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Bridging genomics and healthcare: expert perspectives on integrating genomic data into electronic health records

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Abstract

Clinical genomics is increasingly used in healthcare, yet challenges remain regarding the integration, governance, and long-term management of genomic data. We surveyed 58 experts from 24 countries (recruited through the JA PreventNCD consortium and professional networks) to identify priorities for genomic data integration. Topics included infrastructure, governance, consent, reinterpretation, funding, and clinical decision support. Experts favoured separate but interoperable genomic data storage connected to electronic health records (~74%). Dynamic consent (~86%) and public funding (~86%) received strong support. Genetic counsellors (~90%) and specialist physicians (~79%) were preferred for communicating reanalysis findings. Only one-quarter of respondents considered national frameworks for genomic data integration clear, while reimbursement models were viewed as focused on testing rather than long-term data stewardship. Support was strongest for automated flagging of high-risk variants and pharmacogenomic findings, whereas polygenic risk scores and incidental findings remained contested. These findings highlight key principles and implementation challenges for sustainable genomic healthcare.

Keywords: JA PreventNCD, surveys and questionnaires; clinical genomics; electronic health records; genomic data integration; European Health Data Space; data governance; interoperability; dynamic consent; clinical decision support; federated architecture; healthcare systems Europe

1. INTRODUCTION

Genomic data is rapidly becoming integral to healthcare. High-throughput sequencing technologies and decreasing analytical costs have enabled the growing use of genomics in diagnostics, risk prediction, pharmacogenomics, and personalized therapeutics. Applications include the identification of high-risk genetic variants (e.g., *BRCA1/2* for hereditary cancer predisposition), pharmacogenomic (PGx) findings influencing drug response (e.g., *CYP2C19* and clopidogrel metabolism), carrier status for hereditary conditions (e.g., cystic fibrosis), polygenic risk scores (PRS) for complex disease susceptibility (e.g., breast cancer), and incidental findings unrelated to the original reason for testing (e.g., ACMG secondary findings).¹⁻⁴

As precision medicine expands across clinical specialties, healthcare systems must incorporate genomic information into routine workflows to facilitate access to actionable findings and avoid unnecessary repeat testing when previous test results are not readily available or accessible. However, most electronic health records (EHRs) were not designed to store, interpret, or update genomic data, limiting access to clinically relevant results at the point of care. Integrating genomic information into EHRs and linking it with phenotypic and family history data is therefore an important challenge for healthcare systems.⁵

Existing EHR infrastructures still pose substantial challenges for genomic integration. Key questions include whether genomic data should be stored directly within the EHR or in a separate but interoperable system, how interoperability and clinical usability can be maintained, and who bears responsibility for the long-term management of genomic information.⁶ Unlike many other clinical data, genomic information is inherently dynamic: variant classifications and gene-disease associations evolve over time, requiring periodic reanalysis and reinterpretation to ensure ongoing clinical relevance.⁷

These technical and clinical features create a broader governance gap. There is currently no consensus on who holds responsibility for initiating reanalysis, recontacting patients, or updating records, creating uncertainty across laboratories, clinicians, and healthcare systems.⁸ More broadly, the sensitive and potentially familial nature of genomic data raises important concerns regarding privacy, data access, and appropriate secondary use for various purposes.⁹

Several countries have launched large-scale genomic medicine initiatives, underscoring growing political and scientific momentum toward the integration of genomics into research and clinical care.¹⁰⁻¹² This is especially important in Europe, where implementation remains uneven and national legal frameworks differ substantially. Under the General Data Protection Regulation (GDPR), genetic data are classified as a special category of personal data requiring enhanced protection, but Member States may introduce further conditions for processing genetic, biometric, and health data. This flexibility has contributed to variation in rules governing consent, secondary use, and research access.^{13,14}

The European Health Data Space (EHDS) Regulation, adopted in 2025, seeks to harmonise key aspects of health data use through a primary-use framework for cross-border access to electronic health records and a secondary-use regime channelling research access predominantly through Health Data Access Bodies.¹⁵ However, the EHDS retains specified national discretion, including over additional safeguards for genetic and genomic data and limited exceptions to the right to opt out from secondary use, with implementation rolling out in stages through 2031.¹⁶⁻¹⁸

Existing literature has mainly focused on patient views, single-country cases, or technical feasibility.¹⁹⁻²¹ Few empirical studies have explored expert perspectives across disciplines, jurisdictions, and genomic domains.

To address this gap, we conducted a multinational survey of professionals working in genomics, clinical medicine, bioinformatics, data governance, and health policy. The survey examined key challenges and priorities for genomic-EHR integration, with the aim of informing policy, system design, and implementation planning.

2. METHODS

2.1 Study design

As part of the Joint Action Prevent Non-Communicable Diseases (JAPreventNCD) consortium, a European initiative which seeks to reduce the burden of cancer and other non-communicable diseases, we developed a survey aimed at capturing expert perspectives on the integration of genomic data into healthcare, including electronic health records (Supplementary Appendix 1).²² In the survey, the term "genomic data" primarily referred to germline genomic information relevant to disease risk prediction, prevention, and longitudinal healthcare management. However, as the term was not explicitly restricted throughout the questionnaire, some respondents may have interpreted it more broadly to also include somatic genomic data, which should be considered when interpreting the findings. The survey questionnaire comprised a maximum of 29 questions, including both closed- and open-ended items across six thematic domains (n = number of questions in each domain). In addition, respondents were asked to provide information on their professional profile (e.g., expertise and professional background) to contextualize their responses (n=3). The thematic domains were as follows:

1. genomic infrastructure (n=4),
2. legal and regulatory aspects (n=5),
3. consent, privacy, and data use (n=3),
4. updating and reinterpretation of genomic data (n=6),
5. automation of genomic information in clinical decision support (n=4), and
6. economic considerations (n=4).

Survey items were developed through a literature review and consultation with experts in clinical genomics, health systems, and ethical and legal aspects of genomics. The survey was piloted among members of the JA PreventNCD consortium (n = number of individuals; n=5) to assess clarity, relevance, and completeness, resulting in minor refinements to improve the wording and transparency of the questions. The finalized survey was administered online via LimeSurvey between January 19 and April 6, 2026. Participation was voluntary and anonymous, and reminders were distributed through professional networks during the study period.

2.2 Participants and recruitment

Experts were recruited through the JA PreventNCD network, KU Leuven professional networks, genomics consortia, academic institutions, and policy organisations. Additional participants were identified through publicly available contact information (e.g., via the European Society of Human Genetics) and invited to participate or distribute the survey within their networks. Snowball sampling was encouraged to broaden participation. Eligible participants had expertise in genomics, clinical implementation, health systems, or related policy and ethical domains. Invitations were distributed by email, and informed consent was obtained electronically. Of 174 individuals who initiated the survey, 58 completed it (33% completion rate). The final sample comprised 58 experts from 24 countries, including 21 European countries. Mean and median

completion times were 36 min 57 s and 20 min 10 s, respectively. Given the questionnaire length and specialist target population, the survey captured a diverse range of expert perspectives.

Professional role and organizational affiliation

Respondents represented a range of organisational settings, including hospitals (n=21), public health institutions (n=14), research institutions (n=12), private companies (n=5), government agencies (n=4), and other organisations (n=2) (Figure 1a). These distributions show that the expert panel included stakeholders from both frontline clinical practice and national level health infrastructure, as well as individuals engaged in research, policy, and industry innovation.

Geographical distribution

Participants were geographically diverse, representing 24 countries, with the largest numbers of respondents based in France (n≈10), followed by Germany, Estonia, and Italy (Figure 1b). The study was predominantly European in scope, reflecting its focus on European genomic medicine initiatives and the JA PreventNCD network, although a small number of respondents were based outside Europe. This geographic diversity enabled the inclusion of perspectives from a range of healthcare and genomic medicine contexts.

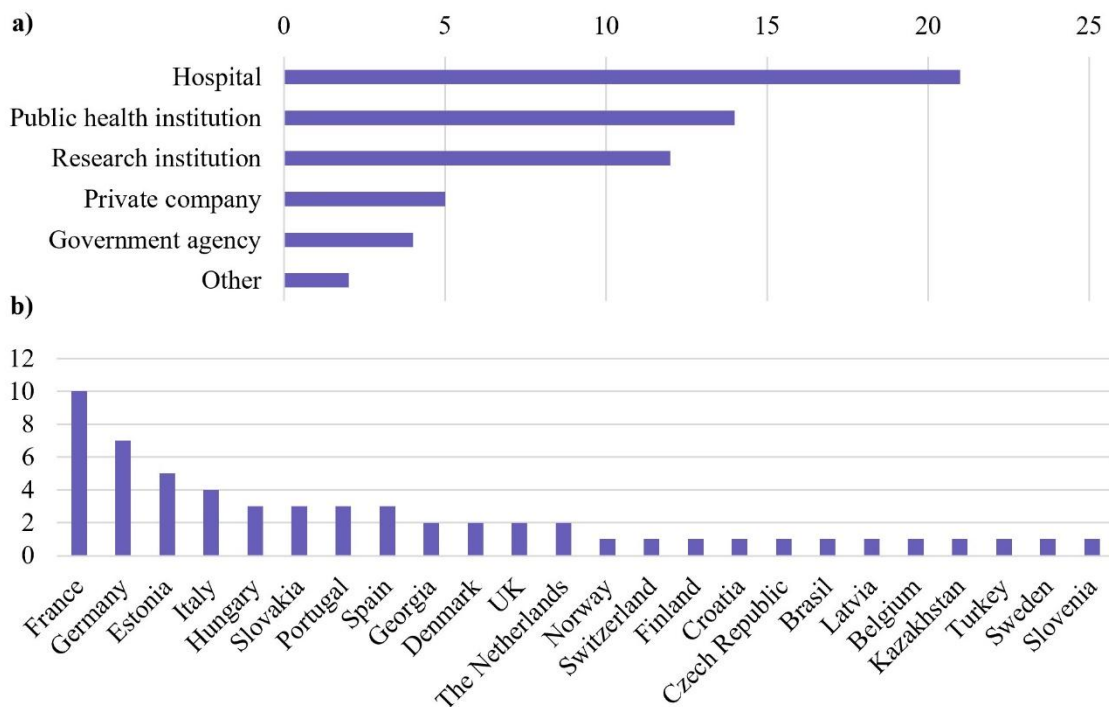


Figure 1. a) Distribution of respondents by affiliation, shown as number of respondents per category. “Other” reflects roles that did not fall neatly within existing organizational types. **b)** Distribution of respondents’ country of current employment, shown as number of respondents per country.

2.3 Data analysis

Closed-ended responses were analysed descriptively using frequencies and proportions. Associations with respondents’ country of employment and institutional affiliation were explored through correlation and

stratified analyses in R (RStudio, version 2026.01.2+418). Pattern analyses were also performed to identify recurring response profiles across key domains.

Open-ended responses were analysed using a question-anchored qualitative content analysis.²³ Responses were coded within their original survey domains using a descriptive codebook developed iteratively by the research team. Two researchers independently coded an initial subset of 25 responses (five per question; Cohen's $\kappa=0.94$). After refining the coding framework by consensus, the remaining responses were coded ($\kappa=0.97$) and grouped into thematic categories aligned with the survey domains. Disagreements were resolved through discussion, and the reconciled codebook was then used to generate question-specific frequency counts. Because responses could receive multiple codes, frequency counts are not mutually exclusive. Qualitative findings were used to contextualise the quantitative results. Findings across the six questionnaire domains were grouped into three cross-cutting implementation areas: clinical usability and implementation; governance, legal frameworks, and consent; and longitudinal management and sustainability.

3. RESULTS

3.1 Clinical usability and implementation

3.1.1 Genomic data sources and infrastructure

In the context of integrating genomic data into EHR systems, identifying relevant data sources is an important first step. Diagnostic genetic testing was selected most frequently (88%; Supplementary Figure 1), whereas all other sources were reported considerably less often ($\leq 38\%$). Patterns of combined use (Supplementary Figure 2) showed that diagnostic testing predominated both alone and in combination with other sources, most commonly neonatal screening and pharmacogenomic panels. Population-level and direct-to-consumer data were rarely included, and only one respondent reported considering all genomic data sources.

Respondents also expressed clear preferences regarding the technical architecture supporting genomic-EHR integration. Overall, 74% (43/58) preferred genomic data to be stored in a separate but securely connected system, compared with 22% (13/58) who supported direct EHR storage and 3% (2/58) who favoured unlinked storage (Figure 2b). Preferences were consistent across respondent groups. Support for separate but connected storage was highest among respondents from healthcare delivery organisations (~86%), where only ~5% favoured direct EHR storage. Respondents from research, policy, and infrastructure backgrounds showed somewhat greater support for direct EHR storage (~30%), although separate connected systems (~70%) remained preferred.

Consistent with these architectural preferences, respondents favoured EHR-linked systems for genomic data-supported clinical decision-making (Figure 2a), particularly national or hospital-based infrastructures (~48-67%). Patient-controlled storage options such as data pods received limited support (~21%), and private insurance-based databases were not selected.

These results indicate a clear preference for modular, interoperable architectures over full EHR integration. Open-text responses reinforced this pattern, most frequently emphasising data protection and privacy (35/52), clinical usability (27/52), and interoperability (26/52). National genomic repositories or specialised genomics platforms were commonly proposed as primary storage solutions (22/52), with 12/52 respondents specifically suggesting federated or decentralised models as potential approaches to implementing such interconnected systems.

3.1.2 Clinical access and use

The survey next examined preferences regarding who should be allowed to access genomic data once integrated into clinical systems (Figure 3a). Clinicians were almost universally accepted as users (90%), while patient-authorised users (~66%) and researchers (~66%) also received substantial support. In contrast, support for government bodies (~33%), private companies (~14%), and insurance providers (~3%) was markedly lower, and these groups were associated with comparatively high levels of opposition or uncertainty.

This ordering was consistent across affiliations (Figure 3b). Clinician access remained the dominant preference across all groups, followed by researchers and patient-authorised users. Government bodies received consistently low support, including among respondents affiliated with government agencies. Although support varied somewhat by affiliation, the overall pattern was stable, indicating a preference for governance models that prioritise clinical use, patient control, and, to a lesser extent, research access, while limiting broader institutional or commercial access to genomic data.

3.1.3 Clinical reporting and decision support

Beyond questions related to EHR integration, respondents were asked which genomic findings should be derived and shared with patients (Supplementary Figures 3-4). High-risk genetic variants received the strongest support for both being derived from available genomic data (~72%) and for being returned to patients (~91%), followed by pharmacogenomic findings (~59% and ~69%, respectively). Support for polygenic risk scores and incidental findings was more mixed for both derivation and communication (~45-48% and ~47-55%, respectively), while carrier screening information for reproductive planning received relatively low support for derivation (~36%). In contrast, support for communicating carrier status for inherited conditions to patients was higher (~72%). Overall, respondents favoured the communication of clinically actionable findings, with more cautious views on broader disclosure and findings of uncertain significance.

The role of automated support systems in sharing information with patients was also assessed. Automation was most strongly supported for high-risk variants (~84%) and pharmacogenomic results (~71%), with lower support for incidental findings and polygenic risk scores (~40-43%) (Supplementary Figure 5). Respondents preferred automated insights to be integrated into clinical decision support tools or a dedicated EHR section (~74% and ~72%, respectively), followed by summarisation in the patient record (~57%) and pop-up alerts (~55%), rather than accessed on request or via a separate module (~31%) (Supplementary Figure 6). Awareness of such tools was low, with 84% of respondents reporting no familiarity.

Taken together, these findings suggest that respondents favour the integration of clinically actionable genomic information within EHR-linked decision support systems, while remaining cautious about the routine use of probabilistic, incidental, or less well-validated findings.

3.2 Governance, legal frameworks and consent

3.2.1 Perceived legal framework clarity and coverage

Respondents differed substantially in their assessment of the legal frameworks governing genomic-EHR integration (Figure 4). Fourteen of 58 respondents (~24%) characterised their national framework as clear, whereas 19/58 (~33%) reported no framework, 10/58 (~17%) considered existing rules ambiguous or only indirectly applicable, and 15/58 (~26%) were unsure. Responses occasionally differed among individuals from the same country, suggesting that these findings reflect variation in respondents' perceptions,

professional backgrounds, and familiarity with the regulatory framework, rather than objective legal status alone.

Among the 14 respondents reporting a clear framework, most reported coverage of clinical diagnostic data and prenatal genomic data (11/14; ~79%), pharmacogenomic data and research-derived findings used clinically (10/14; ~71%), and population or screening data (9/14; ~64%) (Supplementary Figure 7). Open-text responses similarly suggested that regulatory coverage was perceived as strongest for established diagnostic applications and weaker for emerging or secondary-use contexts.

3.2.2 Perceived legal gaps and proposed solutions

Among 54 responses included in the qualitative analysis, the most frequently identified concern was fragmented or outdated legal frameworks (19/54). Respondents described regulatory landscapes that were dispersed across health-care law, research law, and data protection legislation, with few genomics-specific provisions. Several respondents further suggested that implementation barriers arise not only from legislative gaps but also from inconsistent or overly cautious interpretation of existing rules.

Other recurring themes concerned data protection, secondary use, and data sovereignty (12/54); cross-border sharing and interoperability (10/54); consent management (9/54); and access or role delineation (9/54). Less frequent concerns included responsibility for reinterpretation and recontact, protections against discrimination, and unclear retention or deletion policies (3/54 each). Some responses also highlighted uncertainty over what counts as “genomic data”. Four respondents reported no major gap or only a need for clarification (4/54). Detailed coding is presented in Supplementary Appendix 2.

Proposed remedies largely mirrored the gaps identified. Respondents most often called for harmonised, genomics-specific guidance or clearer national legislation (19/54), followed by secure infrastructures and clearer pathways for secondary use (12/54), more granular or revisitable consent models (9/54), and clearer definitions of access rights and professional responsibilities (9/54). A smaller group called for explicit allocation of governance and accountability across the genomic data lifecycle (3/54).

3.2.3 Governance responsibilities

Given the complexity and sensitivity of genomic data governance, respondents were asked which actors should be responsible for governance within EHR systems (Figure 5a). Healthcare institutions received the strongest support (~67%), followed by patient involvement through consent-based control (~62%) and hospital ethics or data access committees (~59%). Government health authorities received more mixed support (~55%), while institutions established under the European Health Data Space framework (~41%) and multistakeholder governance models (~38%) were less frequently endorsed.

This ordering was broadly consistent across affiliations, although some differences were observed (Figure 5b). Respondents affiliated with hospitals appeared more sceptical of hospital-led governance, showing higher levels of opposition or uncertainty than other groups. This pattern may be driven by concerns about burden, liability, and operational responsibility rather than institutional trust. In contrast, patient involvement was consistently supported across affiliations, underscoring the value placed on patient representation and autonomy. Overall, respondents favoured governance models centred on healthcare institutions and patient control, with more limited support for centralised or newly established governance bodies.

3.2.4 Consent preferences

Respondents were also asked which consent approaches they considered most appropriate for genomic data use and reuse in clinical systems (Figure 6). Dynamic consent emerged as the most strongly supported model,

endorsed by ~86% of respondents. Broad consent (~59%) and tiered consent (~55%) received moderate support, whereas per-use explicit consent and use under regulatory frameworks without repeated consent were each endorsed by approximately one-third of respondents.

Despite the clear preference for dynamic consent, responses across all models included varying degrees of uncertainty, suggesting that consent governance remains an evolving and contested area of genomic data management.

3.3 Longitudinal management and sustainability

3.3.1 Reinterpretation triggers

An important consideration in genomic data integration is how interpretations should be updated as scientific knowledge evolves. Respondents favoured event-driven over time-based reinterpretation (Supplementary Figure 8), with new scientific findings (~64%) and changes in patient health status (~60%) identified as the main triggers. Fixed update intervals received less support, although some respondents (~31%) suggested alternative approaches, including periodic, clinically driven, or hybrid strategies. Overall, respondents preferred context-aware reinterpretation guided by emerging evidence and clinical need.

3.3.2 Responsibility for reanalysis

Given this preference for event-driven reinterpretation, attention turns to who should be responsible for reanalysis (Figure 7). Geneticists and clinical genetics professionals, representing individual expertise in genomic medicine, received the strongest support (~81%), followed by healthcare institutions, reflecting responsibility embedded within healthcare organisations (~76%). Genomic service facilities and sequencing centres were also endorsed (~53%), albeit with more mixed views. Support was lower for patients themselves (~29%), government health authorities (~26%), and independent regulatory bodies (~26%), while European-level institutions (~16%) received the least support. Overall, responsibility was anchored in specialised expertise and genomic infrastructures.

3.3.3 Communication of updated findings and workforce readiness

Respondents strongly favoured communication of updated genomic findings by genetic counsellors (~90%), followed by specialist physicians (~79%) (Figure 8). Support was lower for primary care providers (~40%), indicating uncertainty about their capacity to interpret and communicate complex genomic information. Non-clinical or automated approaches received little support (~14%).

Open-ended responses highlighted important workforce challenges. Across 53 free-text responses, education was most often described as targeted to genetics specialists (20/53) or as poor or largely absent (13/53). Respondents also highlighted the lack of recognised genetic counsellor roles (10/53) and insufficient training for non-specialists (8/53). These findings suggest that respondents favour specialist-led reinterpretation and communication models, but also identify workforce capacity and lack of training as a potential barrier to implementation.

3.3.4 Economic sustainability

Respondents viewed the funding of genomic data integration primarily as a public responsibility (Supplementary Fig. 9), with the strongest support for public healthcare systems (~86%) and government bodies (~76%). Support was lower for health insurers (~48%), funding by individual hospitals (~41%), and shared funding models (~34%), and minimal for private companies (~16%) and patients (~12%).

Respondents raised concerns about the long-term sustainability of existing funding models for genomic-EHR integration. Among 25 respondents, funding was most often provided through national insurance or public budgets (11/25), followed by regional or hospital budgets (6/25), time-limited pilots (5/25), and disease-specific schemes (5/25). Several noted that reimbursement typically covers testing but not infrastructure, integration, reinterpretation, or reuse (3/25). Funding was generally more consistent for diagnostic panels than for exome or genome sequencing, and existing structures were often described as poorly matched to genomics' cross-cutting nature.

Cost estimates varied widely (€10-5,000 per patient), clustering around €300-400 for simpler integrations and up to ~€1,000 for more complex cases. Respondents noted that integration costs are difficult to separate from bundled test prices. Of 51 free-text responses, only 14 provided an estimate, while 19 declined and 5 argued for cost-effectiveness or HTA-based reimbursement rather than a fixed ceiling.

Taken together, these findings suggest that respondents view sustainable funding as essential for supporting not only genomic testing, but also the infrastructure, workforce, and ongoing reinterpretation activities required for long-term genomic-EHR integration.

3.5 Figures

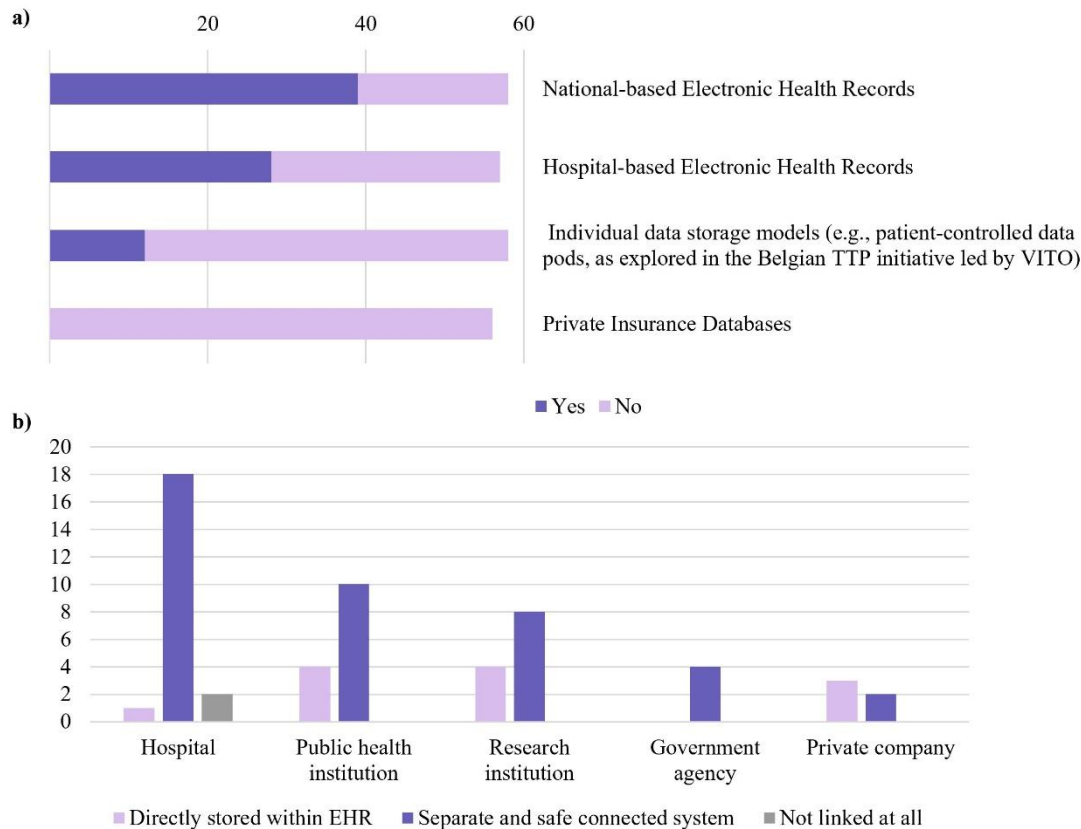


Figure 2. Preferred systems for genomic data integration, **a)** shown as counts of “Yes” (blue) and “No” (purple) responses. **b)** Preferred storage location for genomic data across respondent affiliation categories, shown as counts per option (purple: “Directly within EHR”; blue: “Separate, securely connected system”; grey: “not linked”).

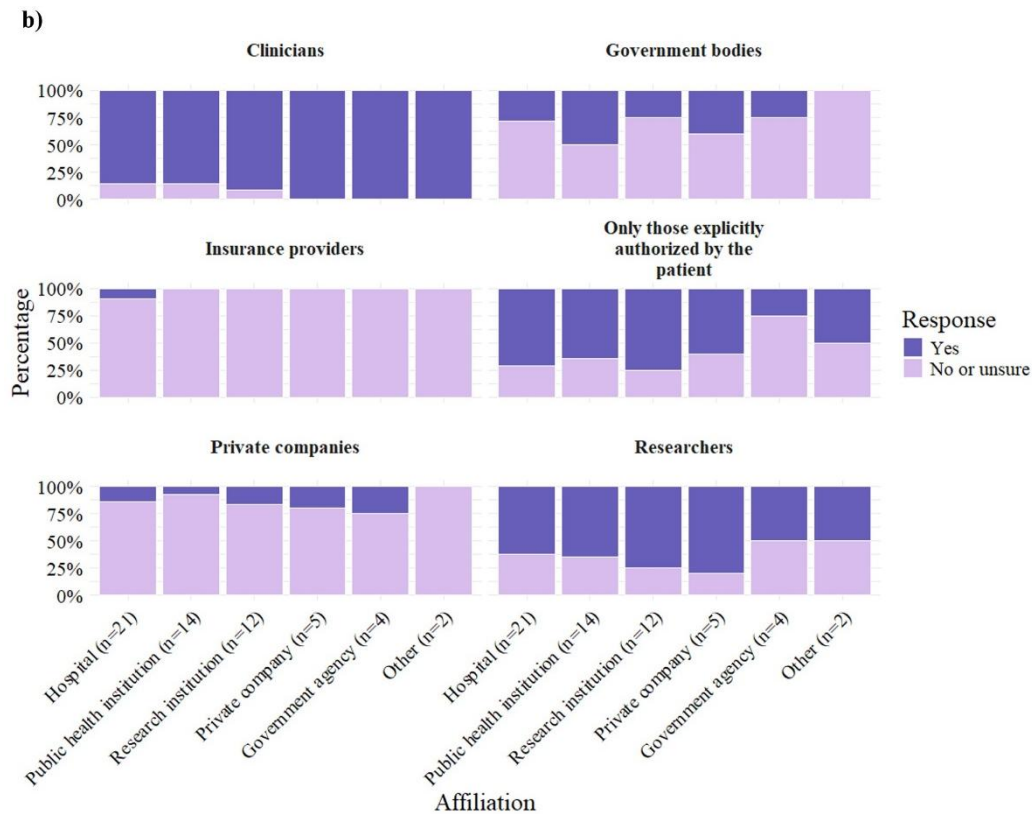
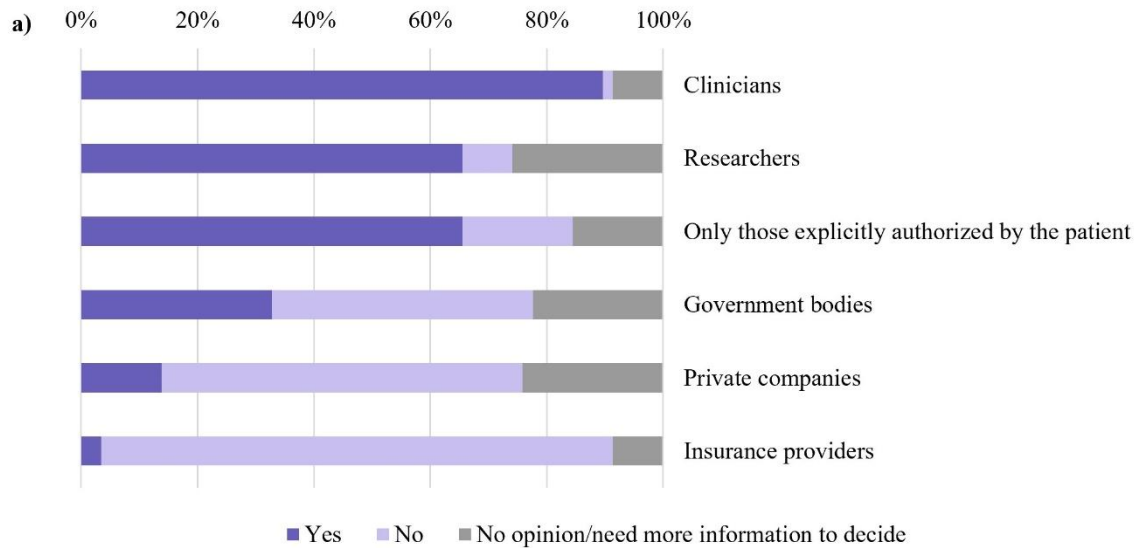


Figure 3. Reported preferences on who should be allowed to access genomic data once integrated into clinical systems, **a)** shown as counts per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)). **b)** stratified by respondent affiliation (percent stacked responses: “Yes” (blue), “No or unsure” (purple)).

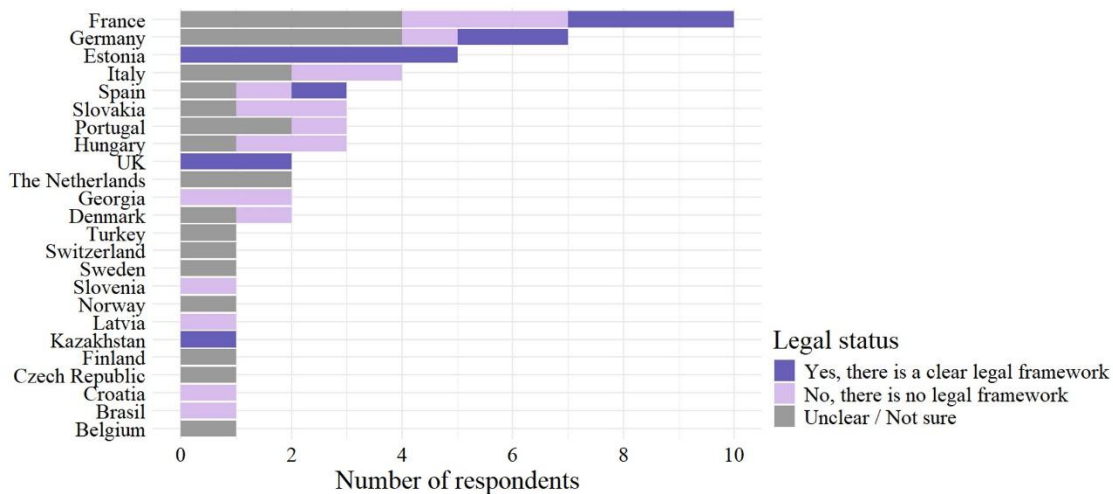
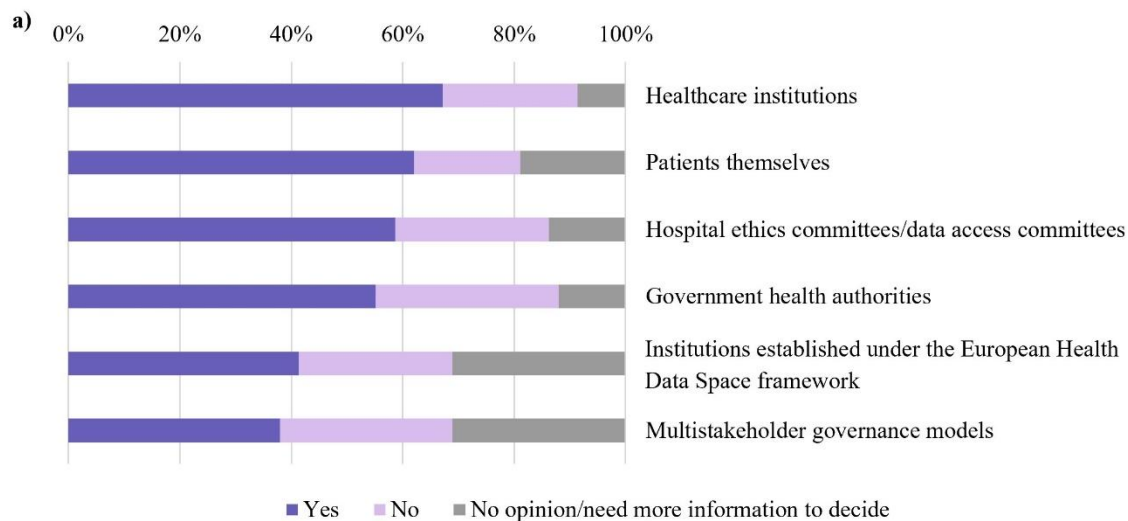


Figure 4. Respondents' perceptions of the clarity of legal frameworks for integrating genomic data into EHR systems by country (blue: "Yes, there is a clear legal framework"; purple: "No, there is no legal framework"; grey: "Unclear/not sure"), shown as number of respondents.



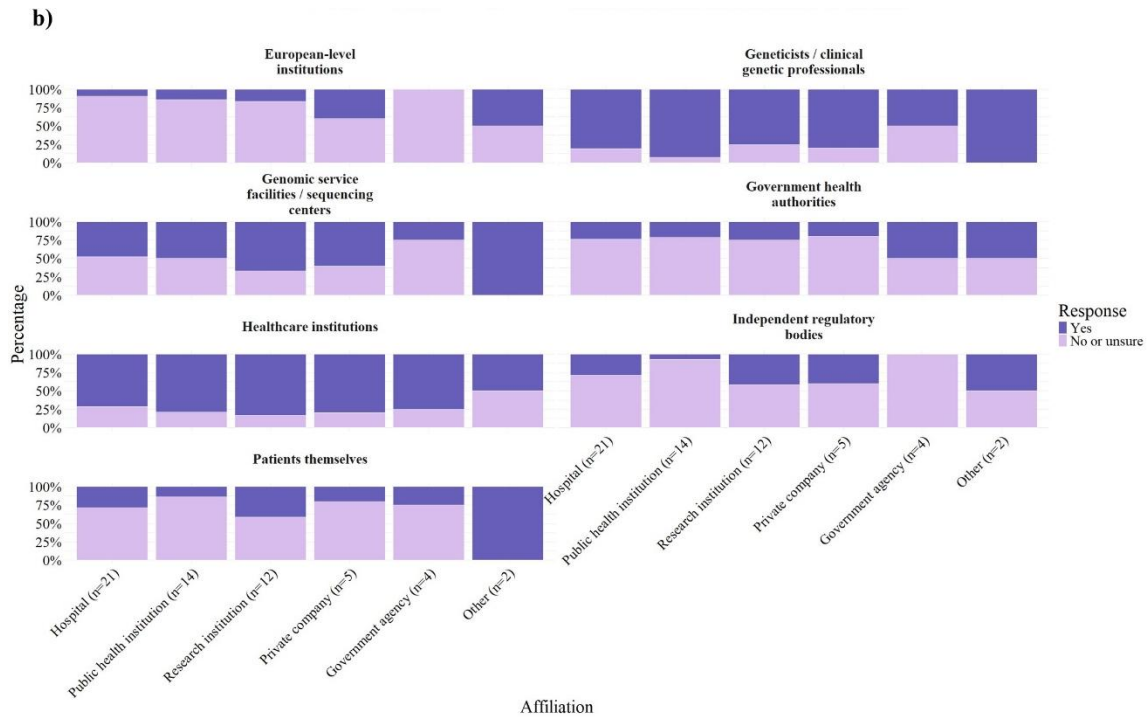


Figure 5. Reported preferences on who should govern access to genomic data after integration into clinical systems, **a)** shown as counts per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)), **b)** stratified by respondent affiliation (percent stacked responses: “Yes” (blue), “No or unsure” (purple)).

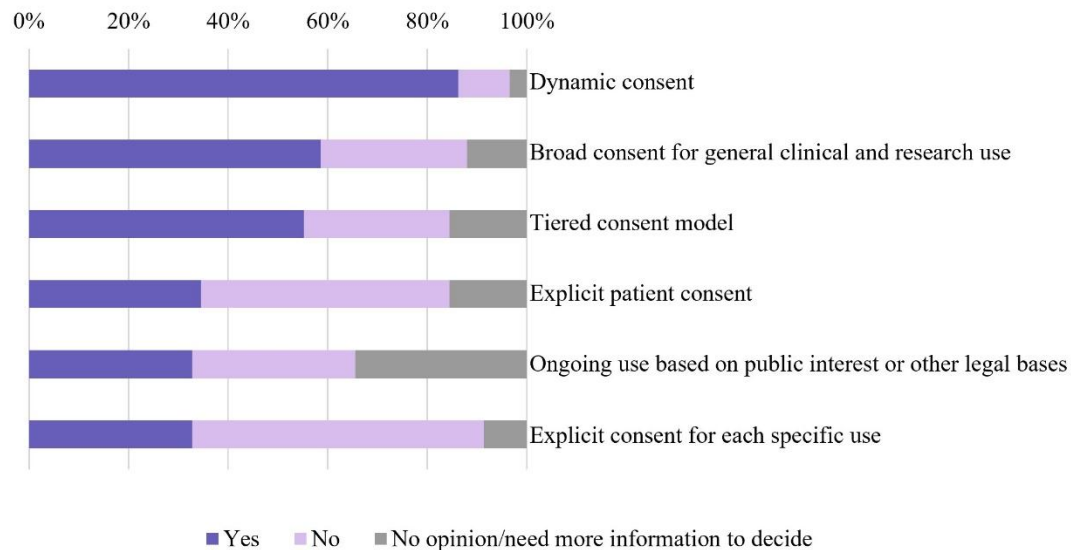


Figure 6. Preferred consent models for the use of genomic data in clinical systems, shown as counts per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)).

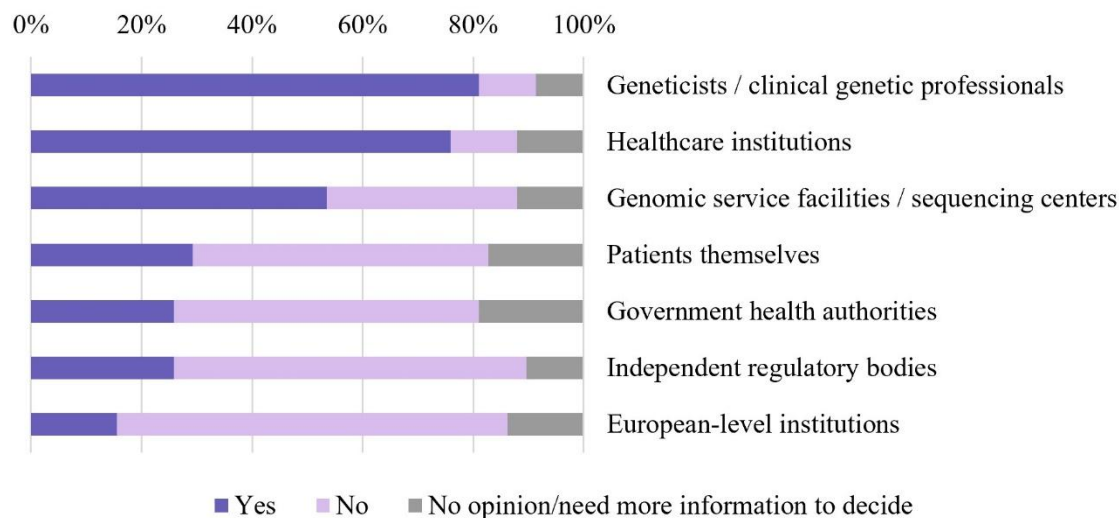


Figure 7. Reported preferences on who should be responsible for managing, overseeing, and initiating reanalysis of genomic data after integration into clinical systems, shown as counts per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)).

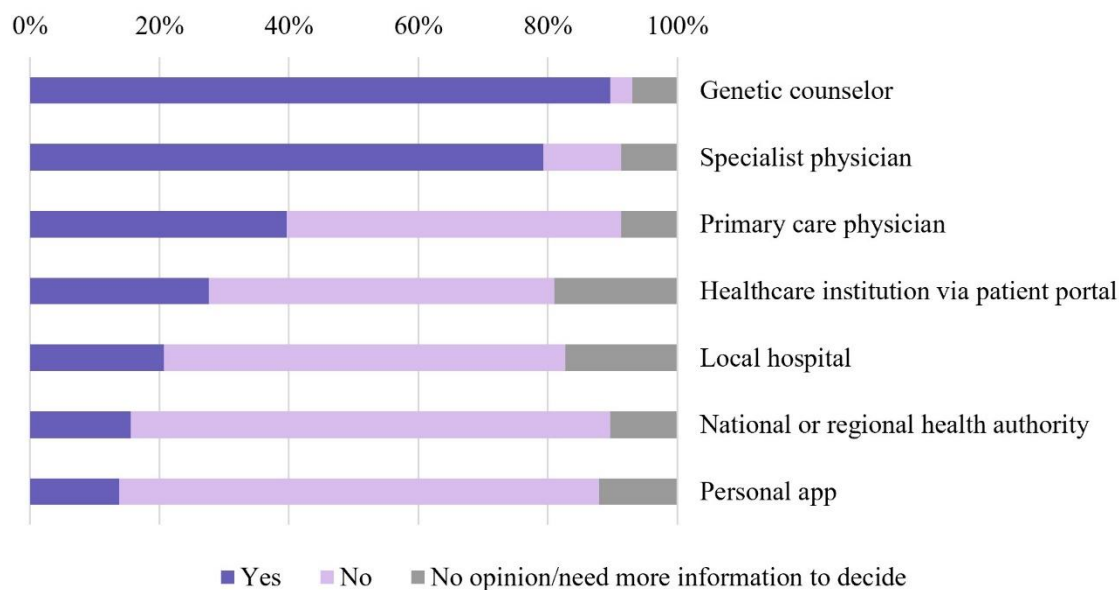


Figure 8. Reported preferences on who should communicate new genomic findings to patients following reanalysis after integration into clinical systems, shown as counts per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)).

4. DISCUSSION

Beyond EHR integration, respondents identified important considerations regarding consent, reinterpretation and reanalysis, communication of findings, funding models, and clinical decision support. While areas of broad consensus emerged across several domains, the results also highlight persistent technical, legal, organisational, and sustainability challenges. Taken together, the findings point to three implementation priorities: modular infrastructure, legal and governance harmonisation, and long-term sustainability.

First, the findings support a modular approach to genomic-EHR integration. Respondents' preference for genomic data systems that are separate from, but securely connected to, the core EHR reflects concerns about the technical limitations of existing EHR systems in handling data volume, lifecycle management, interoperability, and reinterpretation. This aligns with emerging models that position EHRs primarily as access points and decision-support interfaces rather than primary repositories.²⁴ Modular architectures, often centred on national or regional genomic platforms interconnected with EHR systems, may therefore offer a pragmatic balance between clinical usability, scalability, reuse, and long-term governance. However, federated architectures are not a universal solution: recent empirical work highlights substantial technical and governance demands, residual privacy risks, and reduced suitability for some forms of research.²⁵

Respondents strongly favoured national or hospital-based systems over patient-controlled storage models such as data pods, where individuals store and manage their own health and genomic data while granting access to selected providers or organisations.²⁶ This contrasts with ongoing policy discussions promoting greater individual control over health data through patient-managed solutions and raises important questions about potential divergence between expert and patient perspectives.^{27,28} While experts appear to prioritise robustness, standardisation, and governance, it remains unclear to what extent patient preferences would align with this more system-centred approach.

This infrastructure preference also clarifies the type of genomic information experts considered ready for routine integration. Respondents favoured genomic data generated in regulated healthcare settings, particularly diagnostic testing, and prioritised interpreted, clinically actionable outputs such as high-risk monogenic variants and pharmacogenomic findings. By contrast, support was weaker for population screening data, direct-to-consumer data, polygenic risk scores, and incidental findings. These patterns suggest a cautious, clinical-first approach in which integration begins with data of clear provenance, validity, and immediate relevance for patient care, while leaving room for broader applications as evidence, standards, and governance mature.

Second, legal and governance harmonisation remains essential. Although the survey measured perceived rather than independently verified legal clarity, the pattern suggests that implementation barriers may arise not only from gaps in law but also from uncertainty about how fragmented and overlapping regimes apply to emerging genomic uses. The challenge is therefore one of practical implementation as well as legislative clarity.

That perceived uncertainty sits within a fragmented European legal landscape.²⁹ Under the GDPR, processing genetic data requires both an Article 6(1) lawful basis and an Article 9(2) condition; the applicable combination depends on purpose. Explicit consent, where valid, may supply Articles 6(1)(a) and 9(2)(a); clinical care commonly engages Article 9(2)(h), while public-health and research uses may engage Articles 9(2)(i) and 9(2)(j), together with an appropriate Article 6 basis and national safeguards. Article 9(4) permits further national conditions.^{30,31} The EHDS harmonises aspects of primary and secondary use, while retaining specified national discretion over additional safeguards for genomic data (Article 51(4)) and limited exceptions to the right to opt out from secondary use (Article 71(4)); some national variation may therefore remain.¹⁸

Closely linked to legal uncertainty were preferences around consent, access, and governance. Respondents strongly favoured dynamic, revisitable consent models that allow patients to adjust permissions as genomic knowledge and clinical use cases evolve. Implementing such models at scale, however, would require sustained technical and organisational support to record, update, and apply changing preferences within routine clinical workflows. Dynamic consent would not itself determine the applicable legal grounds and conditions for processing, which must still be assessed according to purpose. For scientific research that relies on consent, draft EDPB Guidelines 1/2026 distinguish dynamic consent for particular projects from broad consent for future research within defined areas. They also emphasise the need for sufficient specificity and data protection over time.³²

Respondents also expected access to be tightly governed: clinicians were strongly favoured as primary users, researchers received substantial but lower support, and governmental and commercial access was viewed cautiously. At the same time, respondents supported patient involvement through consent-based control while showing limited support for patient-controlled storage models, consistent with broader calls to strengthen citizen rights and engagement in health data governance.²⁷

Third, genomic-EHR integration will require sustainable implementation models. The dynamic nature of genomic interpretation introduced additional sustainability and responsibility challenges. The strong preference for event-driven reinterpretation highlights the need for adaptive governance models that can accommodate evolving genomic knowledge and patient needs. Responsibility for initiating and communicating reanalysis results was consistently assigned to specialized clinical genetics professionals and genomic services, reflecting recognition of the expertise required. However, open-ended responses revealed a tension between this preferred model and workforce realities: respondents reported gaps in formal recognition of genetic counsellor roles, uneven education quality, and insufficient genomics training for non-specialist clinicians. This mismatch raises important feasibility concerns for implementing safe and scalable reanalysis workflows. Economic considerations further compound these challenges. While respondents strongly supported public funding through national health systems or government budgets, some respondents described reimbursement as test-centric, covering initial sequencing but not downstream activities such as data storage, integration, reinterpretation, and reuse. As a result, infrastructure costs are often absorbed by hospitals or short-term projects, and the reliance on fragmented, project-based funding and disease-specific silos risks undermining both sustainability and equity, ultimately limiting the long-term clinical value of genomic data. Notably, this funding landscape appears misaligned with respondents' preference for national or regional genomic infrastructures, which are unlikely to be sustained through hospital budgets alone and may require dedicated long-term public investment.

Several limitations should be considered. This was an exploratory expert survey with a modest sample size (n=58), and voluntary participation may have introduced selection bias toward individuals already engaged in, or supportive of, genomic data integration. Although respondents represented more than 20 countries, geographic distribution was uneven, potentially weighting findings toward settings with more mature genomic infrastructures or active digital health policies. The study also relied on self-reported expertise and professional roles, and respondents from clinical, research, public health, governmental, and private-sector backgrounds may have interpreted survey items through different disciplinary or operational lenses. Moreover, patient representatives were not included in the survey. As a result, preferences regarding data governance, access, and storage models reflect expert perspectives and may not align with patient views. In addition, legal expertise was not specifically assessed. Consequently, reported views on national legal frameworks may reflect differences in awareness or interpretation rather than the objective legal situation. Open-ended responses were analysed thematically by two independent reviewers, but qualitative coding remains interpretive, and open-ended counts should be read as non-mutually exclusive indicators of recurring themes rather than prevalence estimates. Finally, the findings capture expert views at a single point in time.

As genomic technologies, regulatory frameworks, and digital health infrastructures evolve, perspectives on issues such as polygenic risk scores, data governance, and dynamic consent may shift; longitudinal expert input and evaluation of implemented systems will therefore be needed to complement these findings.

Future research should extend beyond expert opinion by incorporating empirical data from key stakeholder groups. In particular, studies involving citizens and patients, potentially through multi-stakeholder workshops, would be valuable to better understand public attitudes toward the integration of genomic data into electronic health records, assess societal acceptability, and support the development of practical recommendations informed by both patient and expert perspectives. More in-depth engagement with legal experts across the targeted jurisdictions is also needed to validate and further contextualize the legal interpretations identified in this study. Such work would enable more robust comparative legal analyses and support the development of harmonized frameworks for genomic data integration across European health systems.

Overall, this expert survey demonstrates strong support for integrating genomic data into EHR systems through separate, interoperable infrastructures that prioritise clinically actionable information, specialist oversight, and patient involvement in governance; federated models may provide one approach to implementing such infrastructures. However, respondents reported legal uncertainty and workforce limitations, alongside reimbursement gaps beyond initial testing, as barriers to implementation. These findings align with broader European initiatives such as 1+ Million Genomes and Genome of Europe, which aim to strengthen genomic data infrastructures, interoperability, and cross-border collaboration.³³ However, many of these ambitions remain at varying stages of implementation across European healthcare systems. The present findings help identify practical barriers and policy gaps that may inform future implementation efforts.

DECLARATIONS:

Ethical considerations

Ethical approval for this study was obtained from the KU Leuven Privacy and Ethics Committee for Research (PRET) (approval number: G-2025-9981-R2(MAR)) and the KU Leuven Social and Societal Ethics Committee (SMEC) (approval obtained on January 14, 2026). Participation was voluntary, and all responses were collected anonymously. Informed consent was obtained electronically prior to participation. The study did not involve personal or patient level data, and all analyses were conducted on anonymized expert opinions.

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Conflicts of Interest

The authors report no conflicts of interest.

Data Availability

The survey instrument is available as Supplementary Material. Aggregated data supporting the findings of this study are provided within the article and its Supplementary Information. Individual-level survey responses, including free-text responses, are not publicly available because participants were recruited from a relatively small and specialised expert community, creating a potential risk of re-identification. De-identified data may be made available from the corresponding author upon reasonable request and subject to ethical and data protection considerations.

Author Contributions

Conceptualisation: MB, GM, MS, HAP. Methodology: MB, GM, MS, JWH. Data collection: MB. Formal analysis: MB, JWH. Writing — original draft: MB, JWH. Writing — review and editing: all authors. Supervision: GM, MS, JWH. All authors read and approved the final manuscript.

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