European Commission

LUCIA

LUng Cancer-related risk factors and their Impact Assessment

LUCIA Understanding Lung Cancer related risk factors and their Impact

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Executive Board Document Sign Off

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Acronyms & Abbreviations

Term	Description
AI	Artificial Intelligence
EC	European Commission
ECPDC	European Cancer Patient Digital Centre
EGA	European Genome-Phenome Archive
EHDS	European Health Data Space
ELPA	European Liver Patients' Association
EU	European Union
GDI	Genomic Data Infrastructure
GDPR	General Data Protection Regulation
HaDEA	European Health and Digital Executive Agency
MTAs	Material Transfer Agreements

Executive summary

This report provides a summary of the conclusions from the second annual meeting of the "Understanding” (risk factors & determinants) cluster within the EU Cancer Mission. The morning sessions featured scientific updates from each project, while the afternoon focused on "Cancer Mission Data Initiatives," presented by a European Commission policy officer, and discussions on topics outlined in the common work plan deliverable. Key points included the importance of data management, AI in cancer research, risk stratification tools, and best practices in healthcare policy implementation. The meeting underscored the importance of collaborative efforts in addressing cancer research challenges and highlighted future plans for enhancing data sharing, citizen engagement, and addressing inequalities in cancer care.

1 Understanding (Risk Factors & Determinants) Cluster Projects

The DISCERN project is part of a consortium of five projects funded by the European Commission through the Horizon Europe program (HORIZON-MISS-2021-CANCER-02-03). These projects aim to achieve the first objective of the Mission Cancer program: to better understand the impact of risk factors and health determinants on the development and progression of cancer. The projects within this cluster are:

- **GENIAL**: Understanding gene-environment interaction in alcohol-related hepatocellular carcinoma.[1]
- **LUCIA**: Investigating lung cancer-related risk factors and their impacts.[2]
- **ELMUMY**: Elucidating risk factors and health determinants associated with the progression of monoclonal gammopathies to multiple myeloma.[3]
- **DISCERN**: Discovering the causes of three poorly understood cancers in Europe (renal, pancreatic, and colorectal).[4]
- **MELCAYA**: Developing novel healthcare strategies for melanoma in children, adolescents, and young adults.[5]

The primary goal of this cluster is to support the mission objective of understanding cancer, create added value, establish a policy feedback loop, and increase the impact of EU funding. Further details on the EU Mission on Cancer and its objectives are provided in the report from the first annual meeting (D7.4).

2 Understanding Cluster Annual Meeting

The DISCERN project organized the second annual meeting of the Understanding (Risk Factors & Determinants) cluster in Lyon, France, on October 15, 2024. The meeting agenda, detailed in Annex 1, commenced with an opening presentation by the project officer from HaDEA. This was followed by representatives from each project presenting the latest scientific updates during the morning sessions.

The afternoon sessions featured a presentation titled "Cancer Mission Data Initiatives" by a policy officer from the European Commission, followed by discussions on topics outlined in the common work plan deliverable, with updates provided by each working group. Presentation slides from both the morning and afternoon sessions have been shared with all participants. A group photo of the participants can be found in Annex 2. This report primarily focuses on the discussions and outcomes of the afternoon sessions.

3 External presentations

3.1 Cancer Mission data initiatives - Angelo Solimini

The presentation provided an overview of the Cancer Mission's ongoing and future efforts related to digital data. Here are the key points:

Introduction to the Cancer Mission

- The Cancer Mission is part of a larger European program, focused on four main objectives: Understanding Cancer, Prevention, Diagnosis and Treatment, and Quality of Life.
- Beyond research and innovation, the mission includes activities for citizen and patient involvement, awareness programs, and initiatives for young cancer survivors.

Importance of Data

- Data is crucial for researchers and innovators but currently dispersed, making it challenging to utilize effectively.

- Patients gaining control over their health data can empower them and improve their quality of life.

Cancer Mission Data Initiatives

1. **UNCAN.eu**
    - A digital platform to support cancer research by providing tools for data access and sharing.
    - It will cover various data categories, including clinical care, preclinical research, socioeconomics, and exposure data.
    - Designed to integrate with existing research infrastructures and the European Health Data Space (EHDS).
    - A major research innovation action with a budget of €30 million aims to implement this platform.
2. **eCancer Working Group:**
    - Provide advice on the implementation, governance, and financing of the UNCAN.eu and ECPDC digital platforms.
    - Established to provide expertise on overcoming barriers to establishing national cancer data nodes.
3. **European Cancer Patient Digital Centre (ECPDC)**
    - A network of national infrastructures aimed at serving patient needs.
    - It will provide information on the patient journey, access to personal health data, and tools for data sharing.
    - Focused on improving the quality of life for cancer patients and survivors.

- Includes modules for information portals, personal health data collection, and data access tools.
- Development will involve patient organizations, health data experts, and EHDS implementers.

Implementation

- The UNCAN.eu platform will be functional from 2027

3.2 EOSC4cancer project - Lifang Liu

This session was cancelled due to the speaker's unavailability.

4 Discussion on the areas for collaboration within the Understanding (risk factors & determinants) cluster

4.1 Research and Innovation

The research and innovation session, led by the MELCAYA project, focused on various scientific and research collaboration areas within the consortium. The session highlighted key points for enhancing cooperation among different projects.

Key Points for Collaboration

1. **Data Management**
    - **Challenges**: Data fragmentation across projects.
    - **Recommendations**:
        - Use standardized protocols for data management.
        - Create a centralized repository for database sharing.

- Adopt common data exchange protocols and GDPR harmonization.
- Establish workshops to develop legal and ethical frameworks.
- Generate centralized European databases for large-scale studies.
- Publish clinical guidelines based on project results.

2. AI in Cancer Research

- **Challenges**: Data protection and access issues.
- **Strategies**:
    - Use federated learning and synthetic data generation.
- **Recommendations**:
    - Implement standardized information and knowledge models.
    - Employ methodologies and tools for data integration, feature extraction and classification.
    - Develop AI models for personalized risk prediction.
    - Use advanced data analytics tools.

3. Omics Analysis and Environmental Factors

The session highlighted the importance of analyzing omics information to identify new genetic predisposing factors and environmental influences on cancer onset.

- **Challenges**: Lack of adequate infrastructure for data analysis and computational capacity.
- **Suggested Actions**:

        - Create a platform for sharing results and comparing data across projects.
        - Hold regular meetings to share findings.

4. **Cross-comparison and integration of risk stratification/early diagnosis tools**
    - **Goal**: Develop AI-based tools for patient risk stratification in different cancer types.
    - **Challenges**: Specific regulations in each country.
    - **Recommendations**:
        - Collaborate on risk stratification and diagnosis tool integration.
        - Develop standardized assessment frameworks.
        - Streamline ethical approval processes.
        - Create a common format for EU ethical submissions.
5. **Sharing of best practices on implementation of healthcare policies**
    - **Challenges**: Complexity of healthcare systems and complex contexts, particularly across different countries.
    - **Suggested Actions**:
        - Create a platform for policy making and collaboration.
        - Hold meetings at project completion to present findings.
        - Develop a framework to facilitate policy implementation.

4.2 Data management

Project Updates on Data Management

The representative of the LUCIA project provided an update on the data management status of the five projects, setting the stage for in-depth discussions on alignment and best practices. The presentation included detailed slides outlining current progress and challenges.

Main Objectives

The primary objectives are to identify commonalities across projects, align best practices, and integrate these into our data management plans. Recent discussions have emphasized the adoption of a unified approach to repositories. This includes the potential for using the same repositories or at least exchanging information on repositories that could be beneficial for our project data within the FAIR data management framework.

Key Focus Areas

1. **Findability**:
    - Utilizing persistent identifiers to ensure data can be easily located.
    - Adopting standard metadata to improve data discovery.
2. **Accessibility**:
    - Evaluating and selecting appropriate repositories for data storage.
    - Discussing access protocols and restrictions to ensure secure and appropriate use of data.
    - Ensuring metadata is available to enhance data accessibility.

3. **Interoperability**:
    - Addressing the challenge of varying standards across different projects.
    - Implementing qualified references to improve data integration and use.
4. **Reusability**:
    - Providing thorough documentation to standardize data practices.
    - Developing comprehensive metadata to facilitate data reuse.

Practical Organization

The group maintains a regular meeting schedule to:

- Share updates on data management practices within individual projects.
- Discuss common issues, such as the operational status of repositories and legal concerns related to data transfer agreements and informed consents.

4.3 Citizen engagement

Importance of Citizen and Patient Engagement

It was emphasized that citizen and patient engagement is crucial across the cluster projects. Patients bring first-hand knowledge about diseases and can provide valuable input in study design and ensure research findings are relevant and meaningful. Citizen participation can enhance decision-making and public understanding of cancer research, helping translate findings into effective interventions.

Revised Citizen and Patient Engagement Strategy:

Adjustments have been made to ensure the relevance and achievability of engagement plans. Key actions identified include:

- Continuing with social media coordination for message dissemination.

- Dropping the podcast series due to resource constraints.
- Creating a comprehensive summary of each cluster project on the contributor website.
- Producing short video interviews with project leads to explain project goals.
- Planning "Nights of Science" events for 2026/27, dependent on successful funding.
- Exploring further funding opportunities for cluster meetings and future projects.
- Developing webinars and online workshops based on a social lab model.

Social Media Collaboration

To consolidate messaging:

- Regular meetings with communication work packages from all projects.
- Quarterly communications meetings with projects taking turns to lead.
- Developing communication calendars and infographics.
- Establishing reporting platforms to evaluate engagement and effectiveness.

Brochure and Video Assets

Existing brochure and video assets explain the cluster projects but require more comprehensive lay summaries for better understanding. Each project will be asked to provide more detailed summaries.

Short Videos and Webinars

- Short videos with project leads will be designed with input from citizen and patient engagement teams to ensure relevance to a lay audience. This task will focus on the later stages of the projects, once the results start to come in.

- Webinars will outline project work and progress, featuring interactive panels for audience engagement.

Social Lab Workshops

Social lab workshops will be organized towards the end of the project's lifecycle to involve systems, policymakers, and patients in developing new practices based on project results. These workshops will focus on the practical impact of research findings and potential changes to healthcare systems or further research needs. Since LUCIA has already organized a social lab workshop, they will share their experiences and lessons learned with the other projects during the upcoming meetings in 2025.

4.4 Addressing inequalities

The presentation focused on addressing inequalities in access to cancer care in Europe, reviewing a report submitted the previous year. Key discussions included the complexity of measuring inequalities and the need for more comprehensive data collection methods that address vulnerable, underrepresented groups. The group identified four principal areas of focus: cancer prevention, timely diagnosis, care, and the importance of cancer registries. Plans for 2024-2025 involve reviewing the 2018 inequalities report, mapping options, and enhancing communication efforts. The European Liver Patient Association (ELPA), collaborating with Cancer Patients Europe, launched a monthly awareness campaign and organized the European Liver Screening Week. A high-level policy event will address inequalities in cancer care, and an online webinar in the first half of 2025 will review a European Commission report on healthcare inequalities. Future actions include mapping data collection, literature reviews, and a social media campaign on Cancer Day. The cluster also plans further engagement with stakeholders and potential joint events.

5 Discussion and Conclusions

- The EC policy officer and the HaDEA project officer proposed that projects contact the European Health Data Space (EHDS) as a unified cluster rather than individually. This coordinated approach will streamline efforts and prevent multiple requests. They suggest working together to develop a structured plan and then presenting it to the cluster for feedback.

- To address the challenges of data sharing and management in cancer research, it is recommended to leverage existing European research infrastructures. Utilizing platforms such as Euro-BioImaging for imaging data and European Genome-Phenome Archive (EGA) and the Genomic Data Infrastructure (GDI) for genomic data can help accommodate both current and future needs.

- During the discussion, participants highlighted the significant difficulties faced by various consortia in signing data and material transfer agreements (MTAs) due to diverse regulations across countries and institutions. Despite these challenges, valuable experience and knowledge have been gained, which could benefit future projects. It was suggested to consolidate this knowledge into a resource to help other consortia avoid similar delays. This could involve sharing experiences in meetings, emphasizing lessons learned and best practices for efficiently managing MTAs.

- **Addressing Language Barriers in Citizen Engagement:** To make the proposed engagement activities accessible to citizens, especially outside the UK, it is essential to translate materials such as newsletters and brochures into local languages. For webinars, recording sessions and providing subtitles for non-English speakers will be considered. While translation efforts do come with costs and logistical challenges, it is crucial to identify which materials need translation and ensure feasibility within our budget. The cluster is dedicated to translating as many assets as possible to improve citizen engagement.

- The discussion around citizen engagement highlights the importance of not only disseminating information about the projects but also actively involving citizens in the research process. While traditional dissemination efforts, such as raising awareness about the importance of EU-funded research, are crucial, the next step is to ensure that citizens and patients contribute meaningfully to the projects. This could involve gathering insights from them that are useful for enhancing the research. One suggestion is to create a forum or focus group of citizens and patients to provide input, though this idea still requires further consideration and discussion within the team. The challenge lies in striking a balance between involving citizens in meaningful ways and acknowledging the limitations of the specific cluster's work. This topic will be further explored in future brainstorming sessions.

- In conclusion, the discussion highlighted the need for continuous reflection and improvements in the management and execution of cluster activities. Participants acknowledged the additional effort and resources required by the cluster, emphasizing the importance of ensuring that the work remains beneficial both to the policy officers and to the individual projects. One key takeaway was the importance of making the upcoming annual meeting more productive by allowing more time for results to develop. It was suggested that the meeting be organized towards the end of next year to allow for the sharing of more concrete outcomes, focusing on working group discussions rather than extensive individual presentations. Additionally, it was agreed that future meetings should incorporate more external input, with suggestions to invite representatives from other EU projects for broader collaboration. To make the meetings more engaging and effective, a shift towards working groups and focused sessions on common topics, such as clinical studies or omics data, was proposed.

This collaborative work could lead to potential recommendations and whitepapers on relevant topics, such as cross-EU standardization for clinical trials, the AI act, and more. Feedback also highlighted the need for clearer guidance and support in non-scientific aspects of the cluster’s work. The open discussion allowed for valuable insights into improving both the cluster management and the structure of future events, ensuring that the work remains aligned with the goals of the projects while also facilitating collaboration across the broader EU community.

6 Annexes

6.1 Annex 1 – Meeting Agenda

Funded by
the European Union

International Agency
for Research on Cancer
World Health
Organization

EU MISSIONS
CANCER

Discern
Colorectal - Renal - Pancreatic - Cancers

Cancer Mission Cluster Meeting

October 15th, 2024
International Agency for Research on Cancer, Lyon, France

AGENDA

Tuesday October 15th		
9.45 – 10.00	*On-site registration*	
10.00 – 10.05	Welcome and introductory remarks by DISCERN Coordinators	Paul Brennan
10.05 – 10.30	Greetings and presentation by HaDEA’s Project Officer	Laura Garcia Ibanez
	Project Overview and Scientific Update	
10.30– 10.55	DISCERN	Marc Gunter / Aida Ferreiro
10.55 – 11.20	MELCAYA	Adrián López Canosa
11.20 – 11.40	*Coffee break*	
11.40 – 12.05	LUCIA	Yoav Broza
12.05 – 12.30	ELMUMY	Makis Zoidakis
12.30 – 12.55	GENIAL	Clelia Galvanin
13.00 – 14.00	*Lunch break*	
14.00 – 14.20	Cancer Mission data initiatives	Angelo Solimini
14.20 – 14.40	EOSC4cancer project	Lifang Liu
14.40 – 15.00	Research and innovation - MELCAYA	Francesca Crespí Payeras
15.00 – 15.20	Data Management Plan - LUCIA	Silke Fiers
15.20 – 15.40	Citizen Engagement - DISCERN	Ali Stunt
15.40 – 16.00	Addressing Inequalities - GENIAL	Veronika Všetičkova
16:00	*Closing remarks*	

6.2 Annex 2 – Group Photo

7 References

[1] GENIAL factsheet in CORDIS webpage

[2] LUCIA factsheet in CORDIS webpage

[3] ELMUMY factsheet in CORDIS webpage

[4] DISCERN factsheet in CORDIS webpage

[5] MELCAYA factsheet in CORDIS webpage