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Mobilising Collaboration among Stakeholders to Optimise the Growing Potential of Data for Tackling Cancer

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Abstract: Effective cancer diagnosis, treatment and control depend on interactions among numerous distinct factors, from technology to data to skills to sociology. But a crucial influence is the extent to which the health system takes account of the distinct perspectives of the many different groups of interdependent stakeholders concerned with cancer, including patients, practitioners and planners. This paper provides some elucidation as to how far and how efficiently these interactions currently take place in Europe. It also makes some tentative suggestions as to how conscious systematic

interventions could improve cancer outcomes. It is based on a series of expert panels and surveys conducted by the European Alliance for Personalised Medicine (EAPM) that provided information at the national level on three selected parameters: implementation of next-generation sequencing (NGS) and liquid biopsy (LB), attitudes of patients to prevention and practices of sharing genomic data among healthcare professionals (HCPs). The varying data infrastructure highlights the urgent need for substantial improvements to accommodate the increasing importance of genomics data in cancer diagnosis and care. Additionally, we identify disparities in age-specific approaches to cancer prevention, emphasising the necessity for tailored strategies to address unique age group perspectives. Moreover, distinct regional prioritizations in cancer treatment underscore the importance of considering regional variations when shaping future cancer care strategies. This study advocates for collaborative data sharing supported by technological innovation to overcome these challenges, ultimately fostering a holistic and equitable provision of cancer care in Europe.

Keywords: health data; data sharing; data governance; patients; uptake; personalised medicine; next-generation sequencing; policy; cancer; research

1. Introduction

Cancer remains one of the most significant health challenges in Europe and beyond. In 2020, 2.7 million people in the European Union were diagnosed with the disease, and another 1.3 million people lost their lives to it [1]; worldwide, it accounted for nearly 10 million deaths in 2020, or nearly one in six deaths [2]. Incidence continues to vary across the European Union (Figure 1), from 458/100,000 in Bulgaria to 718/100,000 in Ireland in 2019 [3]. Tackling these disparities and improving cancer care depends on a number of factors. One of these factors is making optimal use of novel and costly treatments and addressing variations in practice. Oncologists need to identify the best treatment approaches for particular biomarker-defined subgroups and efficiently identify new priorities for clinical research in an increasingly crowded research arena. Meeting this challenge can be eased by the use of real-world evidence (RWE), which offers vital clues on balancing sustained innovation with the delivery of better value in cancer care [4].

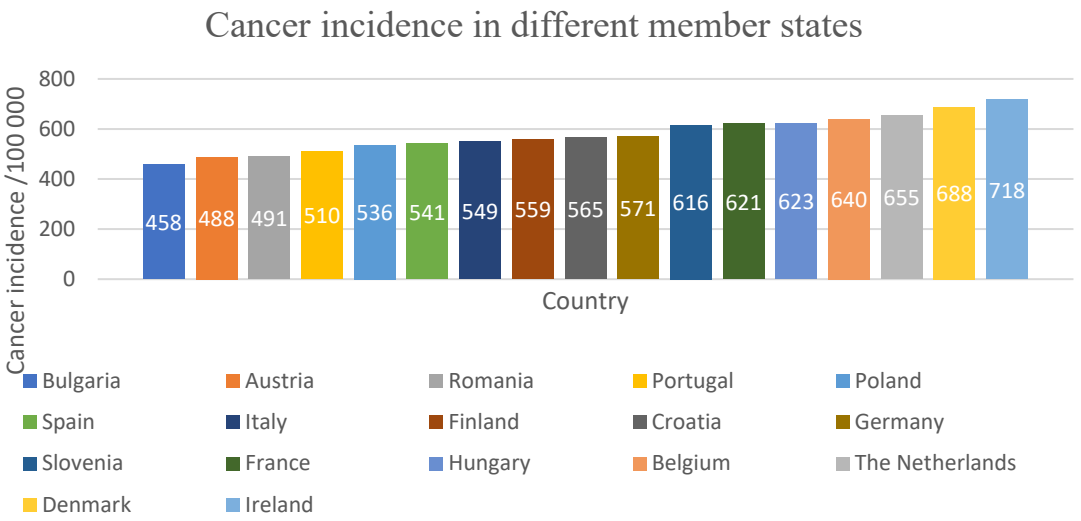

Figure 1. Cancer incidence among various countries across Europe [3].

The possibilities of tackling cancer continue to grow at a rapid rate, with a new understanding of the underlying mechanisms combined with new tools for diagnosis and treatment, and with a widening understanding of the powerful societal and personal factors influencing cancer incidence and treatment, ranging from widening use of NGS to more

carefully planned screening programs and the ever more intensive and productive use of personalised medicine [5,6].

In particular, the growing engagement of and with patients and citizens is shifting much of the traditional thinking about tackling cancer—typified by the growing role now being given to patients in the work of the European Medicines Agency, on which the EMA's Management Board endorsed an updated framework in 2022 [7].

In addition, the pace and intensity of policy engagement are also increasing, both at the international and—particularly for this study—at the EU level. Europe's Beating Cancer Plan aims explicitly to tackle the entire disease pathway, from prevention through early detection, diagnosis and treatment, and quality of life of cancer patients and survivors [8]. The European Health Data Space (EHDS) currently being created will comprise rules, common standards and practices, infrastructures and a governance framework that aims to empower individuals and provide a consistent, trustworthy and efficient set-up for the use of health data for research, innovation, policy making and regulatory activities. There is also increasing recognition of the need for collaboration, as evidenced in exercises as distinct as the European Health Union "in which 27 countries work together to detect, prepare and respond collectively" [9] or the novel integration of genomics in clinical care and public health known as CAN.HEAL [10].

Cancer care is perceived differently by different stakeholders, such as healthcare professionals, researchers, policymakers or patients. Among patients, demand for information related to their disease and treatment is higher among younger patients, female patients, patients recently diagnosed and those in poor health or exhibiting symptoms of anxiety or depression, while demand is lower in patients showing higher satisfaction with their physician and trust for nurses, or receiving more care. Despite the many opportunities for patients to engage in laboratory and clinical research, the complexity of decisions about cancer treatment makes it difficult for patients to understand and also for physicians to explain [11].

Improvements in health and advances in science and healthcare delivery are heavily dependent on the sharing of data [12]. Population-based cancer registries are key sources of information on cancer incidence and survival, and effective use of these data is essential for cancer control, but sharing this information in a uniform, timely and user-friendly manner has been sub-optimal [13]. Sharing information related to the response to targeted drugs of patients with rare mutations or complex mutational patterns is also essential to ensure the advancement of precision oncology. Europe's fragmented system of health informatics prevents comprehensive analysis of the real-world impact of new treatments or precise estimates of the impact of new cancer technologies on health systems. A digital health agenda able to deploy data to underpin cancer research and its real-world translation for the benefit of human health and wellbeing cannot emerge without the relevant bioinformatic, statistical and advanced data analytics skills and frameworks [14]. Accordingly, the development of a knowledge-based database [15], where real-world clinical and molecular data are collected and periodically reviewed by expert pathologists, supports healthcare personnel in the clinical administration of lung cancer patients [16].

But its success depends on the use of data, and access is at present uneven and inconsistent across member states. Public bodies are, in some countries, entitled to access data for monitoring medicines and devices, and access is not always restricted to public actors, although conditions vary according to the nature of other bodies and the intended use. For instance, Germany's governance body, BfARM, currently provides access to data related to insurance and service providers, and to cost and administrative data for which no permission of citizens is needed. But some countries have more than one agency governing data: in Denmark, there are two national bodies that host health data—Statistics Denmark and the Danish Health Data Authority (Table 1) [17].

Table 1. Assessment of the EU Member States' rules on health data and characteristics of governance bodies [17].

Member State	Governance Body	Exists at National Level	Public Sector Entity	Charges Access Fees	Hosts Data	Provides Access to Prescribing and Dispensing Records, and to Hospital Electronic Health Records
Bulgaria	The National Centre of Public Health and Analyses (NCPHA)	√	√	√	√	√
Cyprus	The Ministry of Health and the National Bioethics Committee	√	√	x	x	x
Denmark	Statistics Denmark and the Danish Health Data Authority	√	√	√	√	√
Finland	Findata—an independent central agency	√	√	√	√	x
France	The Health Data Hub—builds on previous initiatives	√	√	x	√	√
Germany	The Research Data Centre at BfArM; National Research Data Infrastructure (NFDI); and Medical Informatics Initiative (MII)	√	√	√	√	√
Ireland	NREC COVID19 (National Research Ethics Committee for COVID-19)	√	√	x	x	x
Latvia	The Centre for Disease Prevention and Control (SPKC)	√	√	x	x	x
Netherlands	Statistics Netherland (CBS)	√	√	√	√	√
Portugal	SPMS—Shared Services of Ministry of Health	√	√	x	x	√

x—not available, √—available.

Standards and models on managing data infrastructure also vary from country to country. The OMOP Common Data Model provides a systematic analysis of disparate observational databases. The aim is to perform systematic analyses using a library of standard analytic routines that have been written based on the common format [18]. The CIMI is an open standard API specification which standardises interactions between cloud environments and ultimately enables users to manage their cloud infrastructure. Mcode is an initiative intended to assemble a core set of structured data elements for oncology electronic health records (EHRs) and allow for easier methods of data exchange between health systems. ICGC ARGO aims to accelerate research in genomic oncology. The OSIRIS set has been organised with a terminology that is designed to be scalable and modular. In the future, other specific terminology aspects will be added according to localization of cancer (breast, lung, digestive tract, etc.), treatment options (chemotherapy, radiotherapy, immunotherapy) and analysis (e.g., other genomics fields). The CDASH Model provides a general framework for creating fields to collect information on case record forms (CRFs) and includes the model metadata. OpenEHR is based on reference models, archetypes and templates (case-specific datasets). FHIR is an interoperability standard intended to facilitate the exchange of healthcare information between healthcare providers, patients, caregivers, payers, researchers and anyone else involved in the healthcare ecosystem. Phenopackets is a standard for sharing disease and phenotype information that characterises an individual person. ISO IDMP focuses on the regulatory domain, where it is currently implemented. ISO 13972:2022 provides principles for the transformation and application of clinical information models across a wide variety of health information technology [19] (Table 2). EHDS, conceived as an integral component of the emerging European Health Union, offers

Europe the prospect of becoming a world leader in cancer health data science and its application [20].

Table 2. Standards and descriptions of each standard [19].

Standard	Description
OHDSI/OMOP	The concept—to transform data contained within those databases into a common format.
CIMI	It is used for managing cloud infrastructure. This specification standardises interactions between cloud environments.
mCODE	mCODE is a step towards capturing research-quality data from the treatment of all cancer patients.
ICGC ARGO	It aims to accelerate research in genomic oncology, aligned by FAIR data principles.
OSIRIS	The OSIRIS network has proposed a list of 130 clinical and -omic items and establishes a minimum dataset for the sharing of clinico-biological data in oncology.
CDISC CDASH	CDASH establishes a standard method of collecting data consistently across studies and sponsors.
OpenEHR	OpenEHR is a non-profit organization that publishes technical standards for an EHR platform along with domain-developed clinical models to define content.
HL7 FHIR	FHIR consists of two main parts: a content model in the form of 'resources', and a specification for the exchange of these resources.

Greater support is also needed for both academic-led clinical trials and RWE studies that can complement and supplement clinical trial evidence and reduce the uncertainties in health technology assessment (HTA) that cause delayed reimbursement decisions [4]. The 2019 data show that in Eastern European countries, no more than 32% of new oncology medicines are reimbursed. The low cost of cancer care in Romania and Poland is largely due to their citizens bearing significant out-of-pocket expenses, accounting for 18.9% and 20% of total health expenditures in 2019, respectively. In Hungary, by contrast, all elements of cancer care are covered through public financing for insured citizens, while only 0.3% of the population in Croatia reported unmet health needs due to cost. Among the countries studied, Germany leads the way in reimbursing new oncology medicines: although it leads in total cost of cancer per capita, statutory health insurance covers 100% of these medicines, enhancing the quality and inclusiveness of the German healthcare system, which is accessible to all its citizens (Figure 2) [3].

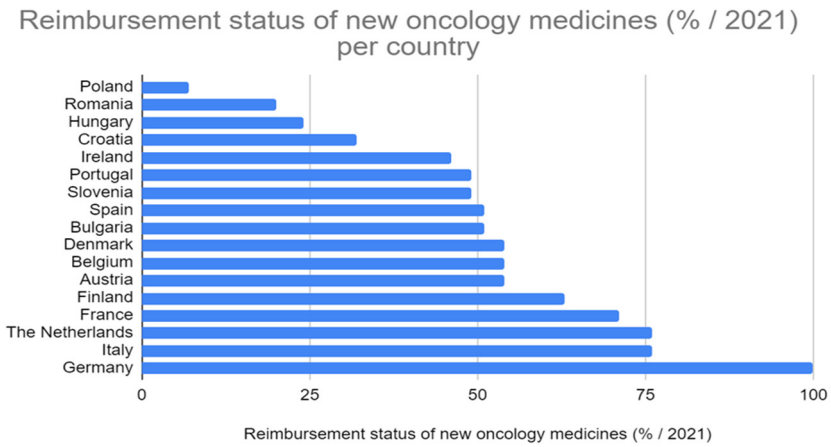

Figure 2. Reimbursement status among different member states [3].

This study set out to explore the nuances of understanding cancer among different stakeholder groups, and to assess similarities and differences in the parameters of technology and infrastructure, patient attitudes and professional engagement in cooperation.

2. Materials and Methods

The European Alliance for Personalised Medicine (EAPM) conducted a series of expert panels and a survey among healthcare professionals from different cancer centres and organisations. Experts involved were from Italy, Germany, France, the UK, Belgium, Croatia, Spain, Poland, Slovenia, Sweden, Portugal, Romania, Ireland, Austria, the Netherlands and Bulgaria. Key experts (n = 80) included oncologists, molecular biologists, pathologists and bioinformaticians from cancer centres throughout Europe.

The European Cancer Patient Coalition (ECPC) and the Childhood Cancer International-Europe (CCI-E) conducted a survey among patients and citizens.

A series of expert panels were conducted to determine the current status of health data sharing and use in EU member states. In early 2023, 28 expert interviews were conducted via Zoom with 2 to 4 experts per interview and recorded.

The analysis of the survey of patients covered breast cancer, prostate cancer, lung cancer, colon and other gastrointestinal cancers, and focused on major European regions (Northern, Eastern, Southern and Western Europe) and 13 countries (Belgium, Bulgaria, France, Italy, Germany, Spain, Slovakia, Romania, Portugal, Netherlands, Luxembourg, Hungary, Greece).

A survey of healthcare professionals from basic clinical labs/research centres, clinical cancer centres and comprehensive cancer centres focused on data and NGS and showed differences in information, attitudes and practices from country to country.

2.1. Series of Expert Panels

The expert interviews were organised by the EAPM and invitations were based on experts' contributions to the peer-reviewed literature on the use of NGS and advanced diagnostics in clinical settings from a data-sharing perspective.

The data infrastructure of each country was evaluated based on defined assessment criteria. Scores or rankings were assigned to each criterion to quantify the quality or readiness of the data infrastructure for NGS implementation. The evaluation provided a quantitative assessment of the suitability of the data infrastructure for NGS implementation.

Following the assessment and scoring of the data infrastructure, the confidence level for each country was calculated. Statistical methods or calculations were utilised to determine the level of confidence associated with the data infrastructure's suitability for NGS implementation. The calculation took into account the scores or rankings obtained during the data analysis. Assigning confidence levels makes it possible to provide an indication of how well-prepared each country is in terms of its data infrastructure for NGS implementation. Higher confidence levels suggest a stronger likelihood of successful NGS implementation, while lower confidence levels may indicate areas that require improvement or further investment.

2.2. A Survey of Patients

The survey among patients and citizens was developed within the context of the '4. UNCAN.eu' initiative. "UNCAN.eu" refers to a collective European effort that seeks to enable a step forward in our understanding of cancer. A key goal of UNCAN.eu is to identify cancer research priorities and expectations from patients and the general public and, ultimately, to consider them in the definition of the portfolio of near-future research and innovation actions [21,22]. A survey was conducted by the ECPC and the CCI-E to take account of patients' and citizens' perspectives. This survey was carried out in the context of a Coordination and Support Action that will generate a blueprint to set up a European Cancer Research Data Hub [23] with the aim of determining cancer research

priorities and expectations from patients and the general public in the same research areas that the scientific community would also identify as its priorities.

Seven pillars were identified:

- Cancer prevention;
- Screening and early diagnosis;
- Sensitivity and resistance to therapy;
- Paediatric cancer;
- Cancer and ageing;
- Survivorship and quality of life;
- Data sharing.

The survey, involving more than 1700 participants from 30 European countries, assessed aspects of cancer research based on 35 measures (Table 3) derived from the seven pillars. Participants were aged between 16 and 70 and included adult cancer patients, cancer survivors and caregivers, paediatric cancer patients, and citizens not directly affected by cancer. Analysing the correlation values between age groups 16–44 and 45 to 70+ for different types of cancer offers critical insights into cancer research and healthcare. Firstly, it enables the design of targeted prevention strategies by understanding how different age groups perceive the importance of cancer prevention measures. Tailoring education and intervention efforts to resonate with specific age demographics can significantly enhance the impact of prevention campaigns. Secondly, age-specific analysis is fundamental for early detection initiatives, as cancer risk and prevalence often vary across different age brackets. By identifying prevalent cancers within specific age groups, healthcare systems can implement targeted early detection programs, potentially leading to early diagnosis and improved treatment outcomes. Moreover, understanding how age influences treatment decisions and responses helps in tailoring treatment approaches to meet the unique needs and preferences of different age cohorts, thus optimising treatment effectiveness and adherence. Additionally, policymakers can utilise the insights from age-specific analysis to inform public health policies and efficiently allocate resources. By comprehending how age shapes perceptions and priorities regarding cancer care, policymakers can plan and distribute resources to meet the specific healthcare needs of diverse age demographics effectively. Furthermore, age-specific analysis aids in prioritising cancer research efforts based on age-related concerns, ensuring that research investments are directed towards areas most relevant to each age group. This targeted approach ensures that research aligns with the distinct challenges and concerns faced by individuals within different age ranges. Customised health communication is another key benefit, allowing for tailored messaging and strategies that are effective for specific age groups. Lastly, hospitals and healthcare facilities can allocate resources more efficiently based on age-specific analysis, ensuring that healthcare provision effectively addresses the varying importance of cancer treatment measures within distinct age categories. In essence, age-specific analysis is a potent tool that guides targeted cancer prevention, early detection, treatment strategies, public health policies, research focus, communication efforts, and resource allocation, ultimately leading to more effective and tailored approaches in the fight against cancer. Comparison was made between major European regions—Northern, Eastern, South and Western Europe—and 13 countries (Belgium, Bulgaria, France, Italy, Germany, Spain, Slovakia, Romania, Portugal, Netherlands, Luxembourg, Hungary, Greece) in the context of breast cancer, lung cancer, prostate cancer, colon and other gastrointestinal cancers.

Table 3. Measure index.

Measure ID	Pillar ID	Measure Name
1	1	Gut bacteria and diet
2	1	Metabolism and exercise
3	1	Chronic inflammation
4	1	Substances causing cancer in the environment
5	1	Prevention of cancer
6	1	Cancer heredity and epigenetics
7	2	Processes occurring before tumour development
8	2	Early cancer mechanisms
9	2	Blood tests for early detection
10	2	Technologies for early diagnosis
11	2	Personalised prevention and early screening
12	3	Blood tests to show sensitivity and resistance to therapy
13	3	The biology of cancer cells (immune system, stem cells, microenvironment, genetics, etc.)
14	3	New therapeutic approaches and drug delivery systems
15	4	Hereditary cancer and epigenetic mechanisms in paediatric cancer
16	4	Cancer and development
17	4	Therapeutic strategies in paediatric cancer
18	4	The study of the immune system relating to paediatric cancers
19	4	Pregnancy and paediatric cancer links
20	5	Determinants of ageing and cancer
21	5	The cell biology of ageing and cancer
22	5	Ageing and the process of ageing in cancer
23	5	Influence of ageing on cancer interventions
24	5	Cancer complications and comorbidities
25	6	Secondary cancers associated with treatment
26	6	Long-term immune-related side effects
27	6	Effects on reproductive functions and fertility
28	6	Effects on the fitness of the heart and lungs and the hormone system
29	6	Cancer treatments' effects on the nervous system
30	6	Comprehensive management and care in cancer survivors
31	7	Generation of data
32	7	Use of data
33	7	Collection of data
34	7	Quality of data
35	7	Control of data sharing

2.2.1. Data Analysis

Cancer Type

The survey assessed participants' perception of importance using a 5-point scale, and the responses were analysed and normalised to a 10-point scale for comparison and ranking. The normalization process involved scaling the responses based on the number of participants who selected each level of importance. Additionally, statistical analysis

was performed to compare the responses across different age groups (16–44 years and 45–70+ years) and across different cancer types.

Statistical Analysis

Correlation was employed to examine the relationship between different age groups. ANOVA was used to compare the means of importance ratings across different demographic groups, categories, cancer types, pillars and measures. It specifically aimed to identify significant differences in importance ratings between different cancer types. The *t*-test was utilised to determine if there were significant differences in importance ratings between two measures or between different age groups. These methods provided quantitative measures to assess relationships and to detect significant differences in the data. They helped support the findings presented in the datasheet by providing statistical evidence. Choosing the appropriate statistical method was crucial and depended on the research questions and the nature of the data being analysed.

Country-Wise and Region-Wise Analysis

The survey aimed to assess participants' perception of importance using a 5-point scale. After collecting the data, each measure was scored by calculating a weighted average of the responses. This scoring method provided an indication of the importance level for each measure across different countries and regions. Statistical techniques such as correlation and ANOVA were used to analyse the data further. Correlation helped explore relationships and ANOVA compared the means across different groups. These analyses made the identification of significant differences in importance ratings among demographic factors, categories and regions possible. By combining scoring methods and statistical analyses, the survey provided a comprehensive understanding of participants' perceptions of importance and offered insights into variations and relationships within the data.

2.3. A Survey of Healthcare Professionals

To take account of the perspective of healthcare professionals, a specifically designed questionnaire was sent to experts. Questions covered sharing genomic data between other institutions in the same country or cross-border; the main purpose of genomic data in the cancer centre; linking data from sequenced genomes to clinical data (EHRs) or other types of data (e.g., biobanks, proteomics); type of information provided to patients/citizens after involving them in NGS testing; type of information provided to patients/citizens before involving them in NGS testing; cancer data infrastructure; and reimbursement status of new oncology medicines (%/2021). Data from the questionnaire were subjected to statistical analysis.

3. Results

3.1. Series of Expert Panels

The confidence levels for each country in the context of data infrastructure for NGS indicate the level of confidence or certainty associated with the data infrastructure's suitability for implementing NGS technology. The confidence level was measured based on the scoring of each measure. Higher confidence levels suggest a stronger likelihood that the data infrastructure in a particular country is well-equipped and capable of supporting NGS implementation effectively.

The levels varied across countries. Austria, Belgium, Bulgaria, France, Ireland, Italy, the Netherlands, Portugal, Romania, Slovenia, Spain, Sweden and the UK all had a confidence level of 0.680087381, indicating a relatively high level of confidence in their data infrastructure for NGS implementation. Germany and Poland had a confidence level of 0.555289021, which suggests a slightly lower level of confidence (Table 4).

Table 4. Confidence level test for data infrastructure for NGS in the participating countries.

* Austria	* Belgium	* Bulgaria	* Croatia	* France	* Germany	* Ireland	* Italy
0.555289021	0.555289021	0.555289021	0.6800873807	0.6800873807	0.6800873807	0.555289021	0.6800873807
* Netherlands	* Poland	* Portugal	* Romania	* Slovenia	* Spain	* Sweden	* UK
0.555289021	0.6800873807	0.555289021	0.555289021	0.6800873807	0.555289021	0.6800873807	0.555289021

* Confidence Level is 95%.

A 95% confidence level in statistical terms indicates the level of confidence or certainty associated with an estimate or result. Specifically, it refers to the range within which the true population parameter (e.g., a proportion, mean, etc.) is likely to fall based on the observed sample data.

In the context of the provided confidence levels for different criteria in various countries, a 95% confidence level means that there is a 95% probability or confidence that the true proportion of a certain feature (e.g., data sharing, security guideline availability, etc.) in the entire population of that country falls within the calculated confidence interval.

A 95% confidence level is commonly used in statistics to express a reasonably high degree of confidence in the estimated values or proportions, but it is important to note that it does not provide absolute certainty. There is still a 5% chance that the true population parameter might fall outside the calculated confidence interval.

From these confidence levels, it can be inferred that these countries, and particularly those with a higher confidence level, have made significant investments and improvements in their data infrastructure to support NGS implementation. This includes establishing the necessary hardware, software, storage capabilities and data management systems required for processing and analysing NGS data.

These are countries that have developed robust networks and collaborations among research institutions, hospitals and other healthcare stakeholders to facilitate efficient sharing and integration of NGS data, and that have implemented appropriate data security measures and adhered to relevant data protection regulations to ensure the privacy and confidentiality of genomic data. However, it must be highlighted that these results are based on the perception of the interviewees rather than on objective data.

3.2. A Survey of Patients

The analysis of the survey involving patients and citizens focused on three areas: cancer types, countries and regions. The survey questions can be found in the Supplementary Materials. The objective of the analysis was to examine the participants' viewpoints on priorities and expectations concerning aspects of cancer research. The findings of the analysis can be summarised as follows:

3.2.1. Cancer Types

Correlation analysis values between the age groups 16–44 and 45 to 70+ for different types of cancer reveal important findings. For prostate cancer, there was a consistently high positive correlation (0.5896 to 0.9961) between the importance of measures across both age groups. The same holds true for breast cancer (0.8692 to 0.9981), indicating a shared understanding of preventive measures across different ages. There was some variability in the correlation values (0.4759 to 0.9903) for other gastrointestinal cancers, indicating potential differences in perceived importance among age groups. However, strong positive correlations were observed for lung (0.7435 to 0.9967) and colon cancer (0.6405 to 0.9938) (Table 5). Overall, the analysis suggests a generally positive and significant relationship between age groups regarding the importance of preventive measures for various cancer types. These findings can guide healthcare professionals and policymakers in developing targeted and effective cancer prevention strategies that consider the perspectives and needs of different age groups.

Table 5. Correlation among the responses of different age groups.

Measure ID	Pillar ID	Correlation among Age Group 16–44 and 45 to 70+					Measure ID	Pillar ID	Correlation among Age Group 16–44 and 45 to 70+				
		Prostate Cancer	Breast Cancer	Other GI Cancer	Lung Cancer	Colon Cancer			Prostate Cancer	Breast Cancer	Other GI Cancer	Lung Cancer	Colon Cancer
1	1	0.9262729768	0.9763985608	0.8487446815	0.8646804113	0.6405452936	19	4	0.9293215856	0.9708945851	0.8900284863	0.9630879641	0.9093697261
2	1	0.9792369451	0.9518528105	0.4759633346	0.9699668008	0.8338111971	20	5	0.5895769129	0.9204739065	0.6392720318	0.7766158214	0.7804118135
3	1	0.9426662451	0.9622156264	0.8555635306	0.9198346707	0.940235275	21	5	0.8692067099	0.9672213565	0.6337694342	0.9050656066	0.9825607014
4	1	0.9551150096	0.9933345226	0.5760184329	0.9967667326	0.9522085247	22	5	0.7280205052	0.9660436937	0.6657540493	0.9381969473	0.9496349292
5	1	0.7173377939	0.9764060315	0.6492344541	0.996724258	0.9482153027	23	5	0.9356056042	0.9047858304	0.9802848037	0.8812820747	0.9526675178
6	1	0.8261856174	0.9825588025	0.8401680504	0.9789263674	0.9834989102	24	5	0.9181395839	0.8695867927	0.9633134713	0.9772372362	0.9848702577
7	2	0.7510020045	0.9788963057	0.9317497214	0.9671450826	0.9654771736	25	6	0.9231612202	0.9474972496	0.8486684248	0.9340932514	0.9272500256
8	2	0.9796940745	0.9958650548	0.9511127087	0.9645230348	0.9893688733	26	6	0.9578051962	0.978148731	0.9903266083	0.9745558381	0.9867799415
9	2	0.8892565366	0.9885884427	0.6691886215	0.982713894	0.9206295003	27	6	0.599169005	0.9939258201	0.8604007285	0.7434563018	0.8945464718
10	2	0.9961325275	0.9924888697	0.8475868968	0.9905950025	0.9824487063	28	6	0.9713573622	0.9400245527	0.8076071442	0.8600469129	0.9874276464
11	2	0.9578967429	0.994784039	0.7615333941	0.9842980462	0.9223883191	29	6	0.9398071268	0.9131692578	0.794661488	0.983620699	0.9867954289
12	3	0.9282676528	0.9940364689	0.8432993811	0.7415841485	0.985889568	30	6	0.7463822355	0.9734306348	0.8791278938	0.9260381343	0.9937876573
13	3	0.8256412638	0.9962001905	0.7287986972	0.9681373549	0.8816925665	31	7	0.8674952622	0.9815228558	0.7463517925	0.9298557579	0.9092466457
14	3	0.8459105317	0.9977314405	0.6085252566	0.9964173969	0.9738061765	32	7	0.9427408481	0.9928073176	0.7627127698	0.955390757	0.9635074976
15	4	0.9112157654	0.9568390514	0.8861469462	0.9899033754	0.9738545441	33	7	0.9346195356	0.9891003526	0.8330863022	0.9875066023	0.9859769052
16	4	0.9334275392	0.9670211012	0.8907986682	0.8890884822	0.9467274786	34	7	0.944349355	0.9981096555	0.7635590272	0.9703894361	0.975524558
17	4	0.9832343342	0.9683571491	0.7789808377	0.985301329	0.9079136585	35	7	0.8242193875	0.996571449	0.8553378061	0.9984137052	0.8889063933
18	4	0.9130407079	0.9601213137	0.7635590272	0.9902727838	0.9746393406							

ANOVA—Cancer Types

The analysis of ANOVA results reveals interesting findings for different age groups. For the age group aged 16–44, there were no significant differences in the mean scores among the different cancer types (F = 0.566, $p = 0.689$). This suggests that within this age group, the perceived importance of cancer prevention measures related to prostate cancer, breast cancer, other GI cancers, lung cancer and colon cancer is similar. The variances within each group are also relatively small, indicating consistency in responses.

On the other hand, for the age group aged 45–70+, the ANOVA results show a borderline significant difference in the mean scores among the different cancer types (F = 2.064, $p = 0.110$). Although the p-value is slightly above the conventional threshold of 0.05, it suggests a trend towards significance (Table 6). This indicates that within this age group, there might be some variations in the perceived importance of cancer prevention measures across different cancer types. Despite this, the variances within each group remain relatively small, implying consistency in responses within each specific cancer type.

Overall, these findings suggest that for the younger age group (16–44 years), the perceived importance of cancer prevention measures is relatively consistent across different cancer types. However, for the older age group (45–70+ years), there may be some variations in the perceived importance across different cancer types, although these differences are not statistically significant.

These insights can be valuable for healthcare professionals and policymakers in tailoring cancer prevention strategies to effectively address the needs and priorities of different age groups.

t-Test

The t-test results reveal variations in the perceived importance of cancer prevention measures between different age groups for specific cancer types.

For prostate cancer, individuals in the 16–44 age group (mean score: 8.746) perceived prevention measures as significantly more important compared to those in the 45–70+ age group (mean score: 8.489) (t = 3.307, $p < 0.05$).

No significant difference was observed in the perceived importance of breast cancer prevention measures between the 16–44 age group (mean score: 8.607) and the 45–70+ age group (mean score: 8.584) (t = 0.724, $p > 0.05$).

Regarding other gastrointestinal (GI) cancer, individuals in the 16–44 age group (mean score: 8.880) perceived prevention measures as significantly more important than those in the 45–70+ age group (mean score: 8.427) (t = 5.700, $p < 0.05$).

For lung cancer, individuals in the 45–70+ age group (mean score: 8.819) perceived prevention measures as significantly more important than those in the 16–44 age group (mean score: 8.664) (t = -3.724, $p < 0.05$).

Similarly, individuals in the 16–44 age group (mean score: 8.853) perceived colon cancer prevention measures as significantly more important compared to those in the 45–70+ age group (mean score: 8.725) (t = 2.424, $p < 0.05$) (Table 7).

In summary, the *t*-test results indicate that age plays a role in individuals' perceptions of the importance of prevention measures for specific cancer types. For prostate, other GI, lung and colon cancers, there were significant differences in perceived importance between the age groups, whereas no significant difference was observed for breast cancer.

Table 6. ANOVA for different cancer types.

ANOVA Age 16–44 Years							**ANOVA Age 45–70+ Years**						
Groups	**Count**	**Sum**	**Average**	**Variance**			**Groups**	**Count**	**Sum**	**Average**	**Variance**		
Prostate Cancer	7	61.19533333	8.742190476	0.3029254392			Prostate Cancer	7	59.564	8.509142857	0.08881862434		
Breast Cancer	7	60.42	8.631428571	0.1110049524			Breast Cancer	7	60.258	8.608285714	0.05729627513		
Other GI Cancer	7	62.406	8.915142857	0.1186940317			Other GI Cancer	7	59.20866667	8.458380952	0.07387020106		
Lung Cancer	7	61.02933333	8.71847619	0.1908039577			Lung Cancer	7	62.08666667	8.86952381	0.1601175873		
Colon Cancer	7	62.07333333	8.867619048	0.09735168254			Colon Cancer	7	61.13866667	8.734095238	0.09707843386		
ANOVA							ANOVA						
Source of Variation	SS	df	MS	F	*p*-value	F crit	Source of Variation	SS	df	MS	F	*p*-value	F crit
Between Groups	0.3717172571	4	0.09292931429	0.5661036276	0.6891235703	2.689627574	Between Groups	0.7879572571	4	0.1969893143	2.064093751	0.1104958938	2.689627574
Within Groups	4.924680381	30	0.1641560127				Within Groups	2.86308673	30	0.09543622434			
Total	5.296397638	34					Total	3.651043987	34				

Table 7. *t*-test for each cancer type between different age groups.

	Prostate Cancer (16–44 Years)	**Prostate Cancer (45–70+ Years)**		**Breast Cancer (16–44 Years)**	**Breast Cancer (45–70+ Years)**		**Other GI Cancer (16–44 Years)**	**Other GI Cancer (45–70+ Years)**
Mean	8.746857143	8.488571429	Mean	8.607428571	8.584	Mean	8.88	8.427428571
Variance	0.402257479	0.1218890756	Variance	0.1290843697	0.08253647059	Variance	0.2417411765	0.155554958
Observations	35	35	Observations	35	35	Observations	35	35
Pearson Correlation	0.7013193955		Pearson Correlation	0.8473585623		Pearson Correlation	0.4554390297	
Hypothesised Mean Difference	0		Hypothesised Mean Difference	0		Hypothesised Mean Difference	0	
Df	34		df	34		df	34	
t Stat	3.306532101		t Stat	0.7235750693		t Stat	5.699785618	
P(T <= t) one-tail	0.001118223344		P(T <= t) one-tail	0.237137899		P(T <= t) one-tail	0.000001057268417	
t Critical one-tail	1.690924255		t Critical one-tail	1.690924255		t Critical one-tail	1.690924255	
P(T <= t) two-tail	0.002236446687		P(T <= t) two-tail	0.4742757979		P(T <= t) two-tail	0.000002114536834	
t Critical two-tail	2.032244509		t Critical two-tail	2.032244509		t Critical two-tail	2.032244509	
	Lung Cancer (16–44 Years)	Lung Cancer (45–70+ Years)		Colon Cancer (16–44 Years)	Colon Cancer (45–70+ Years)			
Mean	8.664	8.819428571	Mean	8.853142857	8.724571429			
Variance	0.2763952941	0.2562937815	Variance	0.1428457143	0.1325431933			
Observations	35	35	Observations	35	35			
Pearson Correlation	0.8861803253		Pearson Correlation	0.6430274191				
Hypothesised Mean Difference	0		Hypothesised Mean Difference	0				
Df	34		df	34				
t Stat	−3.72407529		t Stat	2.424455364				
P(T <= t) one-tail	0.0003542980939		P(T <= t) one-tail	0.01039868626				
t Critical one-tail	1.690924255		t Critical one-tail	1.690924255				
P(T <= t) two-tail	0.0007085961878		P(T <= t) two-tail	0.02079737252				
t Critical two-tail	2.032244509		t Critical two-tail	2.032244509				

3.2.2. Country-Wise Correlation

The correlation analysis reveals interesting patterns and similarities in the perceived importance of measures among different countries. Belgium demonstrated positive correlations with France (0.7499), Germany (0.7373), Italy (0.8759) and Luxembourg (0.8158), suggesting a degree of agreement in their perception of measure importance. France, in turn, showed strong positive correlations with Germany (0.8760) and Italy (0.7552), indicating shared perspectives on the importance of measures. Italy exhibited strong positive correlations with multiple countries, including Belgium (0.8759), France (0.7552), Germany (0.7646), Hungary (0.8178) and Luxembourg (0.5697), suggesting a consensus on the significance of measures among these nations. Similarly, Luxembourg displayed strong positive correlations with Belgium (0.8158), France (0.8668), Germany (0.8462), Italy (0.5697) and the Netherlands (0.7897), indicating a similar perception of measure importance between Luxembourg and these countries. The Netherlands showed moderate positive correlations with Belgium (0.7832), France (0.8425), Germany (0.8188) and Luxembourg (0.7897), suggesting a level of alignment in their perceived importance of measures. Additionally, other countries like Bulgaria, Greece, Hungary, Portugal and Spain exhibited moderate positive correlations with certain countries, implying some degree of similarity in their perception of measure importance (Table 8). Overall, these findings highlight patterns of agreement and consensus on the importance of measures among certain countries, which can be useful for fostering collaboration and cooperation in addressing and prioritising measures.

ANOVA—Country-Wise

The ANOVA analysis revealed significant differences in the perceived importance of measures among the countries ($F = 10.0396$, $p < 0.001$). Portugal had the highest average score (4.5537), indicating a strong perception of importance, while Belgium (4.2223) and the Netherlands (4.1266) had lower average scores. The variance values indicated less variability in responses for countries like Portugal (0.0232), Romania (0.0159) and Hungary (0.0181), suggesting a higher level of agreement. Conversely, countries with higher variance, such as Luxembourg (0.0616), Belgium (0.0621) and Germany (0.0499), showed more diverse opinions (Table 9). These findings emphasise the variations in perspectives and priorities across countries regarding the importance of measures.

3.2.3. Region-Wise Correlation

The correlation analysis of measures for cancer treatment across different regions reveals important insights into the similarities and agreements in the perceived importance of these measures. The findings indicate significant agreement and similarity between certain regions. The Western and Southern regions showed a strong positive correlation (0.9018), suggesting a high level of similarity in their assessment of the measures. Similarly, the Southern and Eastern regions demonstrated a strong positive correlation (0.9251), indicating significant agreement in the perceived importance of measures. Moderate levels of agreement were observed between the Western and Northern regions (0.7202), as well as between the Southern and Northern regions (0.7969). The Eastern region also displayed positive correlations with the Western (0.8189), Southern (0.9251) and Northern (0.8239) regions, indicating varying degrees of similarity and agreement (Table 10). These findings provide valuable insights into the regional perspectives on effective cancer treatment measures, which can inform the development of targeted strategies and interventions for cancer care.

Table 8. Correlation among the responses of participating countries.

Correlation of Measures	Belgium	Bulgaria	France	Germany	Greece	Hungary	Italy	Luxembourg	Netherlands	Portugal	Romania	Slovakia	Spain
Belgium	1	0.6475557544	0.7498715593	0.7373399003	0.5966926059	0.6820707105	0.8758841021	0.8158282088	0.7832400965	0.7592304592	0.6411849041	0.7807426551	0.7740452942
Bulgaria	0.6475557544	1	0.5872358953	0.526827931	0.6416441335	0.6522617738	0.7275400968	0.651953271	0.5424191801	0.7563903232	0.5581737268	0.497672728	0.5682001369
France	0.7498715593	0.5872358953	1	0.8760069617	0.6696757517	0.6204217458	0.7552368839	0.8668425773	0.8424594551	0.8202164339	0.3636101418	0.726664892	0.8093951744
Germany	0.7373399003	0.526827931	0.8760069617	1	0.5909595653	0.6856612166	0.7646475056	0.8462114174	0.8188253529	0.8183372714	0.4183946737	0.7588983554	0.8298239223
Greece	0.5966926059	0.6416441335	0.6696757517	0.5909595653	1	0.69191804	0.7047573668	0.6330712976	0.5210158628	0.7177081717	0.3419602124	0.5174391845	0.5274675803
Hungary	0.6820707105	0.6522617738	0.6204217458	0.6856612166	0.69191804	1	0.8178145204	0.5697028129	0.6202496596	0.7811291529	0.6693190159	0.6379146628	0.7479369975
Italy	0.8758841021	0.7275400968	0.7552368839	0.7646475056	0.7047573668	0.8178145204	1	0.8158654563	0.7377974028	0.8558434446	0.6707957314	0.7731998664	0.8771925745
Luxembourg	0.8158282088	0.651953271	0.8668425773	0.8462114174	0.6330712976	0.5697028129	0.8158654563	1	0.7896559606	0.7647657601	0.460745273	0.7854106064	0.8253155835
Netherlands	0.7832400965	0.5424191801	0.8424594551	0.8188253529	0.5210158628	0.6202496596	0.7377974028	0.7896559606	1	0.7584418	0.4832417907	0.7347269057	0.7454833323
Portugal	0.7592304592	0.7563903232	0.8202164339	0.8183372714	0.7177081717	0.7811291529	0.8558434446	0.7647657601	0.7584418	1	0.5145866079	0.6896646652	0.8150854327
Romania	0.6411849041	0.5581737268	0.3636101418	0.4183946737	0.3419602124	0.6693190159	0.6707957314	0.460745273	0.4832417907	0.5145866079	1	0.5951574127	0.611582652
Slovakia	0.7807426551	0.497672728	0.726664892	0.7588983554	0.5174391845	0.6379146628	0.7731998664	0.7854106064	0.7347269057	0.6896646652	0.5951574127	1	0.7522836171
Spain	0.7740452942	0.5682001369	0.8093951744	0.8298239223	0.5274675803	0.7479369975	0.8771925745	0.8253155835	0.7454833323	0.8150854327	0.611582652	0.7522836171	1

Table 9. ANOVA for different countries.

Groups	Count	Sum	Average	Variance		
Belgium	35	147.78	4.222285714	0.06212991597		
Bulgaria	35	149.16	4.261714286	0.04168521008		
France	35	150.01	4.286	0.04938941176		
Germany	35	154.26	4.407428571	0.04990201681		
Greece	35	151.9	4.34	0.03373529412		
Hungary	35	149.88	4.282285714	0.01812991597		
Italy	35	151.66	4.333142857	0.01771042017		
Luxembourg	35	151.68	4.333714286	0.06163579832		
Netherlands	35	144.43	4.126571429	0.05454672269		
Portugal	35	159.38	4.553714286	0.02323579832		
Romania	35	152.54	4.358285714	0.01585579832		
Slovakia	35	150.79	4.308285714	0.03932638655		
Spain	35	155.53	4.443714286	0.0318005042		
ANOVA						
Source of Variation	SS	df	MS	F	*p*-value	F crit
Between Groups	4.625164835	12	0.3854304029	10.03959922	0	1.774100948
Within Groups	16.96882857	442	0.03839101487			
Total	21.59399341	454				

Table 10. Correlation among the responses of patients from different regions.

Measure Correlations	Western	Southern	Northern	Eastern
Western	1			
Southern	0.9018220214	1		
Northern	0.7201564076	0.7969578047	1	
Eastern	0.818921507	0.9250914256	0.8238586252	1

ANOVA—Region-Wise

The ANOVA analysis examines the average scores of cancer treatment measures across the Western, Southern, Northern and Eastern regions. The average scores for these regions were 4.28, 4.377, 4.277 and 4.299, respectively. The variances within each group were relatively low, ranging from 0.019 to 0.092, indicating consistency in the scores within each region. The ANOVA results indicate that there are no significant differences in the means of the groups, as the *p*-value (0.1601) is greater than the significance level (e.g., $\alpha = 0.05$) (Table 11). This suggests that, on average, the regions had similar perceptions and evaluations of the cancer treatment measures. However, it is important to consider other factors that may influence these assessments. Overall, the findings emphasise the importance of considering regional variations when developing and implementing cancer care strategies.

Table 11. ANOVA for different regions.

Groups	Count	Sum	Average	Variance		
Western	35	149.8	4.28	0.04678235294		
Southern	35	153.21	4.377428571	0.02011966387		
Northern	35	149.7	4.277142857	0.09166218487		
Eastern	35	150.46	4.298857143	0.01865747899		
ANOVA						
Source of Variation	SS	df	MS	F	*p*-value	F crit
Between Groups	0.232385	3	0.07746166667	1.74835644	0.1600884797	2.671177951
Within Groups	6.025537143	136	0.04430542017			
Total	6.257922143	139				

3.3. A Survey to Healthcare Professionals

The questionnaire created for experts had 63 respondents from basic clinical labs/research centres, clinical cancer centres and comprehensive cancer centres. Answers revealed that 88.89% of respondents from basic clinical labs and research centres did not share genomic data with other institutions in the same country or cross-border compared to comprehensive cancer centres, where this percentage was 40%. The majority of respondents from clinical cancer centres and comprehensive cancer centres used genomic data for both research and clinical trials. Most respondents from all three levels of centres indicated that before involving patients/citizens in NGS testing, they provided information regarding the limitations, type of analysis, risks and benefits of the test, and that after testing they provided a report on any positive biomarkers and relevant treatments. Most respondents from all the centres were not familiar with different business models on data, and in comprehensive cancer centres, 14.29% of experts indicated that open access (FAIR = FREE) was the most appropriate model according to them (Table 12).

Table 12. Results of the survey were sent to experts to better assess the uptake and sharing of the genomic data.

Question	Basic Clinical Lab/Research Centre (n = 9)	Clinical Cancer Centre (n = 19)	Comprehensive Cancer Centre (n = 35)	Total
Is your institution sharing genomic data with other institutions in the same country or cross-border?				
No, it is not sharing	88.89%	21.05%	40.00%	41.27%
Yes, at national level	0.00%	47.37%	22.86%	26.98%
Yes, both at the national and cross-border level	11.11%	26.32%	34.29%	28.57%
Yes, cross-border	0.00%	5.26%	0.00%	1.59%
Not available	0.00%	0.00%	2.86%	1.59%
Main purpose of genomic data in your center?				
For research	22.22%	0.00%	8.57%	7.94%
For clinical trials	11.11%	5.26%	5.71%	6.35%
For research and clinical trials	22.22%	78.95%	80.00%	71.43%
Nothing listed	44.44%	15.79%	2.86%	12.70%
Not available	0.00%	0.00%	2.86%	1.59%
Which best describes what information you provide to patients/citizens after involving them in NGS testing?				
No information is provided	11.11%	0.00%	2.86%	3.17%
Report on any positive biomarkers and relevant treatments	44.44%	47.37%	42.86%	44.44%
A summarized NGS testing report	22.22%	26.32%	42.86%	34.92%
Full NGS testing report	22.22%	26.32%	8.57%	15.87%
Not available	0.00%	0.00%	2.86%	1.59%
What type of information do you provide to patients/citizens before involving them in NGS testing?				
No information is provided	11.11%	0.00%	8.57%	6.35%
Limitations of the test	0.00%	5.26%	2.86%	3.17%
Type of analysis	11.11%	0.00%	11.43%	7.94%
Risks and benefits of the test	11.11%	10.53%	25.71%	19.05%
Everything listed here (limitations, type of analysis, risks and benefits of the test)	66.67%	84.21%	51.43%	63.49%

Table 12. *Cont.*

Question	Basic Clinical Lab/Research Centre (*n* = 9)	Clinical Cancer Centre (*n* = 19)	Comprehensive Cancer Centre (*n* = 35)	Total
Do you link data from sequenced genomes to clinical data (Electronic HealthRecords) or other types of data (e.g., biobanks, proteomics...)?				
No, there is no linking	33.33%	21.05%	22.86%	23.81%
Yes, it is done on request	33.33%	15.79%	28.57%	25.40%
Yes, it is done regularly	33.33%	63.16%	48.57%	50.79%
Funding and Allocation of Resources				
For NGS testing used for clinical care for appropriate patients, how are the majority of tests funded for the majority of citizens that receive an NGS result?				
Institution-based research grant/funding	11.11%	5.26%	8.57%	7.94%
National or regional healthcare system	66.67%	84.21%	80.00%	79.37%
Private or public—Supplementary insurance	11.11%	5.26%	11.43%	9.52%
Industry funded	11.11%	5.26%	0.00%	3.17%
Are you familiar with different business models on data? If yes, which one of listed is most sustainable in your opinion?				
All of these, for our type of activity	0.00%	0.00%	2.86%	1.59%
Open access (FAIR = FREE)	11.11%	0.00%	14.29%	9.52%
Channel priced models on data	11.11%	0.00%	11.43%	7.94%
Capacity rationed access	0.00%	5.26%	2.86%	3.17%
Proprietary business model on data	11.11%	10.53%	11.43%	11.11%
None of these	11.11%	5.26%	11.43%	9.52%
I am not familiar	55.56%	78.95%	45.71%	57.14%

4. Discussion

The study's findings on the confidence levels of data infrastructure for NGS in different countries align with previous studies emphasising the importance of robust data infrastructure in personalised medicine [24–27]. These studies highlight the significance of secure data sharing, interoperability and computational resources. The dataset provided valuable insights into ongoing efforts in different countries to establish and enhance their data infrastructure for NGS applications in personalised medicine [28].

Data infrastructure varied across member states (Table 13). In Croatia, national registries collect data on public health priorities and are accessible via the national public health information system. It is mandatory for providers to make pseudo-anonymised cancer data available in the National Cancer Registry. In Hungary, there are different registries, such as the Hungarian Central Statistical Office, which collects data on morbidity and mortality in the population. The National Institute of Health Insurance Fund Management receives data on the provision of health care and the National Cancer Registry offers registration of newly diagnosed cancer patients, follow-up and care monitoring. In the Netherlands, the Netherlands Cancer Registry (NCR) provides data on the care trajectories of people with cancer by registering diagnosis, tumour staging, tumour characteristics and treatments (both procedures and medication received after diagnosis). The French Health Data Hub is born from the political willingness to promote artificial intelligence (AI) in health, identified by the French government as a priority domain where AI technologies could provide a strategic advantage for the nation and for Europe. In Portugal, the National Cancer Registry integrates data from regional cancer registries. The available information includes patient identification, diagnosis, tumour characteristics, treatment and follow-up, including cancer staging, biomarkers and treatment outcomes. Data from

the National Cancer Registry in Poland are not used regularly to assess the quality of cancer care and highlight inequalities. In Italy, regional cancer registries collect and transfer data to the national registry, and the EPICOST Project collects data on cancer costs by region, cancer type and disease stage to support decision making on investment in cancer care. In Denmark, screening reminders are sent automatically via e-Boks, the public digital post box, with instructions on how to participate. The Belgian Cancer Registry provides systematic data collection for all cancer cases. In Germany, epidemiological and survival data about a number of rare cancers are provided in publications based on data provided by the Centre for Cancer Registry Data. In Finland, a new Act on Screening renewed data infrastructure, harmonised data and developed new parameters for the Finnish Cancer Registry. Population-based cancer registries in Spain record all new cancer cases diagnosed in a specific location and are essential information systems to monitor the evolution of cancer and to plan and evaluate cancer control policies. An integrated information system that spans the entire health service is lacking in Ireland. The National Cancer Registry collects information on incidence, staging and treatment in one system, and the Central Statistics Office collects mortality data elsewhere. The Slovenian Cancer Registry provides surveillance data along the whole continuum of cancer care. Data links with other national health care and administrative databases are facilitated by unique resident identification numbers. In Bulgaria, data infrastructure to monitor the burden of cancer and outcomes of care is not fully operational. There is a lack of systematic collection of data in a national cancer registry in Romania. Since 2019, in Austria, the data have included an encrypted unique patient ID which enables the National Statistics Agency to link data in the Registry with other datasets while adhering to data protection principles [3].

Table 13. Data infrastructure in different member states [3].

Member State	Data Infrastructure	Registry
Croatia	-Pseudoanonymised cancer data—available in the National Cancer Registry -Data integration—works well at the primary care level -Little standardisation of data at the secondary care level	Croatian National Cancer Registry
Hungary	-Data links between the screening registry and national registries facilitate the functioning of national early detection programs -The obstacle—a lack of financial and human resources	Hungarian Central Statistical Office National Institute of Health Insurance Fund Management National Cancer Registry
Netherlands	-Data on diagnostics, follow-up care and survival–collected in cancer registry -Nationwide Pathology Databank provides data on pathological diagnosis	Netherlands Cancer Registry (NCR)
France	-French Health Data Hub—AI technologies could provide a strategic advantage for the nation	The French National Registry of Childhood Cancers (RNCE)
Portugal	-Patient-reported data are not yet embedded in information systems	National Cancer Registry
Poland	-E-health services–have a significant role, more than 60% of the population used remote health services in the first year of the pandemic -The COVID-19 pandemic had a positive impact on the process of ongoing data collection in cancer registries and timely analysis	National Cancer Registry
Italy	-Regional cancer registries collect and transfer data to the national registry	A comprehensive national cancer registry—currently in development
Denmark	-After screening is completed, data are stored in the central registry, comprising a comprehensive set of healthcare data	Highly digitalised Central Person Registry
Belgium	-Systematic data collection for all cancer cases	Belgian Cancer Registry

Table 13. *Cont.*

Member State	Data Infrastructure	Registry
Germany	-Increasing interoperability and use of cancer datasets is a priority	Cancer Registry Data
Finland	-Registry—links sociodemographic data with medical records via unique patient identifiers	Cancer Registry
Spain	-Registries—record all new cancer cases diagnosed in a specific location	Population-based cancer registries
Ireland	-Cancer data collection—becoming increasingly electronic	National Cancer Registry
Slovenia	-Surveillance data along the whole continuum of cancer care are provided	Slovenian Cancer Registry
Bulgaria	-Data infrastructure to monitor the burden of cancer and outcomes of care—not fully operational	National Cancer Registry
Romania	-Lack of systematic collection of data in a national cancer registry	National cancer registry
Austria	-The main data source for the epidemiology, diagnosis and treatment of cancer is the National Cancer Registry	National Cancer Registry

Furthermore, the correlations between cancer prevention measures across different age groups, as well as the ANOVA tests within specific age groups, are consistent with previous research highlighting the importance of consistent awareness and action in cancer prevention [29–35]. These findings emphasise the need for age-specific approaches in developing interventions and educational campaigns for cancer prevention.

The t-tests conducted on different cancer types and age groups reflect variations in perceptions and priorities of cancer prevention, which is in line with previous studies highlighting the influence of age-related factors on attitudes and behaviours toward cancer prevention [36–38]. Understanding these variations can help healthcare professionals and policymakers develop targeted interventions and educational campaigns that address the unique needs and beliefs of each age group.

Similarly, the correlations and ANOVA analysis conducted on measures for cancer treatment across countries and regions demonstrate both similarities and differences in the perceived importance and prioritization of these measures. These findings align with previous research that highlights the influence of cultural beliefs, healthcare systems and patient preferences on the prioritization of cancer treatment measures [39,40]. Understanding these country- and region-specific differences is crucial for tailored interventions and addressing specific health challenges.

4.1. Key Findings

The correlation matrix showcases the interplay between data infrastructure and the priorities identified by healthcare professionals and patients in cancer research. A stronger data infrastructure is notably associated with a heightened emphasis on various research aspects. There is a direct relationship between a robust data infrastructure and a focus on cancer prevention and data sharing. Moreover, it is correlated with an emphasis on understanding treatment sensitivity and resistance, indicating a drive for more precise and effective therapies. Interestingly, while data infrastructure positively influences several research domains, it has a slightly inverse correlation with survivorship and quality of life research, suggesting a nuanced relationship in balancing data infrastructure investments with diverse research priorities. Overall, the data underscore the significant role of data infrastructure in shaping and driving the cancer research agenda, aiding in tailored strategies for more effective cancer care and research.

4.1.1. Infrastructure

The study confirmed earlier findings regarding the wide variation in infrastructure across member states in terms of capacity for secure data sharing, interoperability and computational resources. This means some countries are not in a position to facilitate effective care, more particularly in the personalised medicine that is now increasingly available, in principle at least. However, the findings also provide valuable insights into the data infrastructure's suitability for implementing NGS in light of the significant investments and improvements required in hardware, software, storage capabilities and data management systems, along with data on ongoing national efforts to establish and enhance data infrastructure accordingly. We identified countries that have developed robust networks and collaborations among research institutions, hospitals and other healthcare stakeholders to facilitate efficient sharing and integration of NGS data, and that have implemented appropriate data security measures and adhered to relevant data protection regulations to ensure the privacy and confidentiality of genomic data.

4.1.2. Prevention

In light of the desirability of enhanced public awareness and receptivity to cancer prevention, the study explored how far age-specific approaches were employed in developing interventions and educational campaigns. This exercise revealed variations in the perceived importance of cancer prevention measures between different age groups for specific cancer types. We found that age plays a role in individuals' perceptions of the importance of prevention measures for most cancer types, but not for breast cancer. The correlations between cancer prevention measures across different age groups were consistent with previous research [29–35]. These findings can guide healthcare professionals and policymakers in developing targeted and effective cancer prevention strategies that consider the perspectives and needs of different age groups. Moreover, these findings can support the identification of the next cancer research challenges that need to be prioritised to reduce the burden of cancer and improve the quality of life of patients and survivors.

4.1.3. Treatment

Analysis of measures for cancer treatment across countries and regions demonstrated both similarities and differences in the perceived importance and prioritization of these measures, with data from Portugal indicating a strong perception of importance, rather lower than in, for instance, Belgium and the Netherlands. These findings emphasise the variations in perspectives and priorities across countries regarding the importance of measures and also suggest that these patterns can be useful for fostering collaborations and cooperation in addressing and prioritising measures. Analogous variations were identified in perceptions and evaluations at the regional level of cancer treatment measures, urging the importance of considering regional variations when developing and implementing targeted cancer care strategies, and shaping the future of cancer research initiatives.

4.1.4. Genomics Data Sharing

Given the growing importance of genomic data in the diagnosis and care of cancer, this study also explored to what extent the need for improved data sharing and interpretation practices in genomics is being met. The study also sheds light on the practices of sharing genomic data among healthcare professionals and highlights the need for basic understanding and interpretation of next-generation sequencing (NGS) results by oncologists [41,42]. It found that nearly 9 out of 10 respondents from basic clinical labs and research centres were not sharing genomic data with other institutions in the same country or cross-border, in contrast to comprehensive cancer centres, where this percentage was 40%. It also found that most respondents were not familiar with business models on data (Table 12). These findings support the ongoing efforts to enhance data sharing and interpretation practices in the field of genomics and emphasise the role of comprehensive cancer centres in building powerful data lakes/warehouses for research and development.

4.1.5. Correlation among Studies

The correlation coefficient of 0.699 between data infrastructure and the healthcare professionals' and patients' surveys indicates a strong and positive relationship. This suggests that the quality and capacity of data infrastructure have a significant impact on how healthcare professionals and patients respond in the context of genomics and cancer research.

In terms of sharing genomic data, a robust data infrastructure facilitates seamless sharing and exchange of genomic data both nationally and cross-border. This enhances collaboration and accelerates research efforts, contributing to a more comprehensive understanding of genomics and its implications for cancer prevention, treatment and research.

Regarding the main purpose of genomic data, a well-established data infrastructure ensures that data are utilised effectively for research and clinical trials. It allows for the efficient organization and analysis of data, enabling researchers and healthcare professionals to draw meaningful insights from genomic data, thereby advancing research and treatment strategies.

When involving patients in NGS testing, a strong data infrastructure ensures that comprehensive information, including positive biomarkers, treatments, limitations, risks and benefits, is readily available. This empowers patients to make informed decisions and actively participate in their healthcare journey, fostering a patient-centric approach.

Furthermore, linking sequenced genomic data to clinical records or other data types is facilitated by an effective data infrastructure. This integration supports a holistic understanding of patients' genetic profiles and their medical history, aiding personalised treatment approaches and contributing to improved patient outcomes.

In terms of funding and resource allocation, a well-supported data infrastructure can enhance efficiency in utilising funds for NGS testing. It ensures that tests are appropriately funded through mechanisms such as institution-based research grants or funding from national healthcare systems.

Overall, a strong data infrastructure acts as a foundation for the effective utilization of genomic data, positively influencing healthcare professionals and patients by enabling data sharing, supporting research and clinical trials, empowering patients with comprehensive information, facilitating data integration and optimising funding and resource allocation.

4.2. The Study's Strengths and Limitations

4.2.1. Strengths of the Study

The in-depth analysis of data infrastructure, focusing on secure data sharing, interoperability and computational resources, provides essential insights into the varying capacities of member states. This knowledge can be harnessed to strategically allocate investments and improvements in hardware, software and storage capabilities, optimising data management systems for implementing NGS in personalised medicine. The identification of countries with robust networks and collaborations among healthcare stakeholders showcases successful models for efficient data integration and sharing. Implementing similar strategies in other countries could potentially accelerate advancements in cancer care and research. Moreover, this study's exploration of age-specific approaches in cancer prevention offers a foundational understanding, guiding the development of targeted interventions and educational campaigns tailored to different age groups. The insights into perceptions and prioritizations of cancer prevention and treatment measures across countries and regions are instrumental in fostering cross-border collaborations and addressing specific health challenges. Additionally, the study's focus on genomic data-sharing practices underscores the importance of enhancing data interpretation and sharing within the healthcare community, ultimately fuelling advancements in cancer diagnosis and care. To navigate the identified challenges and utilise the study's findings effectively, collaborative efforts, technological innovation and a strategic approach involving various stakeholders are crucial in promoting the seamless and equitable provision of cancer care.

4.2.2. Limitations of the Study

This study also presents certain limitations that must be acknowledged to ensure its appropriate utilization and interpretation. The study primarily focuses on specific cancer types and measures, potentially limiting the generalization of its findings to a broader range of cancers and treatment strategies. A more extensive and diverse scope in future studies could address this limitation. Furthermore, the study acknowledges challenges in data-sharing practices but may not offer comprehensive solutions to overcome these challenges effectively. Future research should explore and propose strategies to facilitate efficient and secure sharing of genomic data. Lastly, the study emphasises the need for closer collaboration and standardization; however, it may not fully delve into the complexities involved in achieving these goals across diverse healthcare systems and regulatory frameworks. Future research should aim to provide actionable insights and strategies to address these complexities and promote harmonization and collaboration effectively.

5. Conclusions

Overall, this study's findings correlate with previous research in the field, emphasising the importance of robust data infrastructure, age-specific approaches in cancer prevention, variations in perceptions and priorities of cancer prevention and treatment and the need for improved data sharing and interpretation practices in genomics. The study is also in alignment with the 13 recommendations of the Board for the Mission on Cancer [43]. Understanding these correlations and factors can guide the development of targeted interventions, tailored educational campaigns and improved utilization of genomic data for personalised medicine and cancer care.

The study also spotlights some of the associated challenges to be overcome for the emergence of a seamless and equitable provision of cancer care across Europe, including support for translational research, greater clarity over acceptability (and reimbursement) of NGS and liquid biopsy testing, promoting closer collaboration among stakeholders and within individual stakeholder groups—particularly on data sharing, continued investment in data infrastructure, closer standardization of data technology practices, greater regulatory readiness to accept RWE, skill development among practitioners and regulators and recognising the variation among patients/citizens in different countries and regions and different age groups in their attitudes to cancer prevention and treatment.

These challenges are not insuperable if collaborative data sharing is supported by technological innovation [44]. The growing consensus is that cancer is best tackled not as a series of isolated actions but at a strategic level that actively involves all stakeholders—HCPs, of course, and patients (as the emerging scope of personalised medicine permits and demands), but equally researchers, drug developers, civil society organizations and regulatory authorities, as well as policy circles and political decision makers.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/jmp4040021/s1, Survey S1: Survey questions for patients and citizens.

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References

1. European Commission. ECIS—European Cancer Information System. 2023. Available online: https://ecis.jrc.ec.europa.eu/ (accessed on 7 June 2023).
2. World Health Organization. Cancer. 2022. Available online: https://www.who.int/news-room/fact-sheets/detail/cancer (accessed on 7 June 2023).
3. OECD. EU Country Cancer Profiles. 2023. Available online: https://www.oecd-ilibrary.org/social-issues-migration-health/eu-country-cancer-profiles_55f07000-en (accessed on 29 March 2023).
4. Lawler, M.; Davies, L.; Oberst, S.; Oliver, K.; Eggermont, A.; Schmütz, A.; La Vecchia, C.; Allemani, C.; Lievens, Y.; Naredi, P.; et al. The Lancet Oncology Commission European Groundshot-addressing Europe's cancer research challenges: A Lancet Oncology Commission. *Lancet Oncol.* **2022**, *24*, E11–E56. [CrossRef] [PubMed]
5. Kerr, D.; Arnold, D.; Blay, J.Y.; Buske, C.; Carrato, A.; Gerritsen, W.; Peeters, M. The Oncology Data Network (ODN): A Collaborative European Data-Sharing Platform to Inform Cancer Care. *Oncologist* **2020**, *25*, e1–e4. [CrossRef] [PubMed]
6. D'Augè, T.G.; Giannini, A.; Bogani, G.; Di Dio, C.; Laganà, A.S.; Di Donato, V.; Salerno, M.G.; Caserta, D.; Chiantera, V.; Vizza, E.; et al. Prevention, Screening, Treatment and Follow-Up of Gynecological Cancers: State of Art and Future Perspectives. *Clin. Exp. Obstet. Gynecol.* **2023**, *50*, 160.
7. WHO. Cancer Prevention and Control in the Context of an Integrated Approach. 2017. Available online: https://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_R12-en.pdf (accessed on 7 June 2023).
8. European Commission. Europe's Beating Cancer Plan; Communication from the Commission to the European Parliament and the Council. 2023. Available online: https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf (accessed on 7 June 2023).
9. European Commission. European Health Union; Protecting Our Health Together. 2023. Available online: https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/promoting-our-european-way-life/european-health-union_en (accessed on 7 June 2023).
10. Can.Heal. Building the EU Cancer and Public Health Genomics Platform. 2023. Available online: https://canheal.eu/ (accessed on 7 June 2023).
11. Josfeld, L.; Keinki, C.; Pammer, C.; Zomorodbakhsch, B.; Hübner, J. Cancer patients' perspective on shared decision-making and decision aids in oncology. *J. Cancer Res. Clin. Oncol.* **2021**, *147*, 1725–1732. [CrossRef] [PubMed]
12. Franklin, E.F.; Nichols, H.M.; House, L.; Buzaglo, J.; Thiboldeaux, K. Cancer Patient Perspectives on Sharing of Medical Records and Mobile Device Data for Research Purposes. *J. Patient Exp.* **2020**, *7*, 1115–1121. [CrossRef] [PubMed]
13. Steliarova-Foucher, E.; O'Callaghan, M.; Ferlay, J.; Masuyer, E.; Rosso, S.; Forman, D.; Bray, F.; Comber, H. The European Cancer Observatory: A new data resource. *Eur. J. Cancer* **2015**, *51*, 1131–1143. [CrossRef] [PubMed]
14. European Commission. Commission Staff Working Document Impact Assessment Report. Accompanying the Document. Proposal for a Regulation of the European Parliament and of the Council on the European Health Data Space. 2022. Available online: https://health.ec.europa.eu/system/files/2022-05/ehealth_ehds_2022ia_1_en_0.pdf (accessed on 15 May 2023).
15. ATLAS. 2023. Available online: https://biomarkersatlas.com/ (accessed on 9 June 2023).
16. Malapelle, U.; Passiglia, F.; Cremolini, C.; Reale, M.L.; Pepe, F.; Pisapia, P.; Avallone, A.; Cortinovis, D.; De Stefano, A.; Fassan, M.; et al. RAS as a positive predictive biomarker: Focus on lung and colorectal cancer patients. *Eur. J. Cancer* **2021**, *146*, 74–83. [CrossRef] [PubMed]
17. OHDSI. Standardized Data: The OMOP Common Data Model. 2023. Available online: https://www.ohdsi.org/data-standardization/ (accessed on 31 May 2023).
18. *ISO 13972:2022*; Health Informatics—Clinical Information Models—Characteristics, Structures and Requirements. ISO: Geneva, Switzerland, 2022. Available online: https://www.iso.org/standard/79498.html (accessed on 31 May 2023).
19. European Commission. Proposal for a Regulation of The European Parliament and of the Council on the European Health Data Space. 2022. Available online: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A52022PC0197 (accessed on 31 May 2023).
20. IQVIA. Impact of RWE on HTA Decision-Making. 2022. Available online: https://www.iqvia.com/insights/the-iqvia-institute/reports-and-publications/reports/impact-of-rwe-on-hta-decision-making (accessed on 29 March 2023).

21. Solary, E.; Blanc, P.; Boutros, M.; Girvalaki, C.; Locatelli, F.; Medema, R.H.; Nagy, P.; Tabernero, J. UNCAN. eu, a European initiative to UNderstand CANcer. *Cancer Discov.* **2022**, *12*, 2504–2508. [CrossRef]
22. Baumann, M.; Celis, J.; Ringborg, U.; Heitor, M.; Berns, A.; Albreht, T.; Arabadjiev, J.; Boutros, M.; Brandenburg, M.; Canhao, H.; et al. Engaging European society at the forefront of cancer research and care. *Mol. Oncol.* **2023**, *17*, 925–945. [CrossRef]
23. Uncan.eu. 2023. Available online: https://uncan.eu/ (accessed on 19 June 2023).
24. Lovrečić, L.; Maver, A.; Glavač, D. Next-Generation Sequencing Data Management Challenges and Infrastructure Solutions. *Genes* **2019**, *10*, 884.
25. Hulsen, T.; Jamuar, S.S.; Moody, A.R.; Karnes, J.H.; Varga, O.; Hedensted, S.; Spreafico, R.; Hafler, D.A.; McKinney, E.F. From Big Data to Precision Medicine. *Front. Med.* **2019**, *6*, 34. [CrossRef] [PubMed]
26. Horgan, D.; Curigliano, G.; Rieß, O.; Hofman, P.; Büttner, R.; Conte, P.; Cufer, T.; Gallagher, W.M.; Georges, N.; Kerr, K.; et al. Identifying the Steps Required to Effectively Implement Next-Generation Sequencing in Oncology at a National Level in Europe. *J. Pers. Med.* **2022**, *12*, 72. [CrossRef] [PubMed]
27. Horgan, D.; Hamdi, Y.; Lal, J.A.; Nyawira, T.; Meyer, S.; Kondji, D.; Francisco, N.M.; De Guzman, R.; Paul, A.; Bernard, B.; et al. Framework for Adoption of Next-Generation Sequencing (NGS) Globally in the Oncology Area. *Healthcare* **2023**, *11*, 431. [CrossRef] [PubMed]
28. Hammer, M.J. Beyond the Helix: Ethical, Legal, and Social Implications in Genomics. *Semin. Oncol. Nurs.* **2019**, *35*, 93–106. [CrossRef] [PubMed]
29. Smith, R.A.; Andrews, K.S.; Brooks, D.; Fedewa, S.A.; Manassaram-Baptiste, D.; Saslow, D.; Brawley, O.W.; Wender, R.C. Cancer screening in the United States, 2018: A review of current American Cancer Society guidelines and current issues in cancer screening. *CA Cancer J. Clin.* **2018**, *68*, 297–316. [CrossRef]
30. Youlden, D.R.; Cramb, S.M.; Baade, P.D. The International Epidemiology of Lung Cancer: Geographical distribution and secular trends. *J. Thorac. Oncol.* **2008**, *3*, 819–831. [CrossRef]
31. Mandelblatt, J.S.; Arora, N.K.; Wolf, A.M.D.; Dolan, N.C.; Wilson, R.; Taylor, D.H. Cancer risk perception among diverse populations in the United States. *J. Natl. Cancer Inst. Monogr.* **2020**, *55*, 36–45.
32. Jemal, A.; Ward, E.M.; Johnson, C.J.; Cronin, K.A.; Ma, J. Annual Report to the Nation on the Status of Cancer 1975-2014, Featuring Survival. *J. Natl. Cancer Inst.* **2019**, *109*, djx030. [CrossRef]
33. Islami, F.; Chen, W.; Yu, X.Q.; Lortet-Tieulent, J.; Zheng, R.; Flanders, W.D.; Xia, C.; Thun, M.J.; Gapstur, S.M.; Ezzati, M.; et al. Cancer deaths and cases attributable to lifestyle factors and infections in China, 2013. *Ann. Oncol.* **2020**, *31*, 582–589. [CrossRef]
34. Doubeni, C.A.; Corley, D.A.; Quinn, V.P.; Jensen, C.D.; Zauber, A.G.; Goodman, M.; Johnson, J.R.; Mehta, S.J.; Becerra, T.A.; Zhao, W.K.; et al. Effectiveness of screening colonoscopy in reducing the risk of death from right and left colon cancer: A large community-based study. *Gut* **2017**, *66*, 1130–1136. [CrossRef]
35. Davidson, K.W.; Barry, M.J.; Mangione, C.M.; Cabana, M.; Caughey, A.B.; Davis, E.M.; Donahue, K.E.; Doubeni, C.A.; Krist, A.H.; Kubik, M.; et al. Screening for Colorectal Cancer: US Preventive Services Task Force Recommendation Statement. *JAMA* **2021**, *325*, 1965–1977. [PubMed]
36. White, M.C.; Peipins, L.A.; Watson, M.; Trivers, K.F.; Holman, D.M.; Rodriguez, J.L. Cancer prevention for the next generation. *J. Adolesc. Health* **2013**, *52*, S1–S7. [CrossRef] [PubMed]
37. Luszczynska, A.; Pawlowska, I.; Czajkowska, Z.; Knoll, N.; Scholz, U. Social support and quality of life among lung cancer patients: A systematic review. *Psycho-Oncology* **2013**, *22*, 2160–2168. [CrossRef] [PubMed]
38. Walsh, S.; Nelson, C. Cancer prevention in primary care: Strategies for the nurse practitioner. *J. Am. Assoc. Nurse Pract.* **2013**, *25*, 42–49.
39. Borras, J.M.; Albreht, T.; Audisio, R.; Briers, E.; Casali, P.; Esperou, H.; Grube, B.; Hamoir, M.; Henning, G.; Kelly, J.; et al. Policy statement on multidisciplinary cancer care. *Eur. J. Cancer* **2014**, *50*, 475–480. [CrossRef] [PubMed]
40. Williams, C.P.; Miller-Sonet, E.; Nipp, R.D.; Kamal, A.H.; Love, S.; Rocque, G.B. Importance of quality-of-life priorities and preferences surrounding treatment decision making in patients with cancer and oncology clinicians. *Cancer* **2020**, *126*, 3393–3396. [CrossRef] [PubMed]
41. Oberst, S. Bridging research and clinical care—The comprehensive cancer centre. *Mol. Oncol.* **2019**, *13*, 614–618. [CrossRef]
42. Schmid, S.; Jochum, W.; Padberg, B.; Demmer, I.; Mertz, K.D.; Joerger, M.; Britschgi, C.; Matter, M.S.; Rothchild, S.I.; Omlin, A. How to read a next-generation sequencing report—What oncologists need to know. *ESMO Open* **2022**, *7*, 100570. [CrossRef]
43. European Commission. Conquering Cancer, Mission Possible. 2020. Available online: https://research-and-innovation.ec.europa.eu/knowledge-publications-tools-and-data/publications/all-publications/conquering-cancer-mission-possible_en (accessed on 20 June 2023).
44. Horgan, D.; Capoluongo, E.; Dube, F.; Trapani, D.; Malapelle, U.; Rovite, V.; Omar, M.I.; Alix-Panabières, C.; Rutkowski, P.; Bayle, A.; et al. Clouds across the new dawn for clinical, diagnostic and biological data: Accelerating the development, delivery and uptake of personalized medicine. *Diagnosis* **2023**. *ahead of print*. [CrossRef] [PubMed]