track them—don't stop at national borders. This makes it difficult for any single country to manage AI surveillance on its own. There's a growing need for international cooperation, not only to share data but also to develop common standards.^{18,19} At the same time, these frameworks need to be flexible enough to work in different cultural and economic contexts.

Overall, the findings indicate that current governance approaches remain principle-driven rather than enforcement-oriented, highlighting a critical need to shift from normative ethical frameworks toward legally actionable and context-sensitive regulatory mechanisms.^{9,12,19} In the end, AI-powered disease surveillance has a lot of potential, but its success depends on how responsibly it is used. Stronger, clearer, and more practical governance is needed to make sure these systems are not only effective, but also fair and trustworthy. Getting this balance right will be key to ensuring that AI truly benefits public health without compromising the rights and trust of the people it is meant to serve.

Limitations

This review was limited to English-language publications and did not include a formal quality appraisal, consistent with scoping review methodology.

Future Directions

Future research should move beyond conceptual analyses to empirically examine how ethical and legal principles governing AI-powered disease surveillance are operationalised in practice, particularly in low- and middle-income settings. Longitudinal and comparative studies assessing the real-world impacts of governance frameworks on equity, accountability, and public trust will be essential to inform adaptive and context-sensitive regulation.

Conclusion

AI-powered disease surveillance holds substantial promise for strengthening public health preparedness and response. However, its responsible deployment depends on robust legal and ethical frameworks addressing privacy, transparency, accountability, equity, and public trust. This scoping review identifies significant global heterogeneity and persistent governance gaps, underscoring the need for context-specific, enforceable, and ethically grounded regulatory approaches.



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