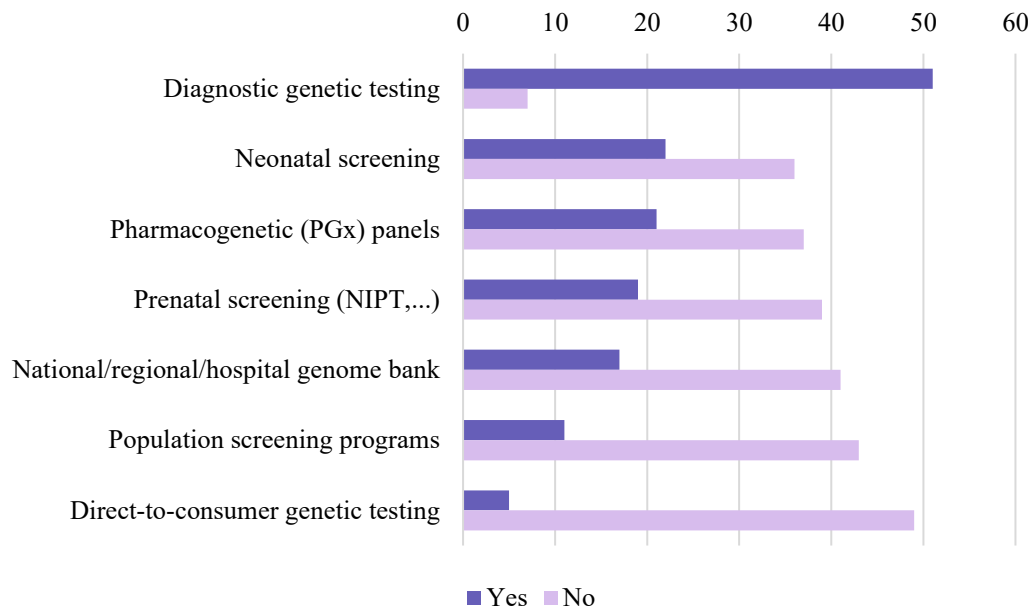
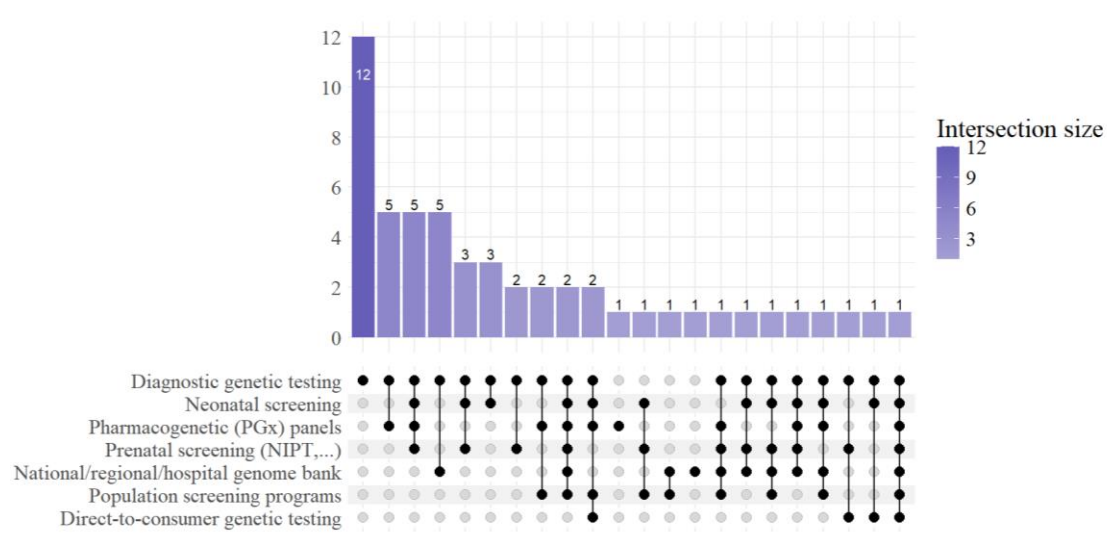


SUPPLEMENTARY MATERIAL

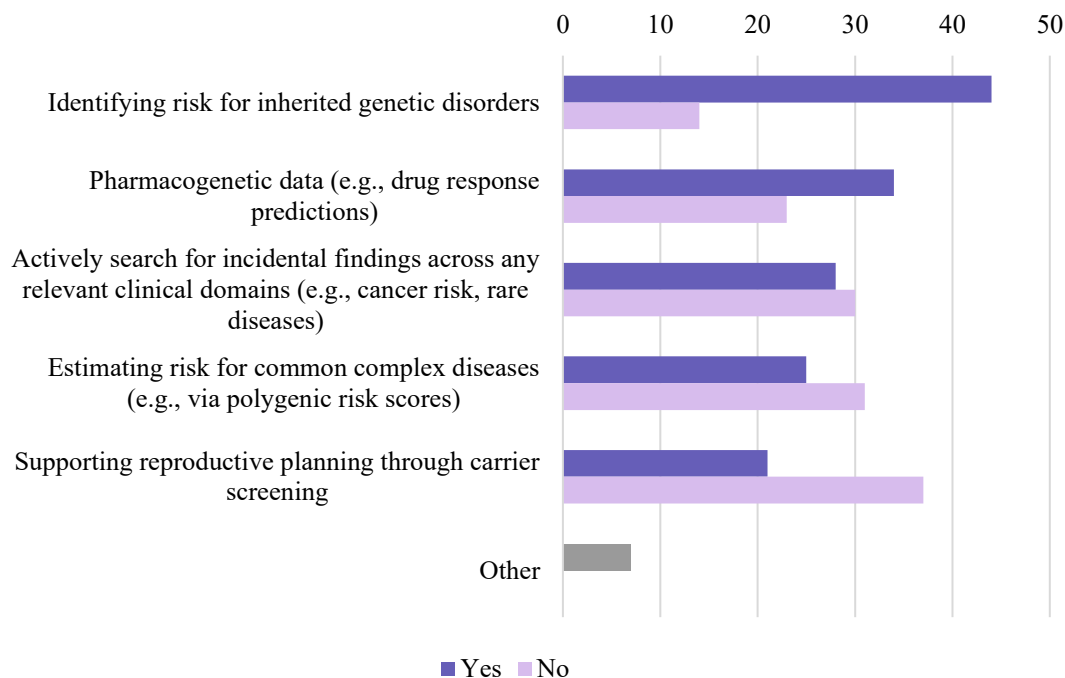
Supplementary Figures



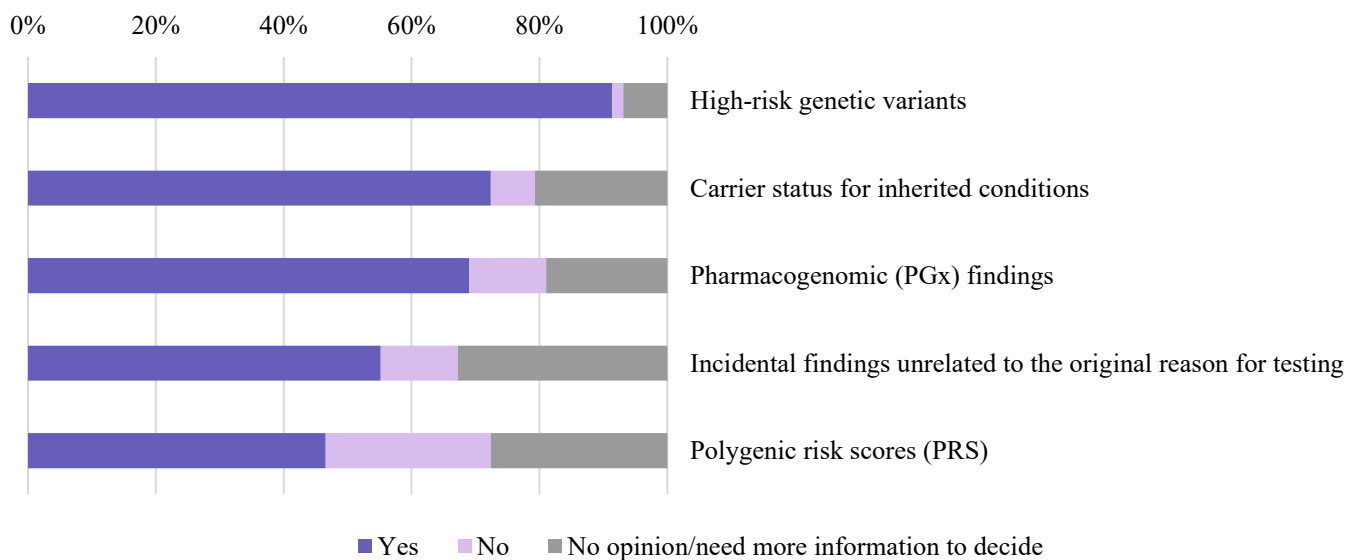
Supplementary figure 1. Reported consideration of different genomic data sources for EHR integration, with counts of “Yes” (blue) and “No” (purple) responses per category.



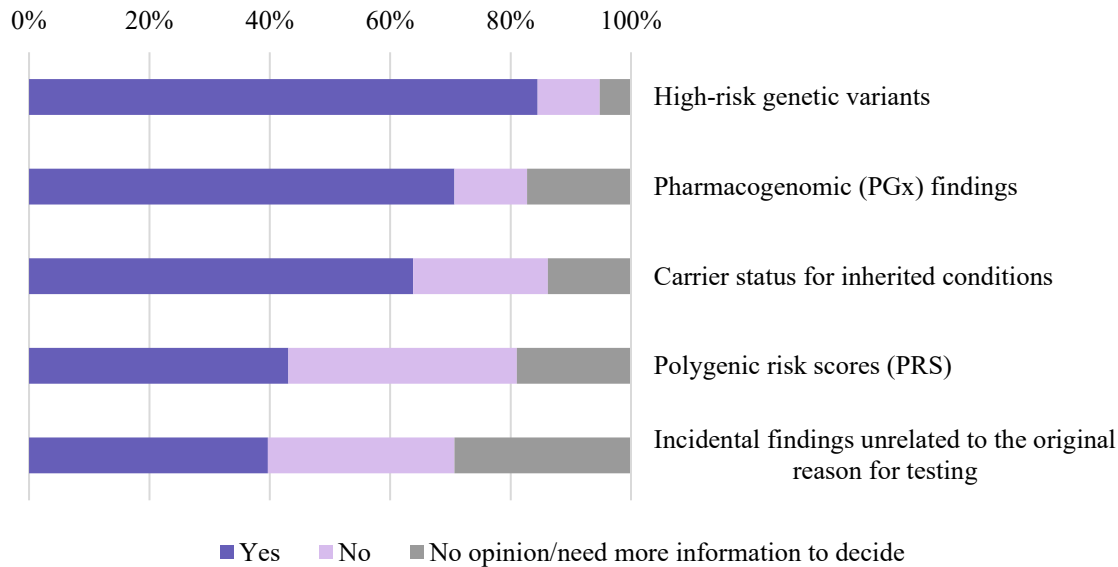
Supplementary figure 2. Combinations of genomic data sources considered for EHR integration. Bars represent the number of respondents per combination (connected dots).



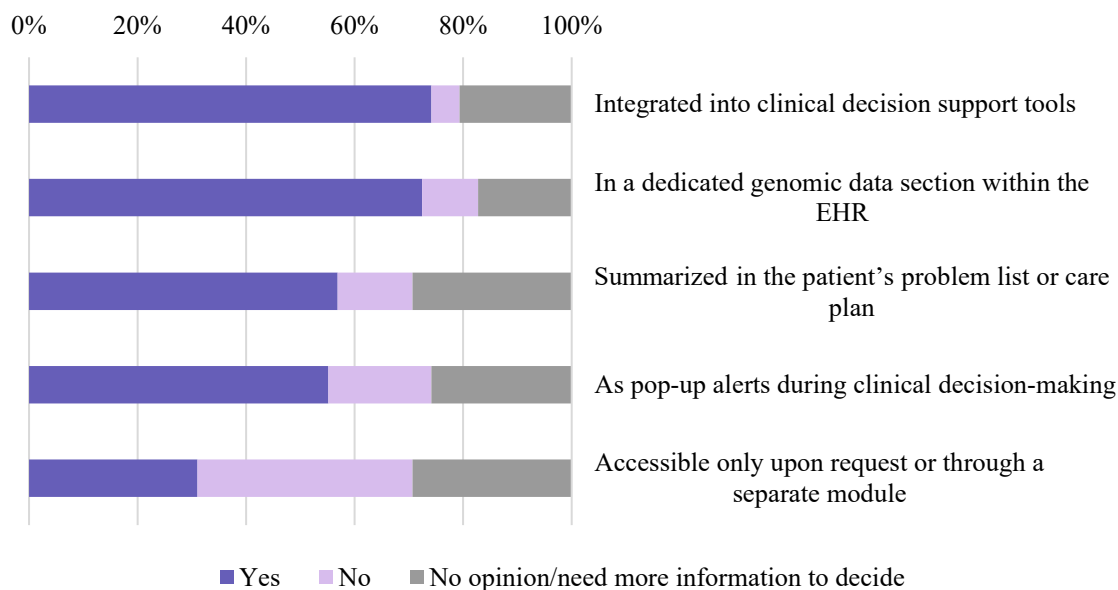
Supplementary figure 3. Types of clinical information respondents would like to derive from integrated genomic data, shown as counts of “Yes” (blue) and “No” (purple) responses.



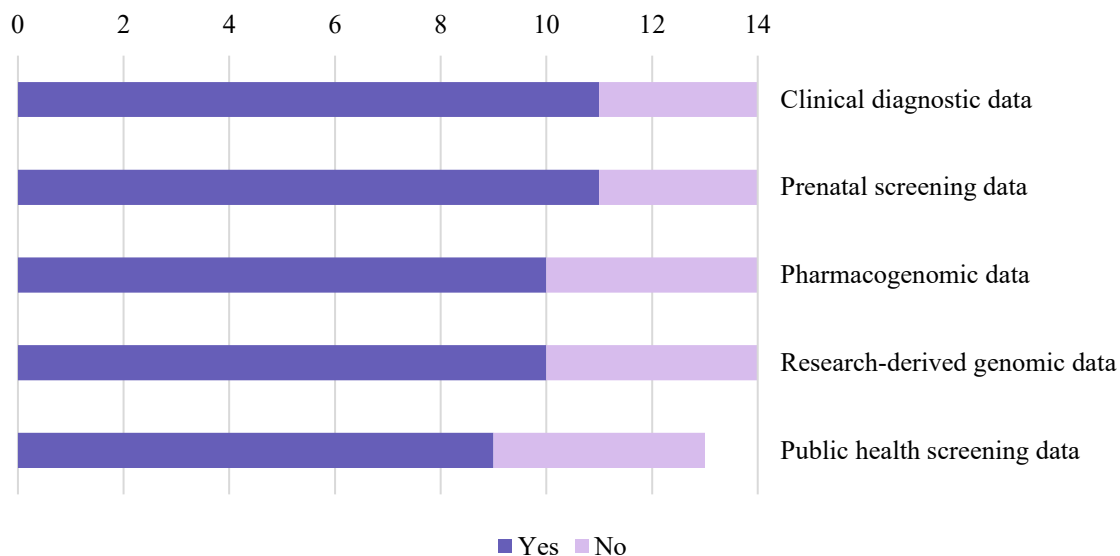
Supplementary figure 4. Reported preferences on which types of new genomic findings should be communicated following reanalysis after integration into clinical systems, shown as counts per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)).



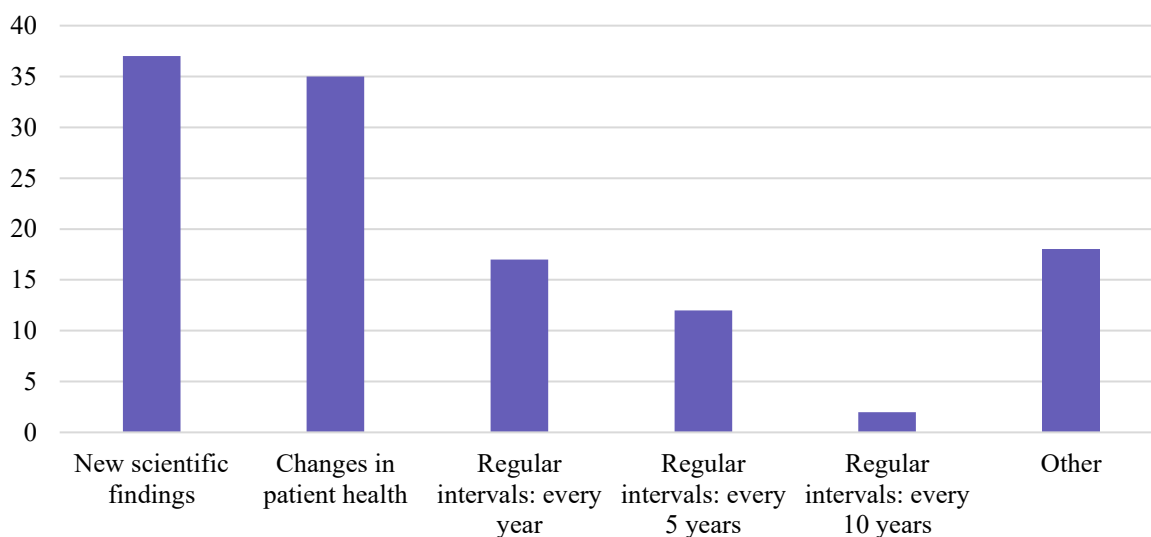
Supplementary figure 5. Reported preferences on which types of genomic information should be automatically generated or flagged after integration into clinical systems, shown as percentage of responses per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)).



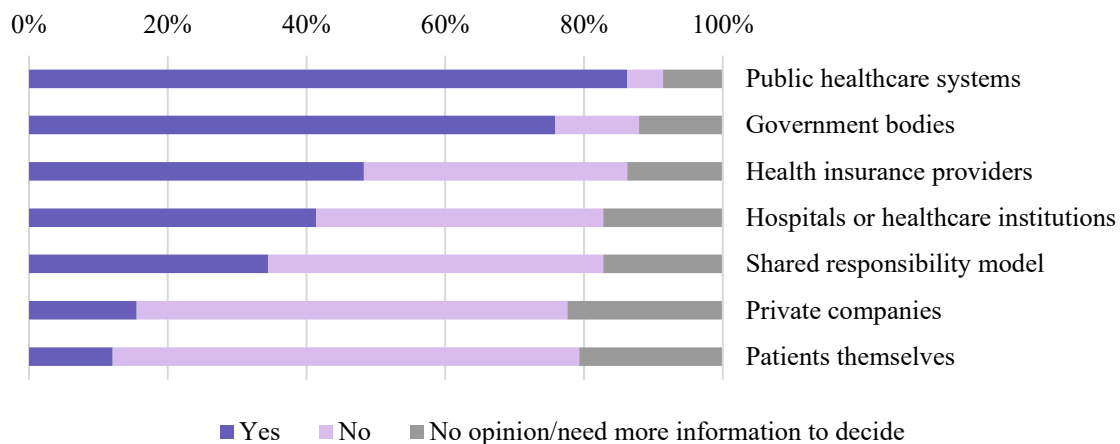
Supplementary figure 6. Reported preferences on how automatically generated genomic insights should be presented within clinical systems, shown as percentage of responses per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)).



Supplementary figure 7. Reported responses to types of genomic data covered by a legal framework for integrating genomic data into EHR systems, shown as counts of “Yes” (blue) and “No” (purple) responses.



Supplementary figure 8. Reported preferences for how often genomic data should be updated or reinterpreted after integration, shown as counts per response option.



Supplementary figure 9. Reported preferences on how the integration and use of genomic data should be funded or reimbursed, shown as percentage of responses per option (“Yes” (blue), “No” (purple), “No opinion/need more information to decide” (grey)).

Supplementary Appendix 1: Survey instrument

The survey instrument used in this study is provided below.

Bridging genomics and healthcare: A survey on genomic data in Electronic Health Records (EHRs)
We at KU Leuven in collaboration with The National Institute for Health Development (NIHD) (Estonia) are conducting this survey as part of the Joint Action Prevent NonCommunicable Diseases (JA PreventNCD) project, which aims to reduce the burden of cancer and other non-communicable diseases (NCDs) in Europe, much of which is preventable. JA PreventNCD supports strategies and policies that address both personal and societal risk factors for cancer and NCDs. **The general objective of the work package we are participating in is to reduce the burden mainly at the personal level**, by providing guidance on integrating information from genetic determinants, demographic, and behavioral characteristics (individual-level factors) into a holistic approach for cancer and NCDs prevention ([WP10 information JA PreventNCD](#)). **This survey seeks insights from EU health institutes and organizations on the integration of genomic data into electronic health records (EHRs)**. EHRs are a digital, comprehensive collection of a patient's health information stored in a secure, networked system that can be shared across different healthcare providers and settings. The integration of genomic data into EHRs holds significant potential for improving healthcare delivery. It could enable more personalized treatment, enhance diagnostic precision, and support early identification of disease risks. Additionally, it could facilitate access to genetic information within clinical workflows and contribute to research and innovation in precision medicine.

The aim of this survey is to understand current practices, assess feasibility, identify barriers, and explore opportunities for collaboration. Your input will help inform future strategies to support the responsible and effective use of genomic data in healthcare systems.

Note:

If you are **already** implementing any of the topics addressed in this survey within your organization or **would like to** implement these topics, we kindly ask you to briefly explain how this is currently being done or how you envision doing so in the future.

If you are **not currently** implementing these practices, we would still greatly value your perspective on these topics.

Before continuing with the survey, please take a moment to read the information letter which explains the purpose of this study, how your data will be used, and your rights as a participant.

[Information letter GDPR](#)

Once you've read the letter, you may proceed with the survey. If you have any questions, feel free to contact us via the details provided in the letter.

We sincerely thank you for your time and contribution.

Marte Berckmans, PhD student ; KU Leuven (Belgium)

Gert Matthijs, clinical laboratory geneticist ; UZ Leuven (Belgium)

Kaire Innos, cancer epidemiologist, The National Institute for Health Development (NIHD) (Estonia)

Mahsa Shabani, associate professor in health privacy law and innovation ; University of Amsterdam (The Netherlands)

There are 29 questions in this survey.

Professional profile

Please indicate your current role and affiliation.*

Please choose **only one** of the following:

- ☐ Public health institution
- ☐ Government agency
- ☐ Hospital
- ☐ Private company
- ☐ Research institution
- ☐ Other

Please briefly describe your area of expertise or professional background.*

Please write your answer here:

Please indicate the country in which you are currently working:*

Please write your answer here:

Genomic infrastructure and information needs

What is the source of genomic (exome, genome, or targeted) data used or considered in your organization for integration into EHRs? *

Please choose **all** that apply:

- ☐ Population screening programs
- ☐ Neonatal screening
- ☐ Diagnostic genetic testing
- ☐ Direct-to-consumer genetic testing
- ☐ Pharmacogenetic (PGx) panels
- ☐ Prenatal screening (NIPT,...)
- ☐ National/regional/hospital genome bank

☐ Other:

Please note: "genomic data" in this survey refers to the underlying genomic data file itself, stored for potential reanalysis or reuse, not just the clinical report derived from it. (Please select all that apply or specify if other. Examples may include: embryo-derived data, tumor profiling, carrier screening, polygenic risk scores, mitochondrial DNA testing, or research-based sequencing cohorts.)

What types of (extra or secondary) clinical information or decision-making support would you most like to derive from genomic data integrated into EHRs? *

Please choose **all** that apply:

- ☐ Pharmacogenetic data (e.g., drug response predictions)
- ☐ Estimating risk for common complex diseases (e.g., via polygenic risk scores)
- ☐ Identifying risk for inherited genetic disorders
- ☐ Actively search for incidental findings across any relevant clinical domains (e.g., cancer risk, rare diseases)
- ☐ Supporting reproductive planning through carrier screening
- ☐ Other:

(Please select all that apply or specify if other.)

If genomic data were to be integrated to support clinical decision-making, what kind of system would you prefer to see this implemented in? *

Please choose **all** that apply:

- ☐ Hospital-based Electronic Health Records
- ☐ National-based Electronic Health Records
- ☐ Private Insurance Databases
- ☐ Individual data storage models (e.g., patient-controlled data pods, as explored in the Belgian TTP initiative led by VITO)
- ☐ Other:

Would you favor integration into EHRs, or do you envision a different kind of setup?

Please suggest any alternatives you believe would be more effective.

(Please select all that apply or specify if other. Examples may include: patient-controlled data platforms, cloud-based genomic decision support tools, or specialized clinical genomics dashboards)

Do you believe genomic data should be stored directly within the EHR, or linked through a separate but connected system? *

Please choose **only one** of the following:

- ☐ Directly stored within EHR
- ☐ Separate and safe connected system
- ☐ Not linked at all

Legal aspects of genomic data use

Is there a legal framework in your country or jurisdiction that allows for the integration of genomic data into EHRs? *

Please choose **only one** of the following:

- ☐ Yes, there is a clear legal framework that allows integration.
- ☐ No, there is no legal framework permitting integration.
- ☐ Unclear/Ambiguous , there is no explicit legal framework, but some experts interpret existing laws as indirectly allowing integration.
- ☐ I don't know, I'm not sure about the legal situation.

Please specify the relevant legislation or regulatory body that facilitates this legal framework (e.g., GDPR, EHDS, national health laws) *

Please write your answer here:

This is an important question as we want to identify initiatives and the legal framework within which they have been established. If possible, include the name of the law, the article(s) or chapter(s) that apply, and a link or reference to the official source.

Which types of genomic data are covered by the legal framework implemented in your country? *

Please choose **all** that apply:

- ☐ Clinical diagnostic data
- ☐ Prenatal screening data
- ☐ Public health screening data
- ☐ Pharmacogenomic data
- ☐ Research-derived genomic data

☐ Other:

(Please select all that apply or specify if other.)

Do you think there are important gaps in current laws (like EHDS, GDPR, or national regulations) that make it harder to use genomic data in clinical care? If yes, what changes or additions would help solve these issues? *

Please write your answer here:

Consider aspects such as consent management, data access and control, reanalysis obligations, differentiation by data type (e.g., diagnostic vs. screening), and cross-border sharing.

Please explain your preference for how genomic data should be stored within clinical systems.*

Please write your answer here:

In your response, consider legal, ethical, and practical aspects such as:

- Data protection (e.g., privacy, security, pseudonymization, compliance with regulations like GDPR)
- Storage architecture (e.g., centralized vs. federated, in-house vs. external, national repositories, patient-controlled data pods)
- Interoperability (e.g., compatibility across systems, cross-border access)
- Clinical usability (e.g., accessibility for healthcare professionals, integration with decision-support tools)

Consent, privacy, and data use

Who do you believe should govern access to and use of genomic data once it is integrated into clinical systems such as EHRs? *

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Government health authorities (e.g., Ministry of Health, national health agencies)	☐	☐	☐
Hospital ethics committees/data access committees (e.g., data protection authorities, bioethics committees)	☐	☐	☐
Healthcare institutions (e.g., hospitals, clinics, medical networks)	☐	☐	☐
Institutions established under the European Health Data Space framework (e.g., Health Data Access Bodies, Trusted Health Data)	☐	☐	☐

<i>Holders, National Contact Points for Digital Health)</i>			
Multistakeholder governance models (e.g., involving government, healthcare providers, patients, and researchers)	☐	☐	☐
Patients themselves (e.g., through consentbased access control)	☐	☐	☐

Who do you think should be allowed to access and use genomic data once it is integrated into clinical systems? *

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Clinicians (e.g., physicians, genetic counselors, specialists involved in patient care)	☐	☐	☐
Researchers (e.g., academic or clinical researchers working on health and genomics)	☐	☐	☐
Government bodies (e.g., public health authorities, regulatory agencies)	☐	☐	☐
Private companies (e.g., pharmaceutical companies, biotech firms, health tech providers)	☐	☐	☐
Insurance providers (e.g., for coverage decisions or risk assessment)	☐	☐	☐
Only those explicitly authorized by the patient (e.g., via dynamic consent or opt-in systems)	☐	☐	☐

How do you think consent for the use of genomic data should be managed once it is integrated into clinical systems? *

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Explicit consent for each specific use (<i>Patients must approve every individual use of their genomic data.</i>)	☐	☐	☐
Broad consent for general clinical and research use (<i>Patients give one-time consent for a range of future uses.</i>)	☐	☐	☐
Tiered consent model (<i>Patients choose from different levels of data sharing, e.g., clinical use only, research use, etc.</i>)	☐	☐	☐
Dynamic consent (<i>Patients can update or withdraw their consent over time through an online platform.</i>)	☐	☐	☐
Explicit patient consent (<i>Managed by healthcare providers (e.g., clinicians or institutions based on initial agreement)</i>)	☐	☐	☐

Ongoing use based on public interest or other legal bases (<i>Permitted under national or EU level regulations (e.g., GDPR, EHDS without repeated patient consent.))</i>)			

Economic considerations in genomic healthcare

How do you think the integration and use of genomic data in clinical care should be funded or reimbursed? *

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Public healthcare systems (<i>e.g., national health services or publicly funded programs</i>)	☐	☐	☐
Government bodies (<i>e.g., ministries of health, EU-level funding initiatives</i>)	☐	☐	☐
Health insurance providers (<i>e.g., private or public insurers covering genomic testing and integration costs</i>)	☐	☐	☐

Hospitals or healthcare institutions (<i>e.g., costs absorbed by the institutions offering genomic services</i>)	☐	☐	☐
Shared responsibility model (<i>e.g., a combination of public, private, and institutional funding</i>)	☐	☐	☐
Private companies (<i>e.g., biotech or pharmaceutical companies funding integration for research or innovation purposes</i>)	☐	☐	☐
Patients themselves (<i>e.g., out-of-pocket payments or copayments for genomic services</i>)	☐	☐	☐

Is the integration and use of genomic data in clinical systems (such as EHRs) reimbursed or funded in your country? *

Please choose **only one** of the following:

- ☐ Yes, it is fully reimbursed
- ☐ Yes, it is partially reimbursed
- ☐ No, it is not reimbursed
- ☐ I don't know

If yes, or partially: how is the integration and use of genomic data in clinical systems reimbursed or funded in your country? *

** Please describe any relevant policies, funding mechanisms, or reimbursement models. You may also note if support varies by type of genomic data, clinical context, or institution.*

Please write your answer here:

In your opinion, what should be the maximum price or reimbursement limit for integrating genomic data into clinical systems (such as EHRs)? *

** Please specify whether this applies per patient, per clinical use, or over time. You may also consider whether different patient groups (e.g., rare disease, cancer) should have different limits.*

Please write your answer here:

Updating and revisiting genomic information

How often do you think genomic data should be updated or reinterpreted once it is integrated into clinical systems? *

Please choose **all** that apply:

- ☐ New scientific findings
- ☐ Changes in patient health
- ☐ Regular intervals: every year
- ☐ Regular intervals: each 5 years
- ☐ Regular intervals: each 10 years

☐ Other:

(Please select all that apply or specify if other.)

Who do you think should be responsible for managing, overseeing, and initiating reanalysis of genomic data once it is integrated into clinical systems? *

**Reanalysis may refer to: (a) updating variant interpretation as scientific knowledge evolves, (b) reassessing previously incomplete or outdated genomic data, or (c) reanalysing stored genomic data for new clinical insights.*

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Government health authorities (e.g., Ministry of Health, national health agencies)	☐	☐	☐
Independent regulatory bodies (e.g., data protection authorities, bioethics committees)	☐	☐	☐
Healthcare institutions (e.g., hospitals, clinics, medical networks)	☐	☐	☐
European-level institutions	☐	☐	☐
Genomic service facilities / sequencing centers	☐	☐	☐
Geneticists / clinical genetic professionals	☐	☐	☐
Patients themselves	☐	☐	☐

If new findings were to emerge from a reanalysis of a patient's genomic data, do you think the patient should be informed? *

Please choose **all** that apply:

- ☐ Immediately, regardless of the type of finding
- ☐ Only if the finding has clinical relevance
- ☐ Only if the finding affects treatment decisions
- ☐ Only if the finding has strong predictive value
- ☐ If they have given consent/requested so

☐ Other:

If new findings were to emerge from a reanalysis of a patient's genomic data, what types of findings should be communicated to the patient? Please start from the premise that the person has consented to be contacted. *

** Actionability and clinical relevance should be assumed where applicable.*

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Polygenic risk scores (PRS) (e.g., risk estimates for common diseases like diabetes or heart disease)	☐	☐	☐
Pharmacogenomic (PGx) findings (e.g., variants affecting drug metabolism or response)	☐	☐	☐
High-risk genetic variants (e.g., BRCA1/2, Lynch syndrome)	☐	☐	☐
Carrier status for inherited conditions (e.g., cystic fibrosis, Tay-Sachs)	☐	☐	☐
Incidental findings unrelated to the original reason for testing (e.g., predisposition to other conditions)	☐	☐	☐

If new findings were to emerge from a reanalysis of a patient's genomic data, how do you think the patient should be informed? Who should be responsible for communicating these findings to the patient? *

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Primary care physician	☐	☐	☐
Specialist physician	☐	☐	☐
Genetic counselor	☐	☐	☐
Personal app	☐	☐	☐
National or regional health authority	☐	☐	☐
Local hospital	☐	☐	☐
Healthcare institution via patient portal	☐	☐	☐

Actionability and clinical relevance should be assumed where applicable.

What is the current state of education for medical professionals regarding the use of genomic information in your country? *

Please write your answer here:

Is this addressed in pre- and post-graduate training for physicians? Is there a structured system for training genetic counselors?

Automated genomic information

What kind of information do you think should be automatically generated or flagged when genomic data is integrated into clinical systems? *

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
Polygenic risk scores (PRS) (<i>e.g., risk estimates for common diseases like diabetes or heart disease</i>)	☐	☐	☐
Pharmacogenomic (PGx) findings (<i>e.g., variants affecting drug metabolism or response</i>)	☐	☐	☐
High-risk genetic variants (<i>e.g., BRCA1/2, Lynch syndrome</i>)	☐	☐	☐
Carrier status for inherited conditions (<i>e.g., cystic fibrosis, Tay-Sachs</i>)	☐	☐	☐
Incidental findings unrelated to the original reason for testing (<i>e.g., predisposition to other conditions</i>)	☐	☐	☐

How do you think automatically generated insights from genomic data should be presented within clinical systems? *

Please choose the appropriate response for each item:

	Yes	No	No opinion/need more information to decide
As pop-up alerts during clinical decisionmaking (e.g., when prescribing medication or reviewing patient history)	☐	☐	☐
In a dedicated genomic data section within the EHR (e.g., alongside lab results or imaging reports)	☐	☐	☐
Integrated into clinical decision support tools (e.g., embedded in drug interaction checks or risk calculators)	☐	☐	☐
Summarized in the patient's problem list or care plan (e.g., flagged as relevant for ongoing management)	☐	☐	☐
Accessible only upon request or through a separate module (e.g., to avoid information overload)	☐	☐	☐

Are you aware of any (commercial or noncommercial) tools or applications that already offer the features described in the previous question? *

Please choose **only one** of the following:

☐ Yes

☐ No

Please detail what tool or application you know: *

Please write your answer here:

Thank you for your time and valuable input.

Your insights are essential for shaping the future of genomic data integration in clinical care.

We greatly appreciate your contribution to this important conversation.

Please follow the automatically loaded link to let us know if you're interested in further collaboration or contact.

Submit your survey.

Thank you for completing this survey.

Supplementary Appendix 2: Codebook for open-ended responses and thematic analysis

This appendix contains the survey codebook, including variable definitions and response categories, as well as the thematic coding framework developed for analysis of the open-ended survey responses.

Codebook for open-ended survey responses

Q14. Gaps in current laws governing genomic data use

Do you think there are important gaps in current laws (like EHDS, GDPR, or national regulations) that make it harder to use genomic data in clinical care? If yes, what changes or additions would help solve these issues?

Code	Label	Definition
LEG-G-01	Fragmented or outdated legal framework	Laws governing genomic data are scattered across multiple regimes (EHR, research, GDPR), not specific to genomics, or have not been updated to reflect current practice. Includes responses calling for a single integrated framework.
LEG-G-02	Ambiguity about what counts as genomic data	Current laws do not define what counts as genomic data (raw reads, VCF, arrays, assembled genomes, clinical report), leading to inconsistent rules on storage, retention, and access.
LEG-G-03	Consent management inconsistent or hard to operationalise	Gaps in informed consent (lack of granular opt-in/opt-out tools, unclear rules on secondary use, reanalysis triggers, withdrawal, or right to erasure).
LEG-G-04	Access control and role delineation misaligned	Legal restrictions limit access to specific specialties (often only clinical geneticists) or fail to differentiate access rules by data type (diagnostic, screening, tumour, PGx).

Code	Label	Definition
LEG-G-05	Interoperability and standardisation gaps	Technical difficulty combining data across institutions or countries due to inconsistent pipelines, formats, base-calling, variant frequency catalogs, or vendor-locked EHRs that cannot ingest structured genomic data.
LEG-G-06	Cross-border sharing barriers	Jurisdictional obstacles to EU- or intra-country cross-border sharing, especially for rare diseases. Includes regional sharing barriers within a single country.
LEG-G-07	Data protection, sovereignty, or secondary-use infrastructure concerns	Privacy and security concerns, sovereignty/data localisation, environmental or storage burden, or absence of legal infrastructure for secondary use and national knowledge bases.
LEG-G-08	Governance, accountability, or ownership unclear	Who owns genomic data (patient, lab, hospital, repository), or who is responsible for reanalysis and communicating updated results.
LEG-G-09	Workforce and process bottlenecks	Shortages of clinical geneticists, regulatory requirements for pre-test counselling or geneticist sign-off, or difficulty onboarding external technical experts under current rules.
LEG-G-10	Anti-discrimination or patient rights safeguards needed	Calls for explicit prohibition of genetic discrimination, time-bound storage, right to erasure or deletion after death, or clearer separation between clinical and research use.
LEG-G-11	No important gaps, or only clarification needed	Respondent states there are no significant gaps, or that current laws are adequate and need only clarification rather than substantive change.
LEG-G-12	Don't know / insufficient familiarity	Respondent declines to opine due to insufficient knowledge of the legal landscape.

Code	Label	Definition
LEG-G-13	Over-regulation or interpretation as implementation barrier	Respondent warns that legal overreach, overcautious or locally inconsistent GDPR interpretation, or excessive regulation itself deters or blocks implementation.

Q15. Storage preference for genomic data in clinical systems

Please explain your preference for how genomic data should be stored within clinical systems.

Code	Label	Definition
LEG-S-01	Strong data protection and privacy (GDPR-compliant)	Privacy, security, pseudonymisation, encryption, GDPR compliance, access logging, or strict access control is explicitly named as a storage requirement.
LEG-S-02	Centralised national repository preferred	Centralised national or regional repository as the storage architecture.
LEG-S-03	Federated or decentralised storage preferred	Federated or decentralised architecture (data stays where generated, queried via federation), often citing privacy or sovereignty.
LEG-S-04	Hospital or institute-level storage preferred	Data stored locally at the producing institute (hospital, lab, biobank).
LEG-S-05	Interoperability and common standards	Interoperability, common pipelines, standard formats (FHIR, Phenopackets), APIs, or cross-system compatibility.
LEG-S-06	Clinical usability for healthcare professionals	Storage and access design must enable clinicians to use the data (with access during care delivery, integration with decision support, and no information overload).

Code	Label	Definition
LEG-S-07	Patient empowerment and consent-based control	Patient can grant, withdraw, monitor, or manage access (through dynamic consent, patient-controlled data pods, or patient-facing apps).
LEG-S-08	Data-type-specific storage, provenance, or versioning	Distinguishes raw data (BAM/VCF) from reports, requires accredited or clinical-grade data sources, time-stamping, versioning, disclaimers, or different access layers for different data types.
LEG-S-09	Cross-border or EU-wide accessibility	Storage must support EU-level or explicit cross-border sharing (through federated nodes, EHDS, or harmonised governance).
LEG-S-10	Opposes integration into EHR	Respondent disagrees with storing genomic data in EHRs at all, citing security, sovereignty, environmental, or autonomy concerns.
LEG-S-11	Don't know / no opinion	Respondent declines to express a preference.
LEG-S-12	Secondary use (public health, research, and knowledge bases)	Storage should enable secondary use beyond the immediate clinical encounter, such as public health use, research, biobank use, knowledge bases, relatives' benefit, or explicitly named research access.

Q21. How genomic data integration is reimbursed in your country

If yes, or partially: how is the integration and use of genomic data in clinical systems reimbursed or funded in your country?

Code	Label	Definition
ECO-R-01	National health insurance or public budgets	Funding via national health insurance, single-payer, social security, national health service, or ministry/state budgets.

Code	Label	Definition
ECO-R-02	Test-dependent or inconsistent funding	Funding depends on the test type (diagnostic panel vs WES vs WGS vs PGx); some are fully covered, some partially, and some not at all.
ECO-R-03	Downstream infrastructure, integration, or reuse insufficiently funded	Reimbursement covers the clinical diagnostic act but may exclude or insufficiently cover data storage, EHR integration, reanalysis, secondary use, or national databases.
ECO-R-04	Fragmented, temporary, or pilot-based funding	Funding from time-limited national initiatives, model projects, or pilot programmes rather than sustained budgets.
ECO-R-05	Eligibility restrictions, disease silos, or indication-based inequities	Funding restricted to specific clinical indications, patient groups, or conditions (cancer, rare disease), or organised in disease-specific silos that conflict with the cross-cutting nature of genomics.
ECO-R-06	Regional or hospital-level budgets	Funding from regional or hospital-level budgets rather than (or in addition to) a national payer.
ECO-R-07	Research-only funding	Funding is available only through research grants, not for routine clinical use.
ECO-R-08	Don't know or non-specific mechanism	Respondent doesn't know the specifics, or names a non-specific mechanism (e.g. "by law").

Q22. Maximum price or reimbursement limit for integration

In your opinion, what should be the maximum price or reimbursement limit for integrating genomic data into clinical systems (such as EHRs)?

Code	Label	Definition
ECO-P-01	Specific monetary value given	Respondent provides a specific price, range, or limit (in EUR, USD, or other), including a stance of "free."

Code	Label	Definition
ECO-P-02	Depends on data type or test type	Limit depends on whether the test is PGx vs panel vs WES vs WGS, or on other technical/data factors.
ECO-P-03	Depends on clinical context or indication	Limit depends on the medical indication, severity, or use case (diagnostic vs prevention vs population-level).
ECO-P-04	No limit for rare disease or cancer	Respondent explicitly says there should be no price ceiling for rare disease or cancer indications.
ECO-P-05	Free at point of care / full public coverage	Respondent says integration should be free at point of care or that the system should cover the full cost without patient payment.
ECO-P-06	Cost-effectiveness or resource-based costing, not fixed ceiling	Reimbursement should be based on HTA, cost-effectiveness, actual time and resources required, maintenance, or lifecycle costs, rather than a simple ceiling.
ECO-P-07	Question is poorly framed	Respondent rejects the question itself (wrong unit of analysis, inability to isolate integration cost from test cost, or missing context).
ECO-P-08	Project vs reimbursement budgets distinct	Respondent distinguishes one-off integration build costs from per-patient reimbursement, including maintenance and lifecycle costs.
ECO-P-09	Price difficult to estimate	Respondent gives a substantive reason that the price is hard to estimate, such as missing context or variation by country, disease, purpose, or technical/data factors.
ECO-P-10	Don't know / no opinion	Respondent declines to answer (no idea, no opinion, n/a).

Code	Label	Definition
ECO-P-11	No fixed ceiling / reimburse full medically justified cost	Respondent rejects a fixed maximum and argues that full or as-needed cost should be covered when medically justified, clinically necessary, or cost-effective.

Q26. State of medical-professional education in genomic information

What is the current state of education for medical professionals regarding the use of genomic information in your country?

Code	Label	Definition
EDU-01	Structured postgraduate training for genetic specialists	Education or training exists for genetics specialists, including clinical genetics, medical genetics, laboratory genetics, residency, specialization, or postgraduate training.
EDU-02	Genetic counsellors not recognised or not trained	Country lacks recognition of the genetic counsellor profession, lacks counsellor training programmes, or relies entirely on MDs for counselling.
EDU-03	Insufficient training for non-specialists or GPs	General practitioners and non-genetics specialists receive minimal training in genomics, limiting their ability to use genomic results in care.
EDU-04	Variable or patchy quality across country or region	Education is uneven (some institutions or specialties have strong programmes, while others have little).
EDU-05	Curriculum exists but inadequate for practice	Curriculum exists but does not equip clinicians for everyday genomic interpretation in their working role.
EDU-06	Public awareness or patient expectations gap	Respondent flags low public understanding of genomics, leading to unrealistic patient expectations or concerns.

Code	Label	Definition
EDU-07	Education poor or largely absent	Respondent describes education as poor, almost none, low, or not addressed in the country.
EDU-08	Pre-graduate medical school inclusion	Genomics or genetics is included in pre-graduate medical curriculum, at least at a basic level.
EDU-09	Developing, continuing, or project-based education opportunities	Developing systems, continuing education, additional courses, rotations, occasional teaching, or other limited training opportunities for practicing professionals.
EDU-10	Don't know / no opinion	Respondent declines to opine.
EDU-11	Genetic counsellor training recognised or available	Country has structured, recognised, or dedicated genetic counsellor education/training.
EDU-12	Adequate or positive overall	Brief positive or adequate evaluation of medical-professional genetics education ('good', 'Fair', 'OK').