Common work plan for scientific collaboration under the "Quality of life (AYA)" cluster

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Project Title	**Acronym**	**Grant No.**
e-health tools to promote Equality in Quality of Life for childhood to young adulthood cancer patients, survivors and their families - a Pan-European project supported by PanCare and Harmonic consortia	e-QuoL	101136549
Understanding and addressing LATE-effects of treatment of AYA cancer survivors with AI-based digital phenotyping and non-invasive holistic approach	LATE-AYA	101214326
smart Mirrors supporting healthier lives of Adolescents and Young Adults after cancer	MAYA	101213323
Patient-centred, evidence-based late effect screening and follow-up care of survivors of adolescent and young adult cancer	PanCare4AYA	101213107
Prediction and prevention of late effects in AYA cancer survivors – An effort to understand, predict and prevent late effects in AYAs 15-39 years of age, with a focus on fertility and gonadal toxicity	PredictAYA	101214879
Co-creation and implementation of an intervention to improve the understanding of TesticulaR cANcer late effects and unmet Supportive CarENeeDs of AYA survivors using eXtended Reality	TRANSCEND-XR	101214413

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List of Abbreviations

AI	Artificial Intelligence
AYA	Adolescent and Young Adult
CCI Europe	Childhood Cancer International Europe
DMP	Data Management Plan
EC	European Commission
EU	European Union
GDPR	General Data Protection Regulation
HADEA	European Health and Digital Executive Agency
NGO	Non-governmental organisation
PROM	Patient-Reported Outcome Measure
QoL	Quality of Life
TC	Testicular Cancer
UNCAN	European initiative to UNderstand CANcer
XR	Extended Reality

1 Executive Summary

Launched in 2021, the goal of the European Union (EU) Cancer Mission[1] is to improve the lives of more than 3 million people by 2030, through prevention, cure and for those affected by cancer including their families, to live longer and better. Projects in the "Quality of Life (AYA)" Cluster contribute to the achievement of the European Cancer Mission's objective to improve the Quality of Life (QoL) of patients and survivors of cancer patients, their families, and loved ones.

The "Quality of Life (AYA)" Cluster is composed of five projects funded under the topic 'HORIZON-MISS-2024-CANCER-01-05 - Improving the understanding and management of late-effects in Adolescents and Young Adults (AYA) with cancer' and one project funded under the topic 'HORIZON-MISS-2023-CANCER-01-04 - Establish best practices and tools to improve the quality of life for childhood cancer patients, survivors and their families in European regions. Projects in the Cluster share the common mission to improve QoL for patients and survivors of AYA cancers.

The 'Common work plan for scientific collaboration under the "Quality of life (AYA)" cluster' sets out the planned activities across the six cluster projects to maximise research synergies and minimise duplication of research effort. The plan will be a living document, maintained by the Scientific Collaboration Working Group, composed of representatives of all cluster projects. Common themes across the projects have been identified, as well as target areas for scientific collaboration. Over the lifetime of the cluster, the Scientific Collaboration Working Group will meet regularly to review the plan and oversee collaborative scientific activities.

[1] https://research-and-innovation.ec.europa.eu/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe/eu-missions-horizon-europe/eu-mission-cancer_en

2 Introduction & Background

According to the European Cancer Information System, each year in Europe, 2.7 million people are diagnosed with cancer, 1.3 million lives are lost to the disease, and by 2040, the number of cancer diagnoses is projected to surpass 3.24 million.

The EU Cancer Mission, alongside Europe's Beating Cancer Plan, represents the European Commission's (EC) strategy to reverse this trend, by uniting research, innovation, and public health policies in ways that cannot be achieved through isolated research or policy actions.

The Mission has 4 key objectives: understanding cancer, prevention and early detection, diagnosis and treatment, and improving Quality of Life (QoL)[1]. Projects in the "Quality of Life (AYA)" Cluster contribute to the achievement of the European Cancer Mission's objective to improve the QoL of patients and survivors of AYA cancer and their families.

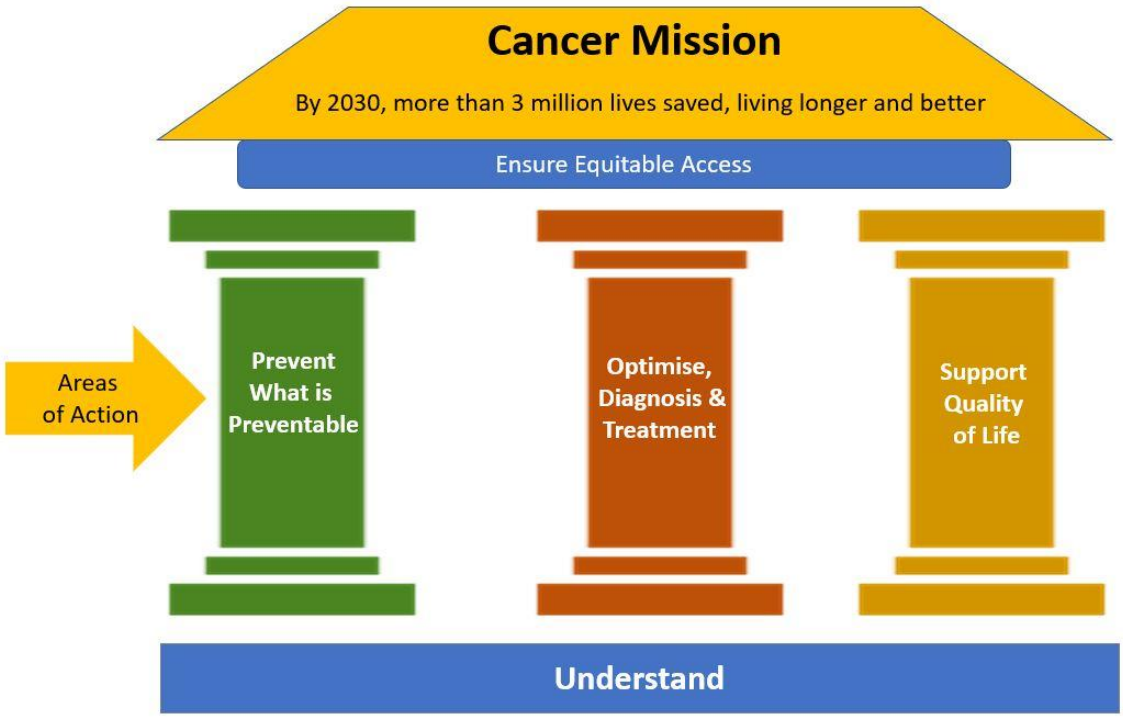

Figure 1 European Cancer Mission Intervention Areas (Source: https://horizoneurope.ie/global-challenges-european-industrial-competitiveness/health/horizon-europe-health-cluster-cancer-mission-eu-funding-for-research-find-out-more)

Each year, more than 150,000 AYA cancers are diagnosed in the EU, and over 1.2 million worldwide. About 300,000 AYA patients live with or beyond cancer in the EU; the majority experience late-effects due to their cancer treatment, including chronic pain, cardiovascular disease, organ and skin alterations, cosmetic sequelae, fertility problems, cognitive and functional impairment, and mental health issues such as depression and anxiety. Survivors may also be at increased risk of second cancers due to the long-term effects of radiation and chemotherapy. The negative impact on education and employment of AYA survivors and, in general, the financial burden borne by them is also commonly observed.

Late effects are particularly challenging for AYA cancer survivors, who often experience them during a critical phase of their lives. Late effects are also challenging for caregivers. The considerable progress made in treating AYA cancers has further exposed gaps in the understanding, prevention and

management of late-effects, which warrant more targeted pan-European research on AYA cancer survivorship.

Projects in the "Quality of Life (AYA)" cluster aim to deliver results that are directed and tailored towards the following expected outcomes:

- Increased awareness and improved understanding of the incidence, severity, and impact of late effects in AYA cancer survivors among healthcare providers, patients, caregivers, and the general public;
- Researchers, innovators, and professionals from different disciplines and sectors ensure accessibility and re-usability of their data, models, tools and technology to support the UNCAN.eu platform;
- Identification of effective interventions and best practices to support AYA patients and survivors in preventing, reducing and better managing late-effects, promoting optimal health outcomes, and overcoming disparities between regions;
- Improved QoL and long-term outcomes for AYA cancer survivors, including improved physical, emotional, and social well-being;
- Cancer patients, survivors and their families benefit from enhanced QoL through better supportive care, personalised counselling approaches, and digital tools that are accessible and affordable, so that consequently, they can better achieve their values and personal life goals;
- Health care professionals, supportive workers and councillors enhance the QoL for childhood cancer patients, survivors, and their families.

As the research activities of the "Quality of Life (AYA)" cluster deliver these common objectives, there is the potential for synergies, as well as overlap and duplication of effort. The Common Work Plan presented here identifies common research themes and areas of scientific collaboration. As most of the projects are in the early stages of their implementation, the work plan will be a living document that is further developed by the cluster's Scientific Collaboration Working Group with specific activities to facilitate collaboration over the cluster lifetime.

3 Common Work Plan

3.1 Mechanisms of Scientific Collaboration & Scope

A Working Group for Scientific Collaboration within the cluster has been formed and includes at least one representative per project. Leadership of the Working Group will rotate; PanCare4AYA will lead the first year and a schedule for subsequent years will be established.

The Working Group will meet at least twice annually, once at the Annual Cluster Meetings and once online to discuss project results and progress versus the Common work plan. Between meetings, activities and results will be shared between projects as they are generated, under the areas of collaboration described above.

Note that collaboration in terms of data management is captured via a separate Working Group and is not covered in the plan presented here. A common chapter on the "Quality of life (AYA)" cluster will be included either in the Data Management Plans (DMPs) of individual projects or as a stand-alone deliverable report (in line with the requirements of the Grant Agreement of each project). The aim of the chapter is to address commonalities in data standards, data validation, data protection and fostering

data exchange, in particular when it comes to sharing project data with a future federated UNCAN.eu data platform.

Similarly, the plan presented in this deliverable does not cover joint communication or dissemination by the Cluster projects, which is addressed via a Working Group on Communication, Dissemination, and Policy. This Working Group is responsible for Cluster deliverables related to the Cluster brochure, Citizen Engagement recommendations to address inequalities, and annual Policy Briefs.

3.2 Research Themes

Cluster projects fall under the three themes set out in the HORIZON-MISS-2024-CANCER-01-05 topic, which overlap with the topic 'HORIZON-MISS-2023-CANCER-01-04'.

3.2.1 Theme 1 - Data-driven characterisation of late effects in AYA cancer survivors

PredictAYA addresses the call to obtain a thorough assessment by cancer type of the prevalence, specific effect(s), severity, time of onset, relative risk, and risk factors associated to late effects in AYA cancer patients, building on data from existing or newly established AYA patient cohorts, ensuring comparability of data across participating countries as appropriate. Under this theme, attention is also paid to social and health determinants, including sex, gender, age and other relevant variables, including socio-economic status, living in rural or remote areas and education.

PredictAYA is a multidisciplinary initiative aimed at improving understanding of late effects in AYAs aged 15–39 treated for cancer using data from population-based registers, genomic biobanks, and new clinical cohorts. The project emphasizes patient involvement and captures care preferences and psychosocial impacts, particularly on reproductive health, sexuality, and QoL. Through collaboration among clinicians, researchers, psychologists, and patients, it adopts a participatory research approach. A key goal is to identify genetic biomarkers for reproductive toxicity and develop guidelines for individualized screening and counselling. Additional research will explore fertility preservation, risks of pregnancy, and associations between treatment-related toxicities and broader health outcomes.

3.2.2 Theme 2 - Evidence-based screening methods for late effects

PanCare4AYA (pancare4aya.eu) addresses the call to develop, test and scale-up evidence-based screening methods for the early detection of late-effects in AYA cancer patients.

PanCare4AYA will improve Survivorship Care for AYA cancer survivors across Europe by developing an international clinical guideline for screening and follow-up. This guideline will be implemented via a novel person-centred screening programme (*AYA Cancer Survivor Screen*). An implementation study involving 1,000 AYA cancer survivors in 11 European countries (Croatia, Czech Republic, France, Germany, Italy, Lithuania, Netherlands, Norway, Sweden, Switzerland, United Kingdom) will be conducted to test the *AYA Cancer Survivor Screen* programme, including peer support. The study will look at effectiveness (empowerment, mental health, psychosocial functioning and other QoL-related outcomes), healthcare delivery and screening-related health, experiences of AYA cancer survivors and HCPs with implementing the state-of-the-art screening programme within a range of different healthcare settings, and feasibility. Innovative digital tools will be used in France, Italy, Lithuania and the Netherlands.

3.2.3 Theme 3 - Innovative, holistic approaches and tools for late effects

LATE-AYA (late-aya.eu), **MAYA** (maya-horizon.eu), **TRANSCEND-XR** (transcend-xr.eu) and **e-QuoL** (equolproject.eu) address the need to develop, test and scale up in real-life settings, innovative, holistic approaches and tools (including digital tools), optimising cancer treatment and follow-up regimens to prevent, reduce and/or effectively manage late-effects, including psycho-social aspects. Approaches focus on a broad range of topics, including mental and physical health, pain management, and wellbeing in general.

LATE-AYA addresses the complex health challenges faced by AYA cancer survivors, including increased risks of cardiovascular disease, infertility, and mental health issues. The project will develop an Artificial Intelligence (AI)-driven digital phenotyping platform that leverages data from smartphones and wearables, such as smartwatches, to monitor physical, psychological, and social well-being in real time. Through a holistic and non-invasive approach, LATE-AYA will enable personalised management of late effects, promote preventive health behaviours, and support social and psychological reintegration. By modelling late-effect and quality-of-life trajectories across AYA subgroups, the project will provide data-driven insights for tailored survivorship care. LATE-AYA will share data and models through the UNCAN.eu platform, fostering European collaboration and long-term impact in digital survivorship care.

MAYA will develop, test and scale up innovative, holistic approaches and tools for managing late effects of cancer treatment in AYA cancer (of any type) survivors. MAYA aims to empower AYA cancer survivors to manage their cardiovascular health through digital tools that address cardiotoxic-related late effects of cancer treatment. The project envisions using the iCARE health hub, which integrates a smart mirror and an AI-powered conversational agent, to deliver personalised care and continuous monitoring. The ultimate goal is to improve cardiovascular outcomes and overall QoL for AYA cancer survivors by managing modifiable risk factors, such as hypertension, diabetes, and obesity, with an expected reduction in the risk of major cardiac events by 30-40%. MAYA will achieve these objectives through advanced AI-driven data analysis, real-time biomarker tracking, and participatory research methods rooted in social innovation, multistakeholder engagement and Living Labs, including a group of patient co-researchers in the project development. The project will test these solutions in real-world settings through clinical studies involving AYA cancer survivors in multiple European countries. By focusing on personalised interventions and continuous health monitoring, MAYA directly aligns with the objectives of the Horizon Europe work programme, particularly the Cancer Mission's goals of improving long-term health outcomes and QoL for cancer survivors.

TRANSCEND-XR aims to transform survivorship care for AYA testicular cancer (TC) survivors. Although TC has a high cure rate, survivors frequently experience serious late effects – such as cardiovascular, endocrine, and psychosocial complications – and often have unmet supportive care needs. Involving 15 partners across 12 countries, TRANSCEND-XR seeks to ethically co-create, test, and implement an extended reality (XR)-based educational intervention that enhances survivors' understanding of treatment-related late effects and supports self-management. Guided by the Medical Research Council's framework for complex interventions, the project comprises three interlinked phases: (1) assessing survivors' needs and co-creating the XR intervention through participatory methods; (2) evaluating its feasibility, effectiveness, implementation, cost-effectiveness, and ethical implications via a multi-country pragmatic randomised controlled trial; and (3) translating results into clinical guidelines

and policy to ensure scalability and long-term sustainability. By integrating empirical bioethics, health economics, and implementation science, TRANSCEND-XR will generate evidence to improve knowledge, QoL, and equity in digital survivorship care across Europe and beyond.

e-QuoL will use e-health tools to promote Equity in QoL for AYA cancer (and childhood cancer) survivors and their families. The project will create an interoperable personalised e-Health tool that can be used alone or linked to existing tools, such as digital survivorship care plans already used in several European countries. Through participatory research, involving cancer survivors, families, associations, networks, health institutes, social sciences and humanities researchers, and industrial partners from 15 different countries, e-QuoL will: i) identify the unmet needs of families and survivors' (including vulnerable groups: young age and cognitive impairments), and ii) adapt accessible and affordable tools to address these needs. These tools will provide a person-centred approach from medical follow-up, preventive behaviours (e.g. physical activity, nutrition), psychological and social support (e.g. education, employment) to related health information (e.g. reproductive issues). Ultimately, e-QuoL will improve survivors' QoL by enabling them to actively engage in their care and better self-manage their health and well-being

3.3 Areas for Scientific Collaboration

Across the themes above, there are opportunities for the project consortia to collaborate scientifically, maximising potential synergies and eliminating duplication of effort. At the online Scientific Collaboration Working Group meeting held 06 November 2025, the following areas for scientific collaboration were identified by representatives of the six Cluster projects. Specific activities to deliver the collaboration will be developed by the relevant projects, for further discussion at upcoming online meetings and at the first Annual Cluster Meeting.

3.3.1 Evidence-based guidelines

Three projects will develop guidelines or generate evidence to inform future guidelines.

- **PanCare4AYA** will develop an international clinical guideline for screening and follow-up of AYA cancer survivors for a wide range of late effects early in the project, as well as a specific guideline on fertility preservation in the latter stages of the project.
- **PredictAYA** will develop guidelines for late effects management within oncofertility.

PanCare4YA and PredictAYA will explore how to avoid overlap and duplication of effort, taking into consideration the timing of guideline development across the two projects. For example, PredictAYA may identify late effect risks that could be included in updates to the PanCare4AYA guideline for screening or inform the development of the fertility preservation guideline.

- **TRANSCEND-XR** will generate robust, multi-country evidence to inform future European guidelines for AYA TC survivorship. By evaluating the clinical, ethical, and economic impacts of an XR educational intervention, the project will provide data on effectiveness, cost-effectiveness, and implementation feasibility. These findings will underpin the development of "ethics-by-design" recommendations and policy guidance for the sustainable and equitable integration of digital tools into oncology care across Europe.

3.3.2 Digital health, including Artificial Intelligence

In line with the EU's digital health agenda, all projects in the cluster involve digital health tools and/or AI.

- **e-QuoL** will develop an e-health tool in order to improve survivors' QoL, based on medical follow-up and psychosocial support.
- **LATE-AYA** will develop an AI-driven digital phenotyping platform by analysing data coming from health records, patient-reported outcome measures (PROMs) and smartphones and wearables to manage late effects of cancer by a personalised non-invasive approach.
- **MAYA** uses the iCARE health hub, which integrates a smart mirror and an AI-powered conversational agent, to deliver personalised care and continuous monitoring. The project will specifically focus on Trustworthy AI guidelines, combining technical, clinical and social sciences aspects, with a strong focus on stakeholders' engagement, namely patients' lived experience, to co-design and develop requirements.
- **PanCare4AYA** includes the use of three different digital tools that use medical data from health records for the delivery of a personalised Survivorship Care Plan. The project will develop non-proprietary algorithms to generate follow-up recommendations based on survivors' treatment history, as well as a Guide on Digital Tools for survivorship care.
- **PredictAYA** will develop an AI-driven late effects prediction model for research use. Insights and best practices from the cluster projects may inform PredictAYA on a roadmap for future clinical implementation of the developed model.
- **TRANSCEND-XR** will create, test and scale an immersive XR-based intervention to support cancer survivors. Through interactive, evidence-based learning environments, it enhances knowledge, self-management, and QoL while reducing health inequalities. The project serves as a proof of concept for how ethically grounded, user-centred digital technologies can be deployed in real-world clinical settings to modernise cancer survivorship care.

Projects will share General Data Protection Regulation (GDPR)-compliant best practices for the use of digital health data and share lessons learned on the implementation of digital tools in research and clinical practice. How research can respond to emerging requirements for the use of AI in healthcare will also be shared amongst projects involving AI (MAYA, LATE-AYA, and PredictAYA).

3.3.3 Participatory research involving AYA cancer survivors & carers

Direct involvement of AYA cancer patients and survivors, survivor representative organisations, and caregivers is essential for the generation of meaningful and significant results, enhancing the impact of the related research activities in each cluster project.

- **e-QuoL** includes participatory research by exploring the unmet needs of survivors and their families. After several literature reviews on the care needs of survivors and their families, focus groups, and online surveys have been conducted. Current gaps in terms of e-health and digital tools were highlighted.
- **LATE-AYA** adopts a patient-involving co-creation approach in the design and implementation of its two-stage clinical study investigating QoL trajectories among AYAs after cancer. The study aims to identify patients' needs, preferences, and determinants of QoL outcomes, thereby informing the definition of the most appropriate intervention strategies at both methodological and content levels. Expert patients and patient advocacy groups will be actively involved through focus groups and individual interviews, ensuring that their lived experience directly contributes to shaping the study design and interpretation of findings.
- **MAYA** places people with lived experience at the centre of its research by involving them directly as co-researchers. The methods for the participatory approaches in MAYA are rooted on a tripod of actions: a) Multistakeholder and multidisciplinary engagement; b) Co-research and patients'

community; c) Living Labs, awareness and capacity-building. Former AYA cancer patients will be recruited to work alongside project partners, contributing their unique perspectives to the project's design, development and implementation. MAYA will also establish a dedicated Patients Community that brings together representatives from patient associations, relevant European networks and NGOs working in related areas, among others.

- **PanCare4AYA** involves AYA cancer survivor representatives throughout the research process, from guideline development to peer support networks throughout the implementation of the *AYA Cancer Survivor Screen*. Patient and carer umbrella organisation CCI Europe is a core project partner, leading the involvement of survivor stakeholders throughout the research project.
- **PredictAYA** will ensure strong patient engagement by co-creating research with AYAs affected by cancer, focusing on reproductive toxicity, fertility, sexual health, and QoL. A Patient and Relatives Advisory Board, including AYA patients, partners, and parents from across Europe, will be established to provide continuous input and ensure diverse perspectives are represented. A mixed-methods study will explore fertility preservation experiences among AYA survivors and healthcare professionals, identifying unmet needs and informing improvements in care. Findings will guide other project components and be shared through guidelines, workshops, publications, and public webinars to promote patient-centred, evidence-based survivorship care.
- **TRANSCEND-XR** adopts a participatory, co-creation model involving AYA cancer survivors, their care partners, and healthcare professionals in every stage of design and evaluation. Using methodologies such as the World Café approach, survivors and their care partners help shape the intervention's content, usability, and cultural relevance. This inclusive process ensures that the final product reflects lived experiences, ethical values, and user priorities – empowering survivors as active contributors to research and innovation in digital health.

Projects will share best practices for participatory research and share lessons learned. If findings from the participatory research are relevant across projects, these will be shared (for example, end-user requirements for digital tools, and so on). Where potentially overlapping input is sought from AYA cancer patients and survivors, survivor representative organisations and caregivers, the projects will consider whether this can be done in collaboration to reduce stakeholder burden (e.g. combining online stakeholder surveys, and so on).

4 Impact & Conclusion

The 'Common work plan for scientific collaboration under the "Quality of life (AYA)" cluster', developed by the Scientific Collaboration Working Group, sets the stage for activities over the lifetimes of the six cluster projects. The projects have been linked to themes set forth in the MISS-2024-CANCER-01-05 call topic and three areas for scientific collaboration have been identified to facilitate synergies between projects and minimise duplication of effort.

Three priority areas for scientific collaboration – evidence-based guidelines, digital health and AI, and participatory research involving AYA survivors and caregivers – have been identified for their potential to generate cross-cutting benefits. Structured collaboration in these areas will allow projects to share methodologies, technical expertise, user requirements, and actionable insights, thereby strengthening the overall quality, relevance, and coherence of project outcomes.

The Scientific Collaboration Working Group will play a central role in ensuring the effective implementation of this plan. Through regular meetings, continues exchange of results and iterative

updates to the work plan, the group will ensure that the document remains a dynamic tool supporting collaboration across the lifetime of the cluster.

Efficient and effective scientific collaboration is essential to maximise the value of the EU funding granted to the cluster projects and enhance their joint impact. The common work plan will enable the cluster projects to achieve a substantially greater scientific impact collectively than they could individually, by strategically aligning their outcomes, eliminating redundant efforts, and driving coordinated joint actions toward the overarching goal of significantly improving the QoL of AYA cancer survivors across Europe.