



MULTI-tumour based prediction and manipulation of immune **R**esponse

Grant Agreement No: 101136926

D6.1 – Stakeholder engagement plan



**Funded by
the European Union**

MULTIR project has received funding from the European Union's Horizon Europe Research and Innovation Programme under Grant Agreement No 101136926

Document Control Sheet

Start date of project:	1 January 2024
Duration:	48 months
Deliverable Title:	D6.1. Stakeholder engagement plan
Deliverable Type:	Report
Dissemination Level:	PU-Public
Work package:	WP6
Deliverable Leader:	NIPH - Norwegian Institute of Public Health
Deliverable due date:	30 June 2024
Revision history:	V1: 6 March 2024 V2: 21 May 2024
Actual Submission date:	17 June 2024



Executive Summary

This deliverable is related to **T6.1 – Development of a stakeholder engagement plan [Lead NIPH, Participants: EDS, PU, All –]**.

MULTIR aims to explore tumor-host interactions to better predict optimal therapeutic approaches using AI-based tools. Stakeholder engagement is important to understand how different stakeholders perceive the usefulness of AI-based risk prediction approaches in healthcare and foresee their applicability in real life. Stakeholder engagement is also important to foster connections, create trust and buy-in. This deliverable provides an overview of the objectives of stakeholder engagement in MULTIR, key stakeholders to engage, activities to conduct with stakeholders, realistic roles and responsibilities of stakeholders and project partners, as well as expected outcomes.

Considering the multi-dimensionality, inter-disciplinary and innovative nature of MULTIR, the following groups of stakeholders have been identified and will be targeted:

- Scientific community (researchers)
- Major EU initiatives
- Industry
- Healthcare professionals & professional societies
- Policymakers
- Patients, caregivers & patient organizations
- General audience

Main stakeholder engagement activities in MULTIR will include:

- **Dissemination activities:** E.g., the project website, newsletters, videos and flyers, press releases, stakeholder workshops, webinars and conferences. The dissemination activities are briefly described in this document and detailed in the D7.2 Dissemination plan.
- **Consultation activities:** Stakeholder workshops, questionnaires to patients and caregivers, health institutions, clinicians, and pharmaceutical companies as well as individual interviews with representatives from patient organizations and professional societies.
- **Collaboration activities:** Together with key stakeholders, the co-creation of recommendations for the rapid uptake of MULTIR research results and the implementation of AI-based risk prediction approaches in healthcare. This will be done in connection with stakeholder workshops, interviews with key stakeholders, and other relevant MULTIR events and meetings, e.g., meetings of the EU Cancer cluster and meetings with other EU projects.
- **Educational activities:** E.g., the development of practical recommendations and educational tools to increase awareness of risk assessment and protective measures for bladder, lung cancers and melanoma, and educational videos.
- **Stakeholder engagement evaluation:** E.g., through surveys, evaluation forms.

All activities are described in more detail in this deliverable.



Table of Contents

1. Introduction	6
2. Methods	6
3. Overall objectives of stakeholder engagement	7
4. Overarching principles for stakeholder engagement.....	7
5. Groups of stakeholders	8
6. Stakeholder engagement activities	9
6.1 Inform	9
6.2 Consult.....	10
6.2.1 Stakeholder workshops	11
6.2.2 Questionnaires to key stakeholders.....	12
6.2.3 Interviews with key stakeholders	13
6.3 Collaborate	14
6.4 Educate	14
7. Stakeholder engagement charter	15
8. Feedback to stakeholders	15
9. Stakeholder engagement evaluation	15
10. Conclusions	16
11. References	16
12. Appendix	17
Appendix 1: MULTIR Dissemination strategy per stakeholder	17
Appendix 2: MULTIR Stakeholder Engagement Charter (Draft).....	18
Appendix 3: Draft program stakeholder workshop 2024	20
Appendix 5: MULTIR Questionnaires to patients and caregivers (Draft version)	23
Appendix 6: MULTIR Questionnaire for health organizations / clinicians (Draft version) ...	25
Appendix 7: Overview of stakeholder engagement activities in MULTIR.....	27
Appendix 8: List of stakeholders (as of June 204 – under regular update)	28



List of Tables

Table 1: Questionnaires to key stakeholders

Table 2: MULTIR Dissemination strategy per stakeholder

Table 3: Overview of stakeholder engagement activities in MULTIR

Table 4: List of stakeholders



1. Introduction

Stakeholder engagement can help understanding how different stakeholders perceive the usefulness of the research conducted in MULTIR and foresee its practical applicability in real life. Stakeholders are *“individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavor”* [1]. Stakeholder engagement is important to foster connections, create trust and buy-in, and accelerate the uptake of research results.

This deliverable is related to **Task 6.1 – Development of a stakeholder engagement plan**. A stakeholder engagement plan provides an overview of key stakeholders to engage, activities to conduct with stakeholders, as well as objectives of engagement and expected outcomes. MULTIR aims to engage a broad range of stakeholders including patients and patient organizations, caregivers, researchers, healthcare professionals, policymakers at the national and international levels, the European Medicine Agency, the pharmaceutical industry, health insurance companies and the general public.

Stakeholder engagement will commence at the beginning of the project and persist throughout its duration. This will enable stakeholders to shape the project's development, ensuring the effective implementation of its outcomes in healthcare and public health policies. Stakeholder engagement will consist of several types of activities to inform, consult, collaborate with, and educate key stakeholders. We will receive stakeholder perspectives on important issues and developments in MULTIR, discuss strategies to address potential challenges and encourage the adoption of MULTIR outputs. Results will be presented in publicly available reports and publications. We will implement mechanisms such as surveys and evaluation forms shared with stakeholders attending MULTIR events to continuously monitor and evaluate the stakeholder engagement process.

The stakeholder engagement plan describes engagement activities targeting stakeholders. These include dissemination activities, which are briefly mentioned in this document and are more thoroughly detailed in the **D7.2 Dissemination plan**.

The stakeholder engagement plan is a living document and may be modified if feedback from stakeholders indicates that other activities are more relevant, or that other topics than those proposed, may be interesting to explore.

2. Methods

To develop this document, information from the MULTIR project description was first extracted as the document already described engagement objectives and activities in some detail. The information was compiled into a draft stakeholder engagement plan. Then, the WP6 (Stakeholder engagement) and WP7 (Dissemination, outreach and exploitation) teams worked together to further develop the document, and all project partners were invited to contribute with comments and suggestions of key stakeholders to invite in the MULTIR engagement activities. An internet search was also conducted to identify additional relevant stakeholders.



3. Overall objectives of stakeholder engagement

Stakeholder engagement in MULTIR aims to fulfill Objective 6 - Develop strategies and recommendations for wider uptake of the MULTIR outputs.

WP6 (Stakeholder Engagement) has been established to ensure the acceptability and adoption of new technologies and approaches developed in MULTIR, including risk prediction information and risk calculators, by a broad range of stakeholders including patients and patient organizations, caregivers, lay people, healthcare professionals and policymakers. This implies investigating the views of stakeholders regarding such approaches. MULTIR aims at engaging at least 40 key national and international stakeholders (O6-KPI-1) and map lay people's perceptions in at least 4 partner countries (O6-KPI-2).

Specific objectives include:

- Understanding barriers and opportunities for the adoption and implementation of AI-based risk prediction approaches and MULTIR tools via interactions with patients, patient representatives, policymakers, regulators, and healthcare providers.
- Evaluate patients', caregivers' and lay people's readiness to use risk prediction information and tools to adopt healthier lifestyles.
- In partnership with key stakeholders, identify strategies for broad adoption of risk prediction information to support prevention, and
- Develop tools to educate patients, caregivers and lay people in the use of risk prediction information to support behavioral change.
- Share findings and tools with stakeholders for broader dissemination.

WP7 (Dissemination, outreach and exploitation) focuses specifically on dissemination toward various stakeholders to:

- Raise awareness of the project and its role in health promotion and improved management of bladder, melanoma and lung cancers.
- Disseminate novel findings.
- Increase the scientific and societal impact through effective dissemination and communication of project knowledge, standards and results during and after the project duration.

Activities targeting stakeholders will be conducted as a close collaboration between WP6 and WP7 to maximize resource use in the project, and impact.

4. Overarching principles for stakeholder engagement

MULTIR will adhere to the following principles when engaging stakeholders in the project:

- **Flexibility** – MULTIR acknowledges that stakeholders have busy schedules and may have limited resources and availability for various reasons, e.g., patient representatives suffering from medical conditions. Engagement in the project should be on the stakeholders' own terms and sufficiently flexible to enable useful engagement of all parties without requiring stringent commitment. Whenever



possible, MULTIR will propose engagement activities that suit the stakeholder's situations, are not too constraining and are relevant for them.

- **Transparency** – MULTIR aims to maintain open and clear communication about project goals, objectives, methods, and outcomes to build trust among stakeholders. Minutes of meetings, information about project progress and feedback on how stakeholder inputs are used, will be shared with stakeholders on a regular basis. If issues arise (e.g., conflicts), every effort will be put in enabling open discussions and reaching solutions together with the stakeholders involved.
- **Inclusivity** – MULTIR will strive to ensure representation of diverse stakeholders in engagement activities to capture a wide range of voices, perspectives and expertise. Efforts will be made to accommodate the diverse needs, preferences, and circumstances of stakeholders, e.g., wheelchair users, in connection with the organization of stakeholder workshops.
- **Respect** – MULTIR recognizes that stakeholders may have varying viewpoints and will acknowledge such diversity and treat all stakeholders with dignity and respect. Unrespectful communication during MULTIR meetings will not be tolerated.
- **Collaboration**: MULTIR aims to collaborate closely with stakeholders to develop recommendations and strategies that are useful for all parties, and will acknowledge their efforts and contribution.
- **Voluntariness**: Stakeholders who participate in MULTIR activities do so on a voluntary basis, without receiving financial compensation. At any time, and without having to provide any explanation, they can stop participating in the project's activities.
- **Ethical aspects** – MULTIR adheres to ethical principles and guidelines in engagement activities and will respect the stakeholder's autonomy, privacy and confidentiality. Ethics approvals will be obtained whenever needed.

5. Groups of stakeholders

Considering the multi-dimensionality, inter-disciplinary and innovative nature of MULTIR, the following groups of stakeholders have been identified and will be targeted for dissemination and engagement activities:

- Scientific community (researchers)
- Major EU initiatives
- Industry
- Healthcare professionals & professional societies
- Policymakers
- Patients, caregivers & patient organizations
- General audience

A list of potential stakeholders to involve in MULTIR is provided in Appendix. This list is a living document that will be subject to change as the project progresses and new contacts are being established, e.g., in connection with the organization of joint meetings with other projects.



6. Stakeholder engagement activities

WP6 and WP7 envision several types of stakeholder engagement activities in MULTIR to:

- **Inform** stakeholders about the project through communication channels such as e.g., website, newsletter, social media, presentations at conferences and webinars.
- **Consult** stakeholders on different matters throughout the project (e.g., through stakeholder workshops, interviews, questionnaires)
- **Collaborate** with stakeholders on the development of recommendations for the uptake of project results and the implementation of MULTIR tools (e.g., risk prediction tools)
- **Educate** stakeholders to increase health literacy and awareness of new technological developments.

The different types of activities will target one or several groups of stakeholders as described below.

6.1 Inform

Activities to inform various stakeholders about the project's activities and results will primarily be led by WP7 and are described in more detail in the **D7.2 Dissemination plan**. An overview of dissemination strategies per group of stakeholders is also provided in Appendix.

Target groups: All

In short, dissemination activities will include:

- **The development of communication channels including** the project's website (that will provide targeted information to patients, caregivers, clinicians, researchers, industrial actors, policymakers, and the general public), social media platforms (e.g., Instagram, LinkedIn), newsletters, videos, flyers, information brochures, leaflets, press releases, use of TV and radio channels.
- **The establishment of synergies with relevant EU projects** to exchange knowledge, share best practices, stimulate discussions among key players, increase outreach of potential stakeholders and seek for complementarities among projects. As an active member of the "Understanding Tumor-Host Interactions" Cluster within the EU Cancer Mission, MULTIR will collaborate closely with other cluster participants to enhance cancer prevention, treatment and care.
- **The organization of stakeholder workshops** to increase stakeholder awareness on relevant topics and encourage their active engagement in the development of recommendations for the rapid uptake of research results and implementation of risk and treatment response prediction approaches. The workshops will be organized as a collaboration between WP6 and WP7 and will include stakeholders from all the categories identified as relevant to the project. The 1st MULTIR Stakeholder workshop is announced to be held on Wednesday, October 2nd, 2024 in Athens, Greece.
- **The organization of web seminars** in the context of running projects (currently 8 collaborative Projects, including Marie Curie training networks and EU collaborative) of MULTIR members (MOS, BRFAA, UK-E, INS). These web seminars have been running



for more than 5 years and serve as excellent platforms for knowledge exchange, networking, training of young investigators and the coordination of activities among different consortia.

- **The organization of information sessions with industrial stakeholders.** In addition to workshops hosting also industrial sector representatives (e.g., pharmaceutical and biotech companies), tailored information sessions will be arranged specifically for this stakeholder group. These sessions, occurring as required over the final two years of the project, aim to gather feedback on the exploitable outcomes of MULTIR and their potential market implementation.
- **The coordination and dissemination of MULTIR publications,** including a Special Issue of a leading journal in the field with relevant contributions.
- **The coordination of MULTIR participation in national/international conferences** on basic and translational research on bladder and lung cancers, melanoma, cancer in general, systems biology and AI.

6.2 Consult

Consultations will be conducted as a collaboration between WP6 and WP7.

Target groups: patients, caregivers, lay people, patient organizations, healthcare professionals (including professional societies), research groups and policymakers.

One main activity will be to consult with various stakeholders to investigate **barriers and opportunities** for the adoption of AI-based risk prediction tools and risk prediction approaches in healthcare. Various genetic and environmental factors influence risk. Certain risk factors are modifiable through lifestyle changes or preventive measures, highlighting the importance of early detection, screening, and adopting healthy behaviors to reduce cancer risk. Risk prediction information will be an important tool to guide prevention. However, it remains unclear to which extent the use of risk prediction approaches is acceptable among various stakeholders. Consulting stakeholders on this issue will be relevant for **T6.2 Mapping of barriers and opportunities** and **T6.3 Exploration of patients' and lay people's readiness for adoption**.

Specifically, we will aim to investigate stakeholder views on:

- Barriers and opportunities for the use of risk prediction information for prevention and treatment purposes, including the adoption of AI-based tools such as digital applications to predict treatment response based on elements of the tumor-host interaction (e.g., issues related to “black box” and reliability of algorithms, issues of discrimination, trustworthiness of Artificial Intelligence, fair access to healthcare and privacy protection),
- Acceptability of patient stratification approaches based on risk prediction models to guide the choice of treatment by different immunotherapies,
- Usefulness of risk prediction approaches to encourage lifestyle changes,
- Preferred informed consent processes for the conduct of multi-site clinical research involving the use of AI-based tools,



- For regulators: steps needed for the registration of a novel in vitro diagnostic predicting drug response and/or outcome.

To consult stakeholders on these topics, we will conduct the following activities:

6.2.1 Stakeholder workshops

Annual stakeholder workshops will be organized in connection with MULTIR consortium meetings and as a collaboration between WP6 and WP7. The 1st MULTIR Stakeholder workshop is announced to be held on Wednesday, October 2nd, 2024, in Athens, Greece.

The workshops will aim to primarily gather MULTIR researchers, patient organizations, caregivers, EU collaborating networks and projects, healthcare professionals, clinicians, and policymakers. The workshops will provide a unique opportunity for the MULTIR researchers to have open discussions and exchange with various stakeholders. In total, **4 stakeholder workshops** are planned between 2024 and 2027.

The first stakeholder workshop (planned to take place in Athens, October 2nd, 2024) will primarily aim to introduce the project to a selected group of stakeholders, discuss plans for engagement in MULTIR and ask for feedback on such plans, as well as discuss what matters to patients and which barriers and opportunities exist for the adoption of risk prediction strategies in cancer management. The second workshop (2025) will aim to discuss project development with stakeholders and identify most salient challenges. Specific topics to discuss will be decided based on what is most relevant for the project at the time the workshop is being held (e.g., patient molecular phenotyping, data sharing and informed consent for multi-institutional validation studies, use of AI in disease management). During the last two years of the project (2026 and 2027), focus will be put on working closely with stakeholders to develop strategies for the uptake of MULTIR research result and the adoption of risk prediction approaches in healthcare. For each workshop, an organizing committee comprising members of MULTIR, including a representative from the MULTIR partner from where the workshop will take place, will be established to develop a workshop program, invite stakeholders and ensure the practical realization of the workshop.

Priority will be given to inviting local stakeholders in the countries where the workshop takes place to ensure that the views and perspectives from different countries are taken into consideration. While focus will be put on inviting patient organizations, caregivers, EU collaborating networks and projects, clinicians and medical doctors to join the first workshops, efforts will be made to engage policymakers in the workshops toward the end of the project and once concrete research results have been obtained and tools have been developed.

The workshops are planned to last for approximately 2-3 hours depending on the topic of discussion. Evaluation forms will be shared with stakeholders at each workshop to receive some feedback on the usefulness of the workshop as well as suggestions for future events. An example of such form is provided in the Appendix. The stakeholders will also be invited to receive regular updates and participate in other MULTIR activities if they wish to do so (e.g., complete questionnaires, participate in interviews). Workshop minutes will be written and shared with participating stakeholders and a short summary of key points discussed during the workshops will be posted on the MULTIR website, with acknowledgment of stakeholder input.

To facilitate participation, MULTIR will offer to cover travel costs for stakeholders attending MULTIR stakeholder workshops. Drinks and lunches/dinners will be provided for free. No financial compensation will be given to the stakeholders for the use of their time.



6.2.2 Questionnaires to key stakeholders

Several questionnaires will be sent to key stakeholders to collect information regarding their views on the use of AI-based risk prediction tools and other relevant key questions. Focus will be put on their experiences of using such tools, challenges and opportunities they envision that the tools may bring, and steps needed to facilitate implementation. This work will be led by **EDS** (WP6) and **EXEL** (WP7).

Several sets of questionnaires will be shared with key stakeholders as described below and summarized in Table 1.

Table 1 – Questionnaires to key stakeholders

MULTIR partner	EDS	EXEL
Target groups	- Patients/caregivers - Healthcare professionals (e.g., social workers, clinicians)	- Health institutions, clinicians, and pharmaceutical companies
Consultation	- Questionnaires sent maximum 3 times throughout project duration - Separate questionnaires for patients and healthcare professionals - First set of questionnaires sent after the Athens stakeholder workshop in October 2024	- Questionnaires sent maximum 2 times throughout project duration - First set of questionnaires sent after the Athens stakeholder workshop in October 2024
Methods of contact	Questionnaires shared: - Through MULTIR partners - Through patient organizations in the MULTIR network	Questionnaires shared: - Through MULTIR partners - Through professional organizations in the MULTIR network
Numbers reached	- Approx. 500 individuals	- Approx. 50-100 individuals

6.2.2.1 Questionnaires to patients and caregivers

This work will be led by **EDS** (WP6). Questionnaires to patients will be prepared and distributed at first place to patients in the project's participating centers and subsequently patient groups such as bladder cancer patients, lung carcinoma and melanoma patients, their families and caregivers as well as respective patient organizations. The questionnaire will investigate patient needs and expectations as well as willingness to adopt AI-based risk calculators, preparing the ground for further trials post-MULTIR. Focus will be put on exploring readiness in groups of people from different European countries using background variables such as socioeconomic, psychological and lifestyle factors (such as sex/gender, socioeconomic background, risk behaviour, everyday habits). The research will be co-designed in partnership with patient organizations working within bladder and lung cancers and melanoma, and other interested stakeholders. The questionnaire is expected to be sent to more than 500 individuals.

The first version of the questionnaire can be found in the appendix of this deliverable. It will be completed online using the [EU survey platform](#) and translated into the main consortium languages (English, Spanish, Greek, French). In addition, before launching the questionnaire,



experts in the MULTIR consortium and patient associations will be consulted to ensure that the questions are asked in a simple and understandable way for patients. The questionnaire includes socio-demographic variables and multiple-choice questions, as well as open-ended questions on aspects such as expectations, needs and confidence in the possibilities of artificial intelligence.

Coinciding with the first workshop of the MULTIR project, the online questionnaire will be launched and will be open for at least two months to reach the expected number of responses (500 individuals).

6.2.2.2 Questionnaires to health institutions, clinicians, and pharmaceutical companies

This work will be led by **EXEL** (WP7). An expected MULTIR output is the evaluation of the potential impact of MULTIR results on health institutions through questionnaires, which will be published and widely disseminated.

As part of our stakeholder engagement plan, we will be sending an informative questionnaire to health institutions, clinicians, and pharmaceutical companies. This initiative aims to gather critical insights into their perceptions and responses to the project's outcomes, specifically the novel biomarkers for therapy and the AI-prediction tool for drug response. Engaging these stakeholders is pivotal, because they are the primary users and beneficiaries of these innovations, next to the patients. By understanding their needs, expectations, and feedback, we can refine and enhance our project deliverables, ensuring greater acceptance and integration into clinical and pharmaceutical practices. A draft questionnaire is provided in Appendix.

Reaching out to 50-100 individuals across these sectors throughout the project's duration will provide a substantial sample size to capture diverse perspectives. The questionnaire will be initially distributed after the first stakeholder workshop. This targeted approach will allow us to collect valuable data on the practical utility, potential barriers, and overall impact of our research outcomes. The feedback obtained will not only guide the final stages of development, but will also inform our exploitation plan, ensuring that our innovations are effectively commercialized and adopted. Moreover, this engagement will foster stronger relationships with key stakeholders, paving the way for future collaborations and facilitating a smooth transition of our tools from bench to bedside.

6.2.3 Interviews with key stakeholders

Digital individual interviews will be organized to collect more in-depth inputs from various stakeholders located in different countries. This work will be led by **NIPH** (WP6).

Stakeholders present at the MULTIR stakeholder workshops as well as other relevant stakeholders, for instance, members of professional societies, representatives from relevant patient organizations and the MULTIR scientific advisory board, will be invited to contribute. Focus will be put on investigating stakeholder perspectives on main challenges and opportunities regarding the use of AI-based risk assessment and prediction tools and risk score information in healthcare for the prevention and management of cancer. Specific focus will be put on melanoma, lung and bladder cancers and on discussing ethical challenges related e.g., to trust in the reliability of the tools as well as issues of privacy protection, discrimination, equitable access to healthcare and protection from harm. The digital interviews are expected to last approximately one hour and will be a good opportunity for the interviewees to outline



the views and perspectives of the organization they represent, potential concerns and wishes of patients and/or professionals, and necessary future steps.

A draft protocol describing the main objectives of the consultations, and including an interview guide, is currently under development and will be presented at the first MULTIR stakeholder workshop in Athens, Greece, October 2nd, 2024 for inputs and comments from stakeholders. The aim is to conduct approx. 10-20 interviews with representatives from patient organizations and professional societies in the period 2024 to 2026. Time will be spent in 2027 on analyzing and summarizing results. Summary results from the consultation will be described in a report to be posted on the MULTIR website. The stakeholders interviewed will be invited to comment on the report and their contributions will be acknowledged. Results will also be shared with the interviewees for use in their own work.

6.3 Collaborate

Target groups: patients and lay people, patient organizations, healthcare professionals (including professional societies), research groups and policymakers

Stakeholders will be invited to jointly identify and develop recommendations for the rapid uptake of MULTIR research results and tools together with the MULTIR researchers. This collaborative process will primarily take place in connection with the stakeholder workshops but also through other activities such as e.g., interviews, and regular interaction with stakeholders at MULTIR events and other relevant meetings. A core objective is to ensure that the expertise and insights of all stakeholders are valued, and that recommendations developed emerge from the combined impact of everyone involved rather than are a result of isolated efforts.

MULTIR will also collaborate closely with the EU Cancer cluster alongside ELMUMY, HIT-GLIO, GLIOMATCH, THRIVE, ARTURO, and SPACETIME. The purpose of this cluster is to facilitate the exchange of information regarding how each project addresses common issues. To facilitate this exchange, the European Commission has designated five topics of focus: Communication and Dissemination, Addressing Inequalities, Citizen Engagement, Data Management, and Research and Innovation. The MULTIR team will lead on the Communication and Dissemination topic, with EXELIXIS leading the effort. MULTIR project members will participate in the work on the other selected topics. The Cancer Cluster plans for regular meetings for interaction and exchange.

6.4 Educate

Target groups: All.

Educational tools will be developed as a collaboration between PU (WP6) and EXEL (WP7):

- **Practical recommendations and educational tools** will be developed targeting patients, lay people and the general public, in collaboration with WP7 and key stakeholders. Focus will be put on increasing awareness and consciousness for prevention and risk assessment for bladder, lung cancers and melanoma, improving knowledge on the risk for environmental exposure and lifestyle habits such as smoking, diet and physical exercise, and considering protective measures (WP6, PU, Task T6.4, year 4).



- **Educational videos** will be posted on the MULTIR website to inform about the project and tools and methods being used and developed (WP7).

7. Stakeholder engagement charter

The MULTIR WP6/WP7 team has developed a stakeholder engagement charter to be shared with relevant stakeholders, e.g., in connection with stakeholder workshops, that provides information about:

- The scope of stakeholder engagement.
- The types of engagement activities the stakeholders can engage in, and expected requirements in terms of time, resources, and expertise.
- The roles and responsibilities of both project team members and stakeholders.
- Expected outcomes of the engagement and compensation measures.

A draft stakeholder engagement charter is provided in Appendix and will be shared at the first MULTIR stakeholder workshop in Athens, Greece, October 2nd, 2024, for review by the stakeholders.

8. Feedback to stakeholders

It should be useful for stakeholders to engage in MULTIR. The project will ensure that stakeholders participating in our activities receive feedback to foster engagement, build trust, and demonstrate that their inputs are valued and utilized. Feedback will be provided as quickly as possible to stakeholders for each type of engagement activity:

- **Stakeholder workshops:** Minutes of meeting will be shared with stakeholders, who will have the opportunity to provide comments and additional input and use the minutes in their own work. Certificates of attendance will also be provided.
- **Questionnaires to key stakeholders:** Summary results will be provided on the MULTIR website and publicly available reports as early as possible.
- **Individual interviews:** Summary results from the interviews will be shared with the stakeholders through a report and short summaries on the MULTIR website.

In the feedback process, focus will be put on describing insights and recommendations that have emerged from the stakeholder's input, and how these insights will be used to guide future actions, inform research processes, or address concerns raised by stakeholders. Potential limitations or constraints that may impact the implementation of stakeholder feedback, e.g., if certain suggestions cannot be immediately adopted or require further consideration, will also be outlined.

9. Stakeholder engagement evaluation

Procedures will be established to continuously evaluate stakeholder engagement in MULTIR and understand the effectiveness of communication, consultation, collaboration, and the overall impact of involving stakeholders. Rapid surveys will be organised in connection with stakeholder workshops to evaluate stakeholder satisfaction with the engagement process, the clarity of communication, and the perceived value of their contributions. The stakeholders will



also have the opportunity to provide suggestions for how future stakeholder engagement activities can be improved or enhanced to better meet their needs and expectations.

Toward the end of the project, the surveys will also assess the extent to which the project managed to ensure that a diverse range of perspectives have been considered and that all relevant stakeholders have had the opportunity to contribute. During the last year of the project, the MULTIR partners will be invited to join discussions led by WP6 and WP7 to assess the extent to which stakeholder engagement contributed to the overall success of the project, and identify tangible impacts on the research, its applicability, or its potential benefits.

Tools such as the PPEET from the Public and Patient Engagement Collaborative at McMaster University, Canada, will be used as a source of inspiration to develop surveys [2]. An example of evaluation form to be used in connection with stakeholder workshops is provided in Appendix.

10. Conclusions

Stakeholder engagement in MULTIR aims to support the development of strategies for the adoption of AI-based risk prediction approaches and tools to be employed within but also beyond the scope of the MULTIR project. It is expected that stakeholder engagement in MULTIR will contribute to promote knowledge transfer. As stakeholders participate in the project, they gain insights into the processes, challenges, and solutions. This knowledge can be retained and applied to future endeavors, contributing to continuous improvement. Stakeholder engagement in MULTIR will also hopefully create a foundation for collaboration in future projects.

11. References

[1] Deverka PA, Lavalley DC, Desai PJ, Esmail LC, Ramsey SD, Veenstra DL, et al. Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement. *J Comp Eff Res.* 2012;1(2):181–94

[2] McMaster University. Public and Patient Engagement Evaluation Tool (PPEET), Version 2.0, August 2018. URL: [Public and Patient Engagement Evaluation Tool - Public & Patient Engagement \(mcmaster.ca\)](https://www.mcmaster.ca/public-patient-engagement-evaluation-tool)



12. Appendix

Appendix 1: MULTIR Dissemination strategy per stakeholder

Table 2

Stakeholder Group	Dissemination Strategy
Scientific community (researchers)	MULTIR website and social media accounts, project workshops, newsletters, flyers, posters, press releases. Engaging with other research initiatives and groups. Peer-reviewed publications in scientific journals. Participation in conferences and project workshops.
Major EU initiatives	MULTIR website and social media accounts, project workshops, newsletters, flyers, posters, press releases. Engaging with other research initiatives and groups. Peer-reviewed publications in scientific journals. Participation in conferences and project workshops.
Industry	MULTIR website and social media accounts, project workshops, newsletters, flyers, posters, press releases. Publishing peer-reviewed articles. Participation in conferences and project workshops.
Healthcare professionals & professional societies	MULTIR website and social media accounts, project workshops, newsletters, flyers, posters, press releases. Peer-reviewed publications in scientific journals. Participation in conferences and project workshops. Project video.
Policymakers	MULTIR website and social media accounts, project workshops, newsletters, flyers, posters, press releases. Peer-reviewed publications in scientific journals. Participation in conferences and project workshops.
Patients & Patient organisations	MULTIR website and social media accounts, project workshops, newsletters, flyers, posters, press releases. Producing user-friendly videos for online visibility on the website.
General audience	MULTIR website and social media accounts, project workshops, newsletters, flyers, posters, press releases. Producing user-friendly videos for online visibility on the website.



Appendix 2: MULTIR Stakeholder Engagement Charter (Draft)

What is MULTIR?

MULTIR is an EU-project (2024-2028) aiming to improve cancer survival using personalized medicine approaches. The project explores how tumors interact with the body in bladder, melanoma, and lung cancer patients, to enhance understanding of treatment response mechanisms. The project utilizes large clinical and molecular datasets from European patients.

The new knowledge generated in MULTIR will support the development of web-based applications using artificial intelligence to predict response to therapy and outcome based on multiple host and tumor features. An overarching goal is to promote a more strategic therapy utilization and mitigate potential toxic effects of current state-of-the-art therapies like immunotherapy. The project will collaborate with relevant stakeholders to investigate barriers and opportunities for the adoption of such risk and therapy response prediction tools in healthcare. The project is led by INSERM (France) and has 17 partners.

Stakeholders' engagement

Be it researchers, policymakers, healthcare professionals, patients or citizens, all stakeholders are equally important as they hold valuable expertise from their own experience. Patients are particularly crucial stakeholders as they are the most directly concerned by treatment response, side effects and daily management of the disease. They will therefore have a central role in all engagement activities and collaborations and can be assured that their voices will be heard.

Why engage in MULTIR?

- To put your valuable experience and expertise at the service of the wider community.
- To be a part of collaborative research and European health democracy.
- To learn about latest developments in bladder, melanoma, and lung cancers research.
- To advocate for the views and needs of those you represent.
- To collaborate with MULTIR and other stakeholders on the development of strategies for the adoption of risk and treatment response prediction models.
- To gain insight into most pressing issues raised by other stakeholders, and exchange viewpoints and experiences.
- To influence how MULTIR research outputs will be translated into clinical applications and policy.

What are MULTIR engagement activities?

- **Stakeholder workshops** gathering researchers, representatives from patient organizations, healthcare professionals, policymakers, patients and lay people to discuss patient views, and barriers, opportunities and strategies for the adoption of AI-based risk and therapy response prediction models.
- **Questionnaires** to patients, caregivers, patient representatives and healthcare professionals to assess willingness to adopt cancer risk assessment and prediction approaches in healthcare.



- **Individual digital interviews** with representatives from patient organizations and professional societies to discuss in-depth risk and therapy response prediction models.
- Multi-network **web seminars** with other relevant research projects and **information sessions** with industrial stakeholders.
- **Dissemination activities** such as short interviews or Q&A content with stakeholders to be included in the project's newsletter and/or website.

What to expect when participating in a MULTIR engagement activity?

- **Flexibility:** You can engage in activities whenever you want and for as long as you want.
- **Transparency:** You will regularly receive information about MULTIR activities and how your inputs are used, e.g., via minutes of meetings, newsletters and news on the MULTIR website.
- **Inclusivity:** You will meet other stakeholders with various backgrounds, perspectives and expertise.
- **Respect:** All viewpoints are welcome and legitimate; we encourage you to express yours.
- **Collaboration:** Help us develop useful recommendations and strategies; your efforts and contribution will be acknowledged, e.g., in MULTIR reports and publications.
- **Voluntariness:** Your participation in the MULTIR activities is on a voluntary basis, and no financial compensation can be provided for your time. You can withdraw from the project's activities any time and without having to provide an explanation.
- **Ethical aspects:** MULTIR adheres to ethical principles and guidelines and will respect the stakeholder's autonomy, privacy and confidentiality. Ethics approvals will be obtained whenever needed.

Efforts will be made to accommodate the diverse needs, preferences, and circumstances of stakeholders, e.g., wheelchair users, in connection with the organization of stakeholder workshops.

Practical information:

- Whenever possible, lunch and/or dinner will be offered in connection with stakeholder workshops and travel costs will be reimbursed (more information to be provided with invitation).
- Audio uptakes of stakeholder workshops will be taken to facilitate notetaking, given that all participants approve. Your informed consent for participation in MULTIR stakeholder engagement activities will be sought whenever needed.

For any question, please contact:

Isabelle Budin Ljøsne (Stakeholder engagement work package): isabelle.budin.ljosne@fhi.no

Kalliopi Thanopoulou (Dissemination work package): kalliopi@exelixism.com



Appendix 3: Draft program stakeholder workshop 2024

MULTIR Stakeholder workshop

Athens, October 2nd, 2024 - 15.00 to 17.30

What is MULTIR?

MULTIR is an EU-project (2024-2028) aiming to improve cancer survival using personalized medicine approaches. To achieve this, the project will use large clinical and molecular datasets from European patients, advanced computational tools and artificial intelligence (AI) to:

- i) Explore tumor-host interactions. i.e., how tumors interact with the body in bladder, melanoma, and lung cancer patients,
- ii) Model and manipulate these interactions to predict optimal therapeutic approaches.

Research outputs will promote a more strategic therapy utilization and mitigate potential toxic effects of current state-of-the-art therapies like immunotherapy.

MULTIR will also develop web-based applications to predict response to therapy and outcome based on multiple host and tumour features. The applications will be developed in collaboration with patients, members of cancer management guideline committees, and regulators, after rigorous testing *in vivo*, *in vitro*, and *ex vivo*, followed by stability and security validation to ensure trustworthiness.

MULTIR is aligned with the Cancer Mission objectives set forth by the EU. The project is led by INSERM (France) and has 17 partners.

Why participate in the MULTIR stakeholder workshop?

- To learn about new approaches in cutting-edge cancer research and how mechanisms and interactions between cancer and the patients' biological background affect therapy.
- To discuss ethical aspects of medical research, including patient rights, data privacy and confidentiality, data anonymization, and the regulation applying to clinical and research trials.
- To discuss challenges and opportunities brought by the use in healthcare of web-based applications to predict response to therapy and outcome.
- To explore potential engagement activities in MULTIR, influence their design and ensure that stakeholder needs and priorities are addressed.

NB: Participation in the workshop does not require any commitment to engage in MULTIR engagement activities in the future.

Who is this workshop for?

- Representatives from patient organizations working with bladder, melanoma, and lung cancers, as well as other types of cancer.



- Researchers, clinicians, e.g., urologists, oncologists, dermatologists, pulmonologists, and others with an interest in cancer.
- MULTIR consortium members and members of the MULTIR scientific advisory board.

How to prepare for the workshop?

- Participants are invited to reflect upon most salient needs to discuss regarding the use of tools to predict response to therapy and outcome and think whether their organization/institution could collaborate with MULTIR.

Preliminary program

15.00	Welcome and presentation of the organizing team & workshop participants
15.15	The MULTIR project Maria Frantzi, Mosaiques Diagnostics, Germany
15.35	Patient rights in MULTIR research – Consent, data privacy and confidentiality Marta Burgos, Eticas, Spain Tonia Vlahou, Biomedical Research Foundation of the Academy of Athens, Greece
15.50	Round table discussion: What is important to patients & healthcare professionals?
16.20	Engage in MULTIR: Why and how? Isabelle Budin-Ljøsne, Norwegian Institute of Public Health, Norway Marta Burgos, Eticas, Spain Kalliopi Thanopoulou, Exelixis, Greece
16.50	Round table discussion
17:15	Workshop evaluation and wrap-up
17.30	Adjourn

A summary report will be sent out to all workshop participants after the workshop.

Also provide informed consent form with invitations, practical information about the venue, hybrid participation, the consortium dinner



Appendix 4: Stakeholder workshop evaluation form (Draft)



WORKSHOP EVALUATION FORM

for participants in the MULTIR workshop

Workshop Date : _____

Location of Workshop : _____

Please rate how much you agree with the following statements.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The workshop had clearly defined objectives.	☐	☐	☐	☐	☐
We were encouraged to participate and interact.	☐	☐	☐	☐	☐
The topics of the workshop were relevant to me	☐	☐	☐	☐	☐
The material was structured in a clear and understandable manner.	☐	☐	☐	☐	☐
The objectives of the workshop were met.	☐	☐	☐	☐	☐
I am content with having attended the event.	☐	☐	☐	☐	☐
I found the discussions held during the workshop to be engaging.	☐	☐	☐	☐	☐
The event's arrangement provided ample time for anyone wishing to share their opinions.	☐	☐	☐	☐	☐
I knew exactly what was expected of me during the entire event.	☐	☐	☐	☐	☐
The discussion moderators encouraged a balanced perspective on the issues discussed.	☐	☐	☐	☐	☐

We appreciate your participation in the survey.
The MULTIR project



**Funded by
the European Union**



Appendix 5: MULTIR Questionnaires to patients and caregivers (Draft version)

1. Please select your profile

1. Patient
2. Caregiver
3. Health professional

In case you have chosen health professional, please choose your profile

1. General Practitioner
2. Nurse
3. Medical specialist
4. Social Worker
5. Others _____

2. Age

3. Gender:

1. Male
2. Female
3. I prefer not to answer

4. Do you have previous experience using technological devices, (as smartphones, tablets)?

1. Yes
2. No

5. On a scale of 1 to 10 where 0 is not at all and 10 is very much, how confident do you feel about artificial intelligence in the medical field?

Nothing

Very much

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

6. Do you use Internet to search for medical information?

1. Yes
2. No
3. I prefer not to answer



7. On a scale of 1 to 10 where 1 is not at all and 10 is very often, how often do you search for information on Internet?

Nothing

Very often

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

8. Do you use Artificial Intelligence tools (as ChatGPT) for medical purposes?

1. Yes
2. No
3. I prefer not to answer

9. On a scale of 1 to 10 where 1 is not at all and 10 is very often, how often do you use Artificial Intelligence tools for medical purpose?

Nothing

Very often

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

10. Do you consider that you have enough information about the functioning of Artificial Intelligence in the medical field?

1. Yes
2. No
3. I prefer not to answer

11. From your point of view, what do you think would be necessary for the use of artificial intelligence applied to the medical field?

--

Thank you very much for your collaboration



Appendix 6: MULTIR Questionnaire for health organizations / clinicians (Draft version)



MULTIR QUESTIONNAIRE

for Health Organizations / Clinicians

Name :

Type of Organization :
(Hospital / Clinic / Research Institution / etc.)

Experience with Cancer Patients

How many cancer patients does your organization typically serve in a year?

What are the most common types of cancer diagnosed and treated by your organization?

What are the major challenges your organization faces in cancer diagnosis, treatment, or management?

Awareness and understanding of AI in Healthcare

Are you aware of the use of artificial intelligence in healthcare, particularly in cancer prediction and diagnosis? **YES / NO**

How would you rate the organization's understanding of AI technology in healthcare?
POOR / FAIR / GOOD / EXCELLENT

What potential benefits do you see in incorporating AI tools into cancer care?

Opinion on the MULTIR Project's Risk Prediction AI Tool

Are you willing to use an AI tool for predicting your risk of developing cancer?
NOT LIKELY / LIKELY / VERY LIKELY

What criteria would your organization consider when evaluating the adoption of such a tool?

What challenges or barriers do you anticipate in implementing AI tools for cancer risk prediction within your organization?



Collaboration and Feedback

Would your organization be interested in collaborating with the MULTIR project team to test or further develop the AI tool? **YES / NO**

What kind of support or resources would your organization require to facilitate the integration of AI tools into your existing healthcare practices?

Privacy and Ethical Considerations

What are your organization's policies and practices regarding patient data privacy and security?

How important is it for your organization to ensure the ethical use of AI technology in healthcare, particularly in relation to patient data and informed consent?

Additional Comments

Is there anything else you would like to add regarding your organization's perspective on the AI tool for cancer risk prediction, or any specific concerns or suggestions you have?

*We appreciate your participation in the survey.
The MULTIR project*



Appendix 7: Overview of stakeholder engagement activities in MULTIR

Table 3

INFORM	CONSULT	COLLABORATE	EDUCATE
Target groups			
All	Patients and lay people, patient organizations, healthcare professionals (including professional societies), research groups, policymakers	Patients and lay people, patient organizations, healthcare professionals (including professional societies), research groups, policymakers	Patients, lay people and the general public
Activities			
✓ Project website ✓ Newsletters ✓ Videos ✓ Flyers ✓ Information brochures ✓ Leaflets ✓ Press releases ✓ TV and radio channels ✓ Collaboration with relevant projects ✓ Stakeholder workshops ✓ Webinars ✓ Information sessions with industrial partners ✓ Publications ✓ Conferences	✓ Stakeholder workshops ✓ Questionnaires to patients, caregivers, patient representatives and healthcare professionals ✓ Individual interviews with representatives from patient organizations and professional societies	✓ Co-creation of recommendations for the rapid uptake of research results and implementation of risk and treatment response prediction approaches in connection with stakeholder workshops, interviews, and MULTIR events and other relevant meetings ✓ Collaboration with the EU Cancer cluster alongside HIT-GLIO, GLIOMATCH, THRIVE, ARTURO, and SPACETIME	✓ Development of practical recommendations and educational tools to increase awareness of risk assessment and protective measures for bladder, lung cancers and melanoma ✓ Educational videos
Stakeholder engagement evaluation (e.g., surveys, evaluation forms)			

Appendix 8: List of stakeholders (as of June 2024 – under regular update)

Table 4

Stakeholders	Contact person	Country	Comments
Major EU initiatives			
European Initiative to Understand CANcer (UNCAN.eu)		EU level	Will be implemented in 2024 if political approval Will develop cancer data hub and use cases MULTIR aims to develop a healthcare dataspace for integration in the UNCAN.eu database
1+Million Genomes (European Reference Networks)		EU level	
Beyond 1 Million Genomes (B1MG)		EU level	Is helping to create a network of genetic and clinical data across Europe. The project provides coordination and support to the 1+ Million Genomes Initiative
SPECTA		EU level	Integrated clinical research infrastructure to support translational cancer research
European Organisation for Research and Treatment of Cancer (EORTC)		EU level	Coordinates and conducts international translational and clinical research on cancer
EORTC- Melanoma group		EU level	Aims to improve the clinical care of patients suffering with cutaneous or ocular melanoma, and to increase knowledge about melanoma acquisition and progression
The European Melanoma Registry (EUMelaReg)		EU level	Collects real-world data from melanoma patients throughout Europe and securely integrates these datasets in a common database



Knowledge Centre on Cancer		EU level	Aims to foster scientific and technical coordination of EU activities on cancer
Healthy Cloud		EU level	Aims to develop best practices on how to efficiently manage health data.
EOSC-Life		EU level (project ended in 2023)	Aims to create an open collaborative digital space for European Life Science, Biological and Medical research brings together the 13 Life Science 'ESFRI' research infrastructures
Joint Action Towards the European Health Data Space – TEHDAS		EU level (project ended, TEHDAS2 to start in May 2024)	Developed European principles for the secondary use of health data
Innovative Health Initiative (IHI)		EU level	EU public-private partnership funding health research and innovation
EIT Health Knowledge Innovation Community		EU level/ headquartered in Munich	Knowledge and innovation community of the European Institute of Innovation and Technology (EIT).
GENIAL : Understanding gene environment interaction in alcohol-related hepatocellular carcinoma (EU project)	Led by Université libre de Belgique	EU project (HORIZON-MISS-2023-CANCER-01-01)	Consortium with expertise in clinical hepatology and AI to improve diagnosis of ALD-HC Started Jan 2023, ends Dec 2027
LUCIA : Understanding lung cancer related risk factors and their impact	Led by Israel Institute of Technology, Israel	EU project (HORIZON-MISS-2023-CANCER-01-01)	Will develop a toolbox for analysis that will include databases, AI models, wearable devices, sensors and multi-omics. Started Jan 2023, ends Dec 2026
ELMUMY : Elucidation of risk factors and health determinants associated with PROGRESSION of	Led by the National and Kapodistrian University of Athens, Greece	EU project (HORIZON-MISS-2023-CANCER-01-01)	Will integrate epidemiological, clinical and experimental datasets in order to create a molecular model of cellular processes associated with the onset of active MM and response to therapy Started Jan 2023, ends Dec 2026



Monoclonal Gammopathies to Multiple Myeloma			BRFAA, MOS and EXEL are beneficiaries of the ELMUMY project
DISCERN : Discovering the causes of three poorly understood cancers in Europe (renal, pancreatic and colorectal)	Led by Centre international de recherche sur le cancer, France	EU project (HORIZON-MISS-2023-CANCER-01-01)	Focuses on the potential new causal risk factors for these cancers, applying innovative exposomics and proteomics scans, as well as geospatial and environmental exposure information from large-scale epidemiological studies Started Jan 2023, ends Dec 2027
MELCAYA : Novel healthcare strategies for melanoma in children, adolescents and young adults	Led by Fundació de Recerca Clínic Barcelona-Institut d'Investigacions Biomèdiques August Pi i Sunyer (FRCB-IDIBAPS), Spain	EU project (HORIZON-MISS-2023-CANCER-01-01)	Aims to establish the molecular profiles of progression from benign congenital nevi to melanoma. Started Jan 2022, ends Dec 2026
HIT GLIO : Targeting tumour host interactions in paediatric malignant gliomas to reinvigorate immunity and improve radio and immunotherapy efficacy	Led by the Nencki Institute, Poland	EU project (HORIZON-MISS-2023-CANCER-01-01)	Will investigate tumour-host interactions to reveal novel targets allowing to find new ways to eradicate mutated tumour cells, improve efficacy of radiotherapy, and reinvigorate anti-tumour immunity. Started Dec 2023, ends Nov 2027
GLIOMATCH : The malignant Glioma immuno oncology matchmaker towards data driven precision medicine using spatially resolved radio multiomics	Led by KU Leuven, Belgium	EU project (HORIZON-MISS-2023-CANCER-01-01)	Aims to develop a platform built with the help of extensive clinical trials and a data-driven approach.
THRIVE : Tumour host interactions in liver cancer of childhood and adults	Led by the University of Barcelona, Spain	EU project (HORIZON-MISS-2023-CANCER-01-01)	Aims to unravel tumour-host interactions in liver cancer that can define mechanisms of cancer predisposition, tumour onset, progression and biomarkers of response and resistance to current therapies.
Industry			



Merck & Co			Melanoma/lung cancer
Novartis			Melanoma/lung cancer
Roche			Melanoma/lung cancer
Iovance Biotherapeutics			Melanoma
Bristol-Myers Squibb			Lung cancer/bladder cancer
AstraZeneca			Lung cancer
Pfizer			Lung cancer/bladder cancer
Eli Lilly			Lung cancer
Janssen pharmaceutical			Lung cancer/bladder cancer
Tollys			Bladder cancer
Vaxiion Therapeutics			Bladder cancer
Incyte Corporation			Bladder cancer
Asieris Pharmaceuticals			Bladder cancer
UroGen Pharma			Bladder cancer
Veracyte			Bladder cancer
Ferring			Bladder cancer
Photocure			Bladder cancer
Healthcare professionals & professional societies			
European Society For Medical Oncology (ESMO)		EU level	Represents more than 35,000 oncology professionals in 172 countries, ESMO is a reference for oncology education and information.
International Bladder Cancer Network (IBCN)	Sita H. Vermeulen, Head of membership Sita.Vermeulen@radboudumc.nl	International/based in the Netherlands	Aims to improve the diagnosis, prevention, and treatment of bladder cancer through the application of biologic markers. 400 members from academia and industry
EAU (European Association of Urology) Section of Urological Research (ESUR)		EU level	Aims to promote basic and clinical research in the field of urology and related areas. Platform for researchers in different disciplines to improve the coordination of experimental research



European Association of Urology (EAU)		Eu Level	European urologic society
European Association of Dermatooncology (EADO)		EU level	Aims to promote, coordinate and improve clinical and laboratory research activities in the field of skin cancer European and international membership of dermatologists, oncologists and clinical as well as basic research scientists
International Association for the study of lung cancer (IASLC)		International	More than 8,000 lung and thoracic cancer specialists from all disciplines and more than 100 countries.
American Society of Clinical Oncology (ASCO)		USA	Network of nearly 50,000 oncology professionals
American Association for Cancer Research (AACR)		USA	More than 58,000 members residing in 141 countries and territories
British Association of Urological Surgeons (BAU)		UK	Network of medical practitioners in the field of urological surgery
German Society of Urology (DGU)		Germany	5,300 members
European Dermatology Forum (EDF)		Office in Switzerland	Non-profit professional organisation dedicated to improving the healthcare needs of dermatology patients in Europe.
Hellenic Collaborating Oncology Group (H HeCOG)		Greece	Non-profit Scientific Society that counts among its members prominent pathologists-oncologists
Policymakers/Regulators			
European Medicine Agency		EU level/located in Amsterdam	
National competent authorities of the Member States of the European Union (EU) and the	Links to authorities provided on the EMA website .		National competent authorities that are primarily responsible for the authorization of medicines available in the EU that do not pass through the centralized procedure.



European Economic Area (EEA)			
Central Board of Health (KESY)	President: D. Mpoumpas	Greece	
Patients & patient organizations			
All cancers			
European Cancer Patient Coalition (ECPC)			450 member organizations
Hellenic Cancer Federation (ELLOK)		Greece	National umbrella organization of 46 cancer patient associations in Greece, representing all cancers, common and rare, as well as pediatric cancer.
German National Cancer Patient Association – (DKFZ)		Germany	Provides information for all types of cancer Includes a German National Cancer Patient advisory panel
Nederlandse Federatie van Kankerpatiëntenorganisaties (NFK.nl)		Netherlands	The Dutch Federation of Cancer Patient Organizations (NFK) is the umbrella organization of 21 cancer patient organizations.
Irish Cancer Society		Ireland	Community of patients, survivors, volunteers, supporters, health and social care professionals and researchers
Österreichischen Krebshilfe		Austria	Contact point for prevention and early detection of cancer, help for patients and relatives and cancer research
Ligue contre le cancer		Switzerland	Advises, supports and informs people with cancer and their relatives Committed to cancer prevention and screening in a targeted manner and promotes independent cancer research.
Asociación Española contra el Cancer		Spain	To alleviate and prevent, as far as possible, the suffering caused by cancer in people, wherever they live and whatever their personal circumstances.
Grupo Español de Pacientes con Cáncer (GEPAC)		Spain	The Spanish Cancer Patients Group (GEPAC) is made up of 111 organizations with national representation.



Hellenic Cancer Society		Greece	A non-profit organization, founded in 1958 to fight of cancer and provide information on cancer and prevention.
Danish Cancer Society		Denmark	A non-profit organization for cancer patients. Supports cancer research.
Bladder Cancer			
World Bladder Cancer Patient Coalition		Worldwide/located in Belgium	Supports bladder cancer patients worldwide
Danish Bladder Cancer Society		Denmark	Supports bladder cancer patients in Denmark
Living with Bladder and/or Kidney Cancer – Dutch Patient Coalition		The Netherlands	Promotes the interests of bladder cancer and kidney cancer patients and brings people affected by the disease together for peer support
Cancer Vessie France		France	Supports cancer bladder patients and their carers
Selbsthilfe-Bund Blasenkrebs e. V. (ShB)		Germany	Association of people suffering from bladder cancer and their relatives who work on a voluntary basis
Neovida.be		Belgium	Association FOR and BY people diagnosed with BLADDER CANCER Mainly aimed at people with a replacement bladder
Cáncer Vejiga España		Spain	Association of people suffering from bladder cancer and their relatives
Asociación Española de Enfermedades Urológicas y Litiasis (AEEUYL)		Spain	Association of people suffering from bladder cancer and their relatives
Melanoma			
The Global Melanoma Coalition		International	Gathers many patient organizations, universities and professional societies worldwide
Melanoma Patient Network Europe		Sweden	Volunteer network addressing problems faced by European melanoma patients. Their work is supported by MPNEsupport, a non-profit organization registered in Sweden



Melanomforeningen		Norway	Association for people who have or have had melanoma / melanoma, their relatives and other interested parties. Works to support patients and next of kin through information, guidance and exchange of experiences with others in the same situation.
FRANCE ASSO Cancer et Peau		France	Built by patient and their families
Melanominfo Deutschland	Chairmen: Astrid Doppler Katharina Kaminski	Germany	Focuses on online-based patient exchange
Lung cancer			
Lung Cancer Europe (LuCE)		EU level/located in Bern, Germany	Work to destigmatise the disease and ensure that those impacted by lung cancer get the care they need to achieve the best possible outcomes.
Global Lung Cancer Coalition (GLCC)		Worldwide	Comprises 43 non-government patient organisations from 30 nations
De l'Air!		France	Patient organization working for prevention and early detection of lung cancer
Cáncer Pulmón España		Spain	Lung Cancer Spain is the division of the Spanish Cancer Patients Group (GEPAC) aimed at providing information and support to lung cancer patients and their families. Its aim is to offer quality and accessible information to better understand the disease and to play an active role in decision-making.
Patientforeningen Lungekræft		Denmark	
Longkanker Nederland		The Netherlands	Lung Cancer Netherlands is the professional patient organization that stands up for patients, families and surviving relatives.
FairLife Lung Cancer Care		Greece	Supports and represents all lung cancer patients in Greece, as well as their families and caregivers.



Scientific community (Researchers, research groups)			
Centro Nacional de Enfermedades Oncológicas (CNIO)		Spain	Its goal is to develop new ways to prevent, diagnose and treat cancer. Has a world-leading research groups and a drug discovery programme.

