From the Meeting of Minds 4 Event Series

The “Cancer Survivorship – AI for Well-being” Cluster Conference

23rd & 24th, February, 2022

A Conference Proceeding Report

#CS_AIW, 26th May 2022

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Foreword

By Tom Flynn (TFC Research and Innovation Limited)

Much dedication and work went unnoticed behind the scene to enable the fourth Meetings of Mind event to be held. Truly grateful to all who contribute to the delivery of a very successful virtual event. You know who you are. My sincere thanks!

The two-day event from the Clusters' Meeting of Mind series of events was the first public engagement for the Cluster – Cancer Survivorship – AI for Well-being. The underlining motivation for this event was to encourage patient engagement and interaction with the Cluster project at the event, which is centered on Cancer Survivorship and how the state-of-the-art technology and solutions under development can better support patients as well as caregivers and clinical professionals. This Meeting-of-Minds event, our fourth, provided a platform for solid cross-fertilization discussions and exchanges. The undertaking was very rewarding. Knowledge transfer and the divulgence information and understanding from different perspectives was welcomed and healthy. The roundtable session, involving many patient associations was enthralling with solid bi-directional discussions manifesting in the process. The knowledge acquired will be deployed to the relevant projects in the Cluster.

I am very grateful to all of our speakers including Barbara Kerstiens, Head of Unit "Combatting Diseases", Research & Innovation DG, European Commission, who provided solid insight on the Cancer Mission and the direction that the Commission is heading.

We now press on with the intent to deliver valued outputs from the individual projects.

Event Chairperson.

Executive summary

This report presents the **4th Meeting of Minds**, organized virtually by **Cancer Survivorship – AI for Well-being Cluster** (#CS_AIW) on February 23rd and 24th, 2022. It was a focused patient-orientated event and developed around a single key question "*How can new technologies better support patients?*" In response, more than 100 stakeholders and interested parties participated and included patients, patient associations, healthcare providers, advocates and IT specialists, researchers and policy makers.

The event enabled details of ten EU funded projects in the Cluster to be individually presented with a focus on the under-development technologies, which are primarily targeted at the care for cancer patients and survivors, including mental health. The collaborating projects in the Cluster are: LIFECHAMPS; ONCORELIEF; MENHIR; PERSIST; QUALITOP; CLARIFY; ASCAPE; REBECCA; CAPABLE and FAITH**.** Their individual presentations provided insight to the ongoing projects work and included individual a Q&A session with the audience.

This report also includes a detailed overview of the roundtable bi-directional discussions with Patient and Researchers engaged in #CS_AIW Cluster. Moderated by *Panos Papachristotu* from Academic Primary Health Care Centre (APC) and with the participation of six speakers, each being a cancer/survivor patient and distinguished researcher or patient activist, the discussion outlined important messages regarding the process of co-development in all stages of the research; the need of providing patients with sufficient information in order to ensure their trust in clinical trials; the security of collected data and the importance of making technologies and decision support systems beneficial for patients and not only for clinicians.

Additionally on Day 2, *Barbara Kerstiens* from DG Research & Innovation of the European Commission delivered a presentation on patient engagement in European research projects and proposals, outlining the opportunities provided through initiatives such as the European Cancer Patient Digital Center and the Beating Cancer Stakeholder Contact Group.

Gerd Murphy, a Psycho-Oncology Nurse at the University College Dublin presented on the impact of cancer on patient mental well-being through the psycho-oncology perspective. In her presentation, she identified a range of unmet needs and the desire for very comprehensive undertaking assessment at an individual level, as well as tailored individual interventions to help overcome gaps and improve mental health well-being of cancer patients and survivors.

Kathi Apostolidis, a Board Member of the European Cancer Patient Coalition presented patients' central role in the implementation of clinical research and underlined their role as active co-creators rather than just as objects in trials.

This report also includes information about the Cancer Survivorship – AI for Well-being Cluster and poll questions results.

Definitions

To support the reading of this report, the following definitions were retrieved from Cambridge Dictionary, unless specified differently.

Artificial Intelligence or AI:	A study of how to produce machines that have some of the qualities that the human mind has, such as the ability to understand language, recognize pictures, solve problems, and learn.
Big Data:	Very large sets of data that are produced by people using the internet, and that can only be stored, understood, and used with the help of special tools and methods.
Immunotherapy:	Treatment that improves ability of the immune system to fight disease.
MoM:	Meeting of Minds concept for scientific research was instigate in the NO-FEAR project, whereby people meet to exchange understanding and knowledge from their differing perspectives. It is not to be associated in its used with legal / contract situations. (#CS_AIW)
Quality of Life:	An individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. (World Health Organization)
(Cancer) Survivor:	A person is considered to be a survivor from the time of diagnosis until the end of life. (National Cancer Institute)

Moderator

CANCER SURVIVORSHIP – AI FOR WELL-BEING

How can new technology better support patients?

Meeting of Minds 4

Welcome All

#CS_AIW

The **4th Meeting of Minds** event aims to **engage with patients** to gather important **feedback** on how **new technologies can be of better support**.

Cluster project members will present their projects, their future work intent and will seek **patient feedback in support** while **demonstrating their platforms**.

February 23rd, 2022: 10 to 17 CET
February 24th, 2022: 10 to 15 CET

MoM4 is recorded.
Moderator: Tom Flynn,
TFC Research and Innovation Limited

The moderator for the Fourth **Meeting of Minds** event was Tom Flynn, Innovation and Business Development Manager, TFC Research and Innovation Limited. He heads up the standardization activities in both the FAITH and NO-FEAR projects, whereby the company is developing a Better Practice Guide Initiative to empower practitioners, experts and users at the pre-standardization stage of development. He has a software engineering background as well as vast experience in project management, operational, standardization and outreach management. A member of CEN TC391 (Societal and Citizen Security), he is experienced working for both multi-national organizations and SMEs across a number of domains including Security, Energy and eHealth. Tom supported SETU Waterford Campus (formally Waterford Institute of Technology) in the H2020 data analytics project, aquaSmart, which was nominated for the Innovation Radar Award. He has worked for the European Commission reviewing the progress of large-scale security research projects. In March 2022, he presented on Interoperability and the Better Practice Guide Initiative at the Security CERIS event for the European Commission. Tom was the President of the 5th European Software Quality Conference; he chaired the European Security Research – The Next Wave and was on the editorial committee for American Society for Quality – Software Quality Journal.

Key points and policy directions outline

Many key messages were echoed throughout the fourth Meeting of Minds event. **At policy level**, the European Commission explained that it has set in train a programme for cancer research having the ambition to improve the lives of more than 3 million people by the year, 2030, through prevention, cure and for those affected by cancer including their families, to live better and longer. A European Beating Cancer Plan has been activated. It is understood that unless decisive action is taken, cancer cases are set to increase by 24 per cent by 2035, which would make it the leading cause of death in the European Union. To this effect in the fight against cancer, the European Beating Cancer Plan has funding of €4 billion to challenge this outcome. **At research and innovation level**, notable points were:

- Technology supports clinicians, it doesn´t replace them! Clinical decision support systems help to close gaps in care, but alone, they will not improve clinical care.

- The importance of patient and patient organization engagement throughout the entire research and innovation process and not just at requirements and validation phases, cannot be overstated. Involving end-users, be it is clinicians or patients or both, throughout the entire cycle for the improvement of cancer patients' quality of life. Health status is a challenge as computer scientists, clinicians and patients have different but complementary approaches. Their understanding is based on experience. Clinical and patients can provide incredible insight along all stages of a project.

- Personalized medicine´s tailor-made prevention and treatment strategies are key to fight cancer and improve patients' well-being. In this sense too, patient engagement is essential to ensure that personalized medicine technologies target patients´ needs (both physical, but also functional and psychosocial) from a scientific evidence-based approach.

- Psychological, behavioral and social factors may influence the disease process. Therefore, it is essential to take mental health, quality of life and activity data into account to improve cancer patients' well-being.

- Breaking away from relying only on traditional electronical health records and exploiting volume and variety of new data sources and real-world data can improve our research potential and provide cost-effective and efficient health care.

About the Cancer Survivorship – AI for Well-being Cluster

Cancer survivors know the full meaning of team effort, be it with the team of oncologists, radiotherapists, psychologists and care-givers in support of that dreaded journey when cancer is detected and treatment is necessary. The road to recovery can be long and endearing. Survivors also know the value and importance of mental strength during the treatment process and throughout the entire recovery stage. Ryunosuke Satoro, a famous Japanese writer, once said *"Individually, we are one drop. Together, we are an ocean!".* His message is clear, and so it is for the #CS_AIW. We are our own kind of ocean. We don't work in silo. We collaborate and are an engaging team. Our work, for as much as possible, is shared across the Cluster so that both collectively and individually, project's benefit from the cross-fertilization engagement process and on-going Cluster activities. Through dialogue, we listen and learn from our experiences in the individual projects and from different perspectives too, so that ultimately, the projects' main outputs benefit the patient and clinical experts.

The CS_AIW Cluster ('Cancer Survivorship – AI for well-being') was setup by TFC Research and Innovation Limited (TFC), a member of the **FAITH** project. Individual projects in the Cluster were brought together based on common interest regarding cancer survivorship, mental health, quality of life and well-being, depression and patient support. Presently, the Cluster comprises of ten engaging EU supported projects centered in the space of cancer survivorship and mental health and through engagement with patients, healthcare providers and researcher, different views are captured, which are used to help verify and validate the ongoing individual project work. This process contributes to ensuring that the technical outputs of the projects are in lined with what is needed and will be welcomed by the intended users. Naturally, the technical research maturity levels of each project will vary across the Cluster, but we put that understanding left of center, so that we can help to maximize the effectiveness of project outputs. It was also decided not to be concerned about which Directorate General the individual project was positioned within; instead, it was the subject matter of the individual projects that drove the connectivity. In Quarter 4 2020, TFC contacted a number of identified and potentially interested projects and invited them to join the Cluster and building on from the initial outreach. With both **ONCORELIEF** and **MENHIR**, the initial Meeting of Minds event from the series was held. A closed event, it focused in mental health. Virtual, it took place on the 28th January 2021. With tremendous engagement, collaboration and participation of these projects, much insight from persons who have lived with mental health issues addressed the audience and articulated their experiences for the benefit of the clinical and technical partners working across the three projects, two of which, ONCORELIEF and FAITH, were at requirements capture stages of their individual projects. This was timely, so that the captured knowledge and understanding could be used and applied to the ongoing project work.

Subsequent virtual Meeting of Minds and closed events *(i.e., MoM3 and MoM3+) were held on the 30th September, 2021 in round-table mode and separately (MoM3+) in the technical shared knowledge space and experiences on common items of interest. These include exchanges on how best to manage clinical trials during the pandemic lockdown, the patient recruitment and on common data items. The MoM3+ event was led by the **LIFECHAMPS** project. The MoM3 round table event was led by **FAITH**. It was a business-orientated event designed to challenge the projects with regards to project positioning and take up of results. Pre-defined questions were answered in advance and the moderator drove the discussions. Each project at the round table included both a clinical and business orientation member of the consortium. Based on our principal of not working in silo mode, much knowledge and understanding was shared, which included remote participation of the audience, who members of the individual Cluster projects.

The cross-fertilizing projects, sharing knowledge and understanding for the common good of the patients, healthcare providers and scientific researcher in the Cluster include the following European Commission supported Horizon 2020 projects:

- **LIFECHAMPS** – focused on integrated cancer care for the older cancer champions based on Big-Data and quality of life behaviour;
- **ONCORELIEF** – working to improve the Quality of Life and developing mobile applications for cancer patients after treatment and for clinicians;
- **MENHIR** – working on mental health monitoring through interactive conversations;
- **PERSIST** – developing Big Data platform, mHealth application and multimodal sensing network to improve the Quality of Life of cancer survivors;
- **QUALITOP** – monitoring multidimensional aspects of Quality of Life after cancer Immunotherapy and developing an open smart digital platform for prevention and patient management;
- **CLARIFY** – developing actionable knowledge for improving cancer long survivors’ Quality of Life;
- **ASCAPE** – working on an AI-powered framework, clinical testing and patient engagement;
- **REBECCA** – developing a patient mobile application and a web browser plugin to improve intervention of care choices and analyze data to better understand how treatment affects Quality of Life;
- **CAPABLE** – *aiming to develop a support system for improving the Quality of Life of cancer home patients by combining technologies with socio-psychological models and theories *(**NEW Member – Announced at MoM4**)*;
- **FAITH** – addressing post-treatment consequences of anxiety and depression through Artificial Intelligence based technologies.

Since the fourth Meeting of Mind event took place, a number of exchanges and individual project meetings have since taken place. We aim to develop a Better Practice Guide based on the initiative being developed in the NO-FEAR project and we plan to kick start a series of Podcast centered on cancer survivorship issues for the benefit of whom we serve, cancer patients, their healthcare provider and care-givers. We press on!

Overview of the Fourth Meeting of Minds event

On February 23rd and 24th, 2022, the #CS_AIW organized the 4th Meeting of Minds (MoM4). It was a focused patient-orientated event and developed around a single key question "***How can new technologies better support patients?***" In response, more than 100 stakeholders participated over the two days of the event. The audience included patients, patient associations, healthcare providers, advocates and IT specialists, researchers and policy makers. Moderated by Tom Flynn (*TFC Research and Innovation Limited*), these two days were really engaging for all the participants and the presenters. Each project in the Cluster, individually presented their ongoing project activities, demonstrated their technologies, which are under development and received audience feedback, which was gratefully appreciated. Collectively and individually, the members of Cluster projects listened and learned to the audience to obtain stakeholder insights. The MoM4 event helped to strengthen understanding for a better delivery of what is needed by the patients, clinical professionals and their care-givers. It was a pleasure to welcome the **CAPABLE** project to the Cluster, building momentum to strengthen project exchanges.

To single out any one presentation would be inappropriate. There were many solid presentations and good interact engagements throughout. Instead, we are very pleased to have prepared an overview of each session, starting in order of presentation from Day 1 into Day 2.

Day 1*:*		
Session 1	*Gerd Murphy, University Hospital Waterford.* *The impact of cancer on patient mental well-being - A Psycho-Oncologist perspective.*	*Page 12*
Session 2	*Dr. Zoraida Callejas, University of Granada.* *The MENHIR experience: MENHIR corpus collection and analysis, user modelling, conversational interaction design and personalization.*	*Page 15*
Session 3	*Prof. Panos Bamidis & Dr. Antonis Billis, Aristotle University of Thessaloniki.* *Integrated cancer care for the older cancer champions based on Big-Data and QoL behaviourome: the LifeChamps project.*	*Page 18*
Session 4	*Tom Flynn, TFC Research and Innovation.* *Open discussion on the morning and an outline of the afternoon session and audience Q&A chat.*	*N/a*
Session 5	*Sotiris Diamantopoulos, EUS Software.* *ONCORELIEF - Quality of life in cancer survivors; can we measure it and improve it?*	*Page 22*
Session 6	*Gary McManus, WIT, Stefanos Venios (Suite5), Xenia Beltran (UPM).*	*Page 24*

	The FAITH Project - Improving the Quality of Life in cancer survivors through the use of technology for the identification & analyses of depression markers - An understanding	
Session 7	*Victoria Cal, Gradiant and Gazihan Alankus (Emoda Software).* *PERSIST (Presentation & Demo) - Introduction to PERSIST ecosystem and demonstration of the patient application.*	*Page 27*
Session 8	*Delphine Maucort Boulch, Hospices Civils De Lyon.* *QUALITOP - Where we are and what next!*	*Page 30*
Session 9	*Patient & Research - Round Table discussion with patients on engaged Cluster projects – Moderator, Panos Papachristotu.*	*Page 33*

***Day 2**:*		
Session 1	*Barbara Kerstiens, European Commission.* *European Commission presentation on patient engagement in research projects and proposals.*	*Page 38*
Session 2	*María Torrente, SERMAS HUPHM & Pedro Sousa (Holos)* *CLARIFY. Platform: actionable knowledge for improving cancer long survivor´s quality of life.*	*Page 41*
Session 3	*Kathi Apostolidis, Past President European Cancer Patient Coalition.* *Patient engagement in clinical trials.*	*Page 44*
Session 4	*Tom Flynn, TFC Research and Innovation Limited.* *Discussion on the morning and an outline of the afternoon session.*	*N/a*
Session 5	*Ionnais Avramidis, UBITECH.* *ASCAPE: AI-powered framework, clinical testing and patient engagement.*	*Page 47*
Session 6	*Ioannis Sarafis, AUTH and Lazaros Apostolidis (CERTH-ITI).* *REBECCA: Vision and demonstration of the patient mobile application and the web browser plugin.*	*Page 51*
Session 7	*Antonis Billis, Aristotle University of Thessaloniki & Tom Flynn, TFC* *The Cancer Survivorship - AI for well-being - Cluster: Where are we and where collaboratively we are going.*	*Page 53*
Session 8	*Silvana Quaglini, University of Pavia.* *The CAPABLE project (CAncer PAtients Better Life Experience).*	*Page 55*

We trust some of the individual’s session summaries, below, will be of use and value to you.

#CS_AIW MoM4 - Day 1

Session 1: The impact of cancer on patient mental well-being - A psycho-oncology perspective

Presenter: Gerd Murphy, Psycho-Oncology Nurse, Health Service Executive

Gerd Murphy is an advanced Psycho-Oncology nurse with 23 years of experience as mental health nurse, working in the field of Liaison Psychiatry since 2011. She specialized in advanced nursing practice in psycho-oncology in 2018. She is currently a co-investigator working with the University College Dublin (UCD) and Saint Vincent's Hospital, Dublin. She's participating in a study titled: "Cancer Care for People with Significant Mental Health Difficulties (SMHD) – Understanding the Facilitators and Barriers to Care".

CANCER SURVIVORSHIP – AI FOR WELL-BEING

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Session 1

#CS_AIW

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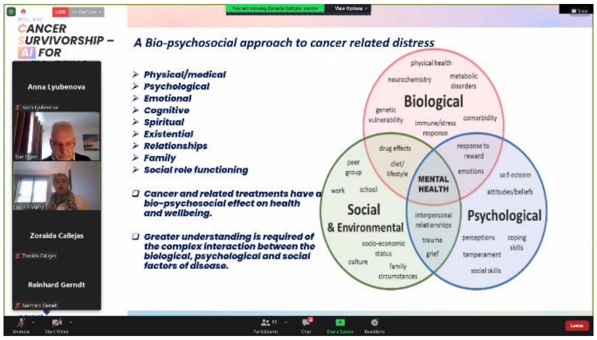
Gerd Murphy
Psycho-Oncology Nurse
University College Dublin



A Bio-psychosocial approach to cancer related distress

- Physical/medical
- Psychological
- Emotional
- Cognitive
- Spiritual
- Existential
- Relationships
- Family
- Social role functioning

☐ Cancer and related treatments have a bio-psychosocial effect on health and wellbeing.

☐ Greater understanding is required of the complex interaction between the biological, psychological and social factors of disease.

Session content highlights

Psycho-oncology is a multi-disciplinary specialty focusing on the psychological, social, behavioral and ethical aspects of cancer care for individuals affected by cancer, their care givers and families. Psycho-oncology addresses two specific dimensions of cancer: 1. / The psychological responses of patients to cancer at all stages of the disease; 2. / The psychological, behavioral and social factors that may influence the disease process.

The cancer diagnosis has a significant impact on psychological and social aspects of life, as well as on existential concerns. Mental health difficulties can occur at any time from the time of diagnosis onwards.

Approximately one third of persons with cancer in general hospital settings, experience clinically significant common mental disorders.

Distress during cancer journey is defined as a multi-factorial unpleasant emotional experience of a psychological, social and spiritual nature; it extends along a continuum, ranging from common normal feelings to problems that can become disabling.

There is a range of unmet psychological/mental health needs that really have a devastating impact on patients' well-being. This leads to reduced quality of life, negative impact on clinical treatment outcomes, lack of engagement to cancer treatment, increased use of healthcare resources, and increased risk of suicide in patients.

"Regardless of the amount of support services that are in place, when they are going home to the same maybe financial worries, issues with their children, issues with work, really, it's very hard for them to move forward regardless of the amount of counseling support we have in place, physiological support we have in place." **– Gerd Murphy, Registered Advanced Nurse Practitioner Psycho-oncology at Health Service Executive.**

When we are looking at supporting peoples' mental health during the cancer care and beyond stages, we have to consider the bio-psycho-social approach to mental health.

Main barriers for access to mental health support include lack of standardized distress screening, lack of awareness of available resources, time constraints, place of care environment, communication difficulties, patient concealing distress, perceived stigma, challenging behaviour, lack of education and training for oncology care providers.

"Only 40% of survivors reported having had a discussion with their clinicians about how cancer may have affected their emotions or relationships." **– Gerd Murphy, Registered Advanced Nurse Practitioner Psycho-oncology at Health Service Executive.**

Artificial Intelligence projects can improve mental well-being for individuals throughout the experience of cancer by increasing awareness, normalizing the experience of distress, providing education and information, early detection and alerting as well as identifying key supports to initiate timely and responsive interventions to improve health outcomes and quality of life.

Q&A

This session provoked a question about patients with brain tumors and how it can affect their ability to receive psychological support. In cases of specific brain cancers or brain metastasis, the individual can experience a devastating range of symptoms and side effects, such as personality changes, behaviour changes, mood changes, but also cognitive changes. The response to an individual who has experienced a brain cancer or metastasis to the brain very much depends on an individual basis. That really does highlight the need for a very comprehensive bio-psycho-social assessment and a much-tailored intervention in each specific case.

Key message of the session

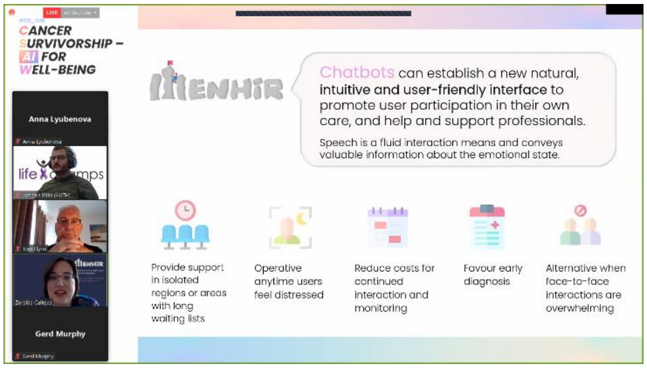
Mental health presents a substantial aspect of the cancer patients' and survivors' well-being, which is still not properly addressed. Although emotional distress in cancer patients may be a normal experience, it may become pathological when affecting the treatment or the life of the patient. There is a range of unmet needs in this regard. A very comprehensive assessment is needed on an individual level, as well as tailored individual interventions to overcome this gap and improve the mental health well-being of cancer patients and survivors.

#CS_AIW MoM4 - Day 1

Session 2: The MENHIR experience: MENHIR corpus collection and analysis, user modelling, conversational interaction design and personalization

Presenter: Zoraida Callejas, Associate Professor at the University of Granada, Coordinator of the H2020-MSCA-RISE project MENHIR

Zoraida Callejas is an Associate Professor at the University of Granada (Spain), from which she obtained a PhD in Computer Science in 2008. Her research focuses on areas related to dialogue systems, conversational systems, emotion processing, affective computing and user modeling. She has published more than 150 contributions to scientific journals, books and conferences, and has published 2 books. She is currently coordinating the H2020 MSCA-RISE project, MENHIR (823907), on interactive conversations for mental health, the Andalusian R&D&i project BonAppPetit (P18-RT-4550) related to the use of conversational systems to foster healthy habits in children and the Spanish R&D&i project GOMINOLA (PID2020-118112RB-C21, PID2020-118112RB-C22) focused on multi-task dialogue management for conversational agents based on micro service orchestration.



Chatbots can establish a new natural, intuitive and user-friendly interface to promote user participation in their own care, and help and support professionals.

Speech is a fluid interaction means and conveys valuable information about the emotional state.

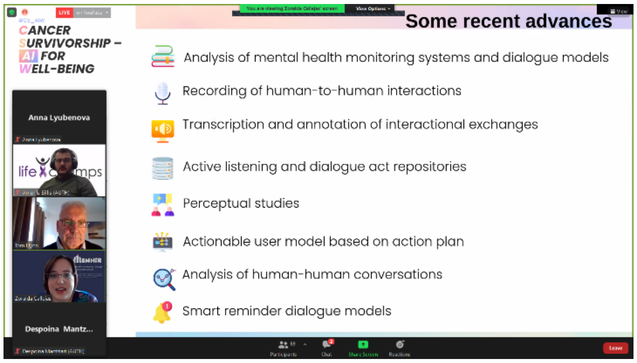
Provide support in isolated regions or areas with long waiting lists

Operative anytime users feel distressed

Reduce costs for continued interaction and monitoring

Favour early diagnosis

Alternative when face-to-face interactions are overwhelming



Some recent advances

- Analysis of mental health monitoring systems and dialogue models
- Recording of human-to-human interactions
- Transcription and annotation of interactional exchanges
- Active listening and dialogue act repositories
- Perceptual studies
- Actionable user model based on action plan
- Analysis of human-human conversations
- Smart reminder dialogue models

Session content highlights

Mental e-health applications have the potential to improve mental health literacy and facilitate access to mental healthcare by offering flexible, trustworthy and immediate means of accessing help.

"Chatbots can establish a new natural intuitive and user-friendly interface to promote user participation in their own mental health care and support professionals." – Associate Professor Zoraida Callejas.

Chatbots can establish a more intuitive and user-friendly interface to engage users in the management of their well-being and support mental health professionals. The H2020 MSCA Research and Innovation Staff Exchange (RISE) project, MENHIR (Mental Health monitoring through InteRactive conversations), has developed a sustainable collaborative network around the development of conversational technologies for mental e-health including organizations from the academic and non-academic sectors: University of Granada (Spain, academic, coordinator), Action Mental Health (UK, non-profit), Ulster University (UK, academic), University of the Basque Country (Spain, academic), Intelligent Voice Ltd. (UK, industrial), Ulm University (Germany, academic), Università degli Studi della Campania Luigi Vanvitelli (Italy, academic), and GLOBIT (Germany, industrial). The focus of the network is to train staff to acquire new knowledge, skills, research and innovation capabilities, and career development perspectives by means of cross-sectorial secondments.

"Technology should assist us in maintaining a good physical health, but also in achieving our mental health goals." - Associate Professor Zoraida Callejas.

MENHIR started in February 2019 and will continue until February 2024. During this session, Prof. Callejas presented the multiple challenges addressed by MENHIR in this time, including relevant aspects related to adaptive decision making, conversational models and communication styles, analysis of verbal and non-verbal cues, and personalized interaction taking into consideration that they are heterogeneous in terms of age, gender, mental health condition, progression, and responses to system's strategies. Prof. Callejas emphasized the importance of participatory research based on co-creation, ethics and good practices for data storage, annotation and sharing, as well as continued dissemination and communication.

In addition, some lines for current and future work were presented for which the feedback of users is key, including acceptability and usability of mental health chatbots, best user state and progress monitoring and feedback strategies, policies for adaptive dialogues and effective communication and generalization of results.

Q&A

MENHIR posed two questions in a poll:

- Do you use conversational systems (e.g., mobile assistants such as Siri or smart speakers like Amazon Alexa) in your daily life?

  The number of responses for each possible answer was: frequently (4), sometimes (7), never (14), neutral / do not know (0).

- Would you consider using a chatbot such as the one proposed in MENHIR to help you improve/manage your mental health?

  The number of responses for each possible answer was: I would use it (9), I would consider using it (11), I would not use it (6), neutral / do not know (0).

It was interesting to see that 44% of the respondents uses conversational systems in their daily life at least sometimes, whereas 56% has never used them. However, when asked whether they would use a chatbot such as the one proposed in MENHIR to improve or manage their mental health, 77% would consider or definitively use it.

Regarding the questions posed by the audience, ethical aspects and trust issues were to the foreground. These facets are explicitly addressed in MENHIR in multiple ways, e.g., in the reliability of the sources of the information provided to users, the non-intrusive support to both mental health experts and users, as well as in the personalization of the interaction between the user and the system. A key aspect is the co-creation of the technology with its final users, in the case of MENHIR with people suffering from anxiety or mild depression.

Key message of the session

Chatbots can encourage users to improve their mental health and well-being in a myriad of ways: fostering literacy, helping individuals to access mental health services, providing personalized interactions, offering continued monitoring, and establishing a setting that users may feel as not stigmatizing or judgmental, thus making it more attractive for users who find it difficult to disclose in person.

The H2020-MSCA-RISE, MENHIR project, has established a multidisciplinary and cross-sectorial network with innovative training opportunities to address the development of groundbreaking chatbot technologies for mental health, following a participatory research principle.

Audience feedback was positive.

#CS_AIW MoM4 - Day 1

Session 3: Integrated cancer care for the older cancer champions based on Big-Data and QoL behaviouroume: the LifeChamps project

Presenters: Prof. Panagiotis Bamidis, Project Coordinator, Aristotle University of Thessaloniki and Dr. Antonis Billis, Scientific Coordinator, Aristotle University of Thessaloniki.

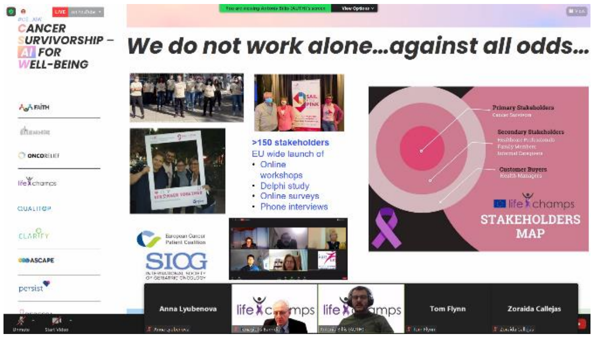
Prof. Panagiotis Bamidis is a professor of Medical Physics, Informatics and Medical Education in the School of Medicine at the Aristotle University of Thessaloniki, Greece. He designs, implements and evaluates IT and Assistive Technologies systems that improve everyday activities of elderly or other vulnerable groups and improves their health of life quality or improves the education and training of health professionals.

Dr. Antonis Billis is an Electrical and Computer Engineer and holds a PhD in the research area of digital. He is PostDoc Research Fellow in the Lab of Medical Physics and Digital Innovation, at the Medical School of Aristotle University of Thessaloniki. His research focuses on ehealth / mhealth, digital biomarkers, clinical decision support systems, as well as assistive technologies for vulnerable population. In addition, he has more than 10 years of research experience in national and EU projects.


Meeting of Minds 4
Session 3

Panagiotis Bamidis is a Professor of Medical Physics, Informatics and Medical Education and Director of the Lab of Medical Physics and Digital Innovation in the School of Medicine at the Aristotle University of Thessaloniki (AUTH), Greece. He designs, implements, and evaluates IT and Assistive Technologies systems that improve everyday activities of elderly or other vulnerable groups and improves their health or life quality or improves the education and training of health professionals.

Antonis Billis is an Electrical and Computer Engineer and holds a PhD in the research area of digital. He is PostDoc Research Fellow in the Lab of Medical Physics and Digital Innovation, at the Medical School of Aristotle University of Thessaloniki. His research focuses on ehealth/mhealth, digital biomarkers, clinical decision support systems, intelligent remote patient monitoring systems, as well as assistive technologies for vulnerable population. In addition, he has more than 10 years of research experience in national and EU projects.


We do not work alone…against all odds…

>150 stakeholders
EU wide launch of
- Online workshops
- Delphi study
- Online surveys
- Phone interviews

Session content highlights

The **LIFECHAMPS** project aims to integrate cancer care with a focus on Quality of Life, specifically of older adult patients with breast, prostate cancer, or melanoma after treatment. The consortium is composed of 15 partners based in 10 different countries.

"I want to thank all the partners for joining hands in the common endeavour of using technology for well-being and improvement of quality of life for cancer survivors." - **Prof. Panagiotis Bamidis.**

The key societal challenge that the project is trying to address is the "ageing stigma". Based on data, cancer diagnosis happens usually at a later age in life, i.e., the risk of cancer increases as people advance in age.

The LIFECHAMPS project is a Big-Data driven integrated care solution for geriatric oncology to counterbalance this problem. What the project attempted is undergoing is collecting data from different gadgets and digital solutions to create digital biomarkers. These biomarkers, along with the self-reported symptoms, measure and experiences from patients, are collected in a Big-Data infrastructure with High Performance Computing (HPC) enablers, which aim to create a multimodal analysis that will provide good digital frailty phenotypes indexes with the aim of classifying patients in frail, pre-frail and fit classes.

Specifically, the mobile app will allow participants to complete questionnaires, i.e., patient, reported outcome measures of patients, related to quality of life, symptoms, symptom's burden, etc. Additionally, the mobile app can guide patients in carrying out activities for dealing with their anxiety like breathing exercises, or listening to music.

The patients will be using a number of devices, which will be passively or actively monitoring their Quality of Life. The devices that have been integrated in the LifeChamps platform, at present are: a fitness tracker (the FitBit tracker); a smart scale; some unobtrusive sensors placed in the different rooms of the patients' homes; smart home devices, like smart plugs, that can monitor a patient's electronic appliances usage patterns like when they use their TV daily; a smart textile, a t-shirt that can be used to monitor vital signs in greater detail via sensors embedded in the T-shirt; and there is the option of monitoring the UV radiation exposure of melanoma patients thought the open service, OpenUV.

Furthermore, there is a component devoted to healthcare professionals. All the information collected from the patients will be appropriately processed, with the intent to provide meaningful insights to healthcare professionals and caregivers.

"These technology projects, in order to move forward, need to go through a procedure of including as many stakeholders as possible." **– Dr. Antonis Billis.**

Q&A

Q1. Do you find that the ageing stigma is prevalent across Europe or maybe certain regions?
I would say that it is probably more unified around countries and cultures in the sense that it is very much age-oriented, as it is called. But we have started to sort of facing it already now, through discussions we have had with the societies, as well as clinicians and clinical teams. Each one of the major obstacles in designing the pilots and how older adults/patients are going to be using technologies, perhaps they may not be able to etc. etc. We have started facing this problem already.

Q2. Quality of Life depends on the life goals patient has. Are these life goals taken into account?
Definitely there is some kind of profiling involved regarding the patients when we take them onboard on the mobile app. So, there are some kinds of questionnaires, through which we try to document the needs and expectations of patients, so we take them into consideration in order to personalize the contents of the mobile app and the different Quality of Life assessments that we are trying to perform.

Q3. Barriers and limits are really important. Are you finding common barriers across all areas based on what you've heard today?
Yes, I think there are a lot of common things, also appearing in the design of the various apps and dashboards, taken already into account. Different groups, of course, present differences (i.e., cancer types) but also common aspects. For example, if I can share with you the feeling of safety you have to provide for in your technology application, it is a common thing. It is something that all patients share, I think that all humans share. As humans, we would like to feel secure in our everyday life and if this is promoted with participation in a trial or a technology or in whatever system later on, it will be taken seriously into account and will increase adherence, engagement and stuff like that.

Q4. Is trust critical in the design and is it linked with engagement that they produce in these projects?
I think that is what I actually mentioned earlier on with regards to safety. I think the lack of trust is a barrier and I was mentioning the safety, sort of, environment that something like this may create, a project like this may create for patients, will counteract with this barrier, which is the lack of trust, a sort of phobia, perhaps, toward something new etc. and will account for that.

Key message of the session

The LifeChamps project aims to integrate cancer care with a focus on Quality of Life, specifically of older adult patients with breast, prostate cancer, or melanoma after treatment. The key societal challenge that the project is trying to address is the “ageing stigma”. The LifeChamps project is a Big-Data driven integrated care solution for geriatric oncology to counterbalance this problem. The project is aiming to collect data from different gadgets and different digital solutions creating digital biomarkers.

Feedback from the participating audience was positive.

#CS_AIW MoM4 - Day 1

Session 5: ONCORELIEF - Quality of life in cancer survivors; can we measure it and improve it?

Presenter: Sotiris Diamantopoulos, Research & Innovation Manager, EXUS Software Ltd.

Sotiris Diamantopoulos is research and innovation manager at EXUS. He holds a PhD in Computer Networks from the Democritus University of Thrace, Greece, along with a M.Sc. and a 5-year Diploma in Electrical and Computer Engineering from the same department. His research interests reside in the area of trustworthy AI solutions for the benefit of the public, and privacy-preserving cloud technologies. Since joining EXUS in 2019, he has been steering four H2020 projects on secure storage technologies, cloud computing, and eHealth.

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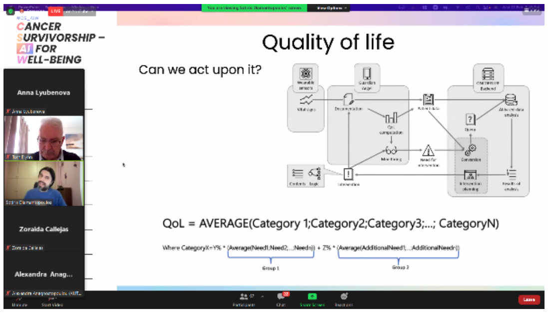

Quality of life

Can we act upon it?

QoL = AVERAGE(Category 1;Category2;Category3;...; CategoryN)

Where CategoryX=Y% * (Average(Need1;Need2;...;Needn)) + Z% * (Average(AdditionalNeed1;...;AdditionalNeedn))

Session content highlights

The project, ONCORELIEF, concentrates on the Quality of Life, because it can be a determinant and predictor of post-treatment health status and also because it is very useful metric by itself. The Quality of life needs to be personalized; it can focus on changes, but also on absolute values.

ONCORELIEF includes three types of data: wearable sensors, questionnaires and medical records; using these types of data, the project can use an index of how well a person feels. The ONCORELIEF Smartko wearable measures different body parameters. The Guardian Angel mobile application plays two roles: i/ provides the interface for transmitting data from the wearable and ii/ provides interacting interface for the cancer survivor. The application includes questionnaires, data charts and notifications. Medical record data are also incorporated in the application.

The project defines the QoL index as an average of specific categories. It also includes a web-app for clinicians. The clinicians are able to review patients' data from the questionnaires, the QoL parameters, certain details related to patient's bio-signals, and recommended suggestions provided by the system.

Q&A

Q1. Is there a method you apply of benchmarking? Are you using a customization mechanism?
The QoL index has been defined in a clear way for the clinical trial. It needs to be made more dynamic, more adaptable to each patient needs. More adjustable calculation of the index will be added at the end of the project.

Q2. Do you make any geographic adjustments of the index?
This is something done within the experimental part but not in the clinical trial part.

Q3. Who is the owner of the data – is it the patient?
The data are stored in ONCORELIEF Server and the owner is the patient.

Key message of the session

The project, ONCORELIEF, concentrates on the Quality of Life. The project includes data coming from: wearable sensors, questionnaires and medical records. With these types of data, the project can use an index of how well a person feels. The project defines the QoL index as an average of specific categories. It also includes a web-app for clinicians.

Feedback from the audience was positive.

#CS_AIW MoM4 - Day 1

Session 6: The FAITH Project - Improving the Quality of Life in cancer survivors through the use of technology for the identification & analyses of depression markers - An understanding

Presenters: Gary McManus (SETU Waterford Campus) – Project Coordinator, Stefanos Venios (Suite5), Xenia Eugenia (Xenia) Beltran Jounsaros (Universidad Politécnica de Madrid)

Gary Mc Manus specialized in computer science at the Waterford Institute of Technology (now SETU Waterford Campus). He has over 20 years' experience in the IT industry. He has extensive experience in the development of products and through his work in the Walton Institute (part of SETU Waterford Campus) and has managed several international and national projects.

Stefanos Venios is Computer & Electrical Engineer in Informatics. He has over 12 years' experience in business analysis and project management on software development projects. In Suite5 Data Intelligence Solutions and is an expert in eHealth, Ageing Personal Data Management and Blockchain.

Maria Eugenia (Xenia) Beltran Jounsaros is Information System Engineer, specialized in Biomedical Engineering and Health International Management. She is Senior R&D Project Manager and Head of Big Data in Life5Tech. Her areas of interest are AI, analytics and decision support systems, Health Technology Assessment (HTA) and health data compliance.

CANCER SURVIVORSHIP –
AI FOR
WELL-BEING

Meeting of Minds 4

#CS_AIW

Gary Mc Manus specialized in Computer Science at the Waterford Institute of Technology. He has over 20 years experience in the IT industry. He has amassed extensive experience in the development of products and through his work in the Walton Institute has managed several international and national projects.

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Maria Eugenia (Xenia) Beltrán Jaunsarás, is Information Systems Engineer, specialised in Biomedical Engineering and Health International Management. She is Senior R&D Project Manager and Head of Big Data in LifeSTech. Her areas of interest are AI, analytics and decision support systems; Health Technology Assessment (HTA) and health data compliance.

Session content highlights

Cancer patients face several challenges, which can affect their mental health and potentially, lead to anxiety, depression and therefore, reduce their quality of life. As the world population increases in age, globally, we face rising occurrence of cancer. In parallel, advances in medical science ensures that more people are surviving cancer. Some cancer survivors may feel that their self-perceived quality of life is affected, experiencing feelings of anxiety and depression after treatment has completed. Presently, FAITH is addressing this post-treatment consequence of anxiety and depression.

FAITH is creating an innovative solution that uses Artificial Intelligence / Federated learning-based technologies to track targeted depression markers in Cancer survivors to be able to monitor downward trajectories in these markers, and ultimately, inform their point of care of these declines.

Through the FAITH AI Angel app, Cancer survivors who begin to experience such declines will have an opportunity to be more aware of their mental health situation, receive as early as possible intelligent post-cancer support, and therefore, in the end, improve their quality of life and the decision-making process.

The main objectives for FAITH are to:

1. Design and implement FAITH AI App modules that capture data of potential depression markers in 4 areas (i.e., Sleep, Activity, Nutrition, and Voice) through device-based behaviour tracking, validated questionnaires and trials follow up,

2. Perform 3 observational trials (i.e., in IE, PT & ES) to capture and generate prospective data for building the predictive depression model,
3. Develop a Federated Learning AI solution that identifies and analyses depression markers using prediction models at the edge and
4. Demonstrate applicability, usability, effectiveness & value of FAITH concepts, models, techniques & framework through a clinical validation of the AI solution with real end users.

The project has hypothesized that a combination of continuum monitoring of daily activity, sleep, voice and nutrition can be predictive of depressive symptoms when compared and correlated to HAM-D (Dep. Severity) and HADS (self-rated depression and anxiety) results in Cancer survivor patients.

The current status of the project was presented to the audience showing a video of the FAITH AI app in use as well as the set-up of the clinical trials for the project.

Key message of the session

By using the FAITH app solution, Cancer survivors will be brought to the attention of their healthcare services if, and when, their depression markers start to show signs of downward trajectories. This means they can be offered intelligent post-cancer support as early as possible, helping to identify trends, which could affect their quality of life.

Audience feedback was positive.

#CS_AIW MoM4 - Day 1

Session 7: PERSIST (Presentation & Demo) - Introduction to PERSIST ecosystem and demonstration of the patient application

Presenters: Victoria Cal González, Gradiant and Gazihan Alankus, Emoda Software.

Victoria M. Cal González is Telecommunication Engineer specialized in Telematics. Among her academic interests are Theory is the Signal and Communications AI research. Victoria developed several projects and joined the eHealth area in Gradiant, where she is dedicated to the research, development and management of projects, focusing in the subjects related to Clinical Decision Support.

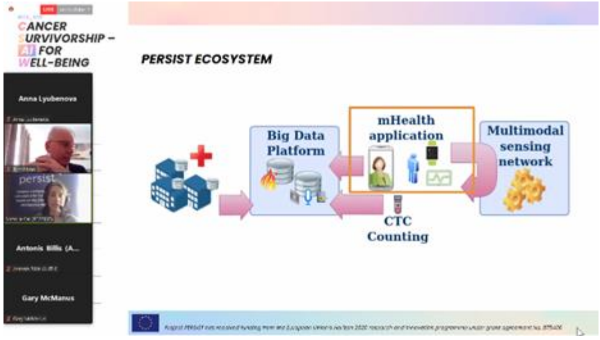
Gasihan Alankus is Computer Engineer with a PhD in Computer Science, developing motion-based computer games for people with stroke, and studied the usability and effectiveness of these games. He conducted research in Human-Computer Interaction, Computer Graphics, Robotics and Wireless Senior Networks.

Meeting of Minds 4
Session 7

#CS_AIW

Victoria M. Cal González is Telecommunication Engineer specialised in Telematics. Among her academic interests are Theory of the Signal and Communications IA research.
She developed several projects and joined the eHealth area in Gradiant, where she is dedicated to the research, development and management of projects, focusing in the subjects related to Clinical Decision Support.

Gazihan Alankuş is in Computer Engineer with a Ph.D. in Computer Science, developing motion-based computer games for people with stroke, and studied the usability and effectiveness of these games.
He conducted research on Human-Computer Interaction, Computer Graphics, Robotics and Wireless Sensor Networks.



PERSIST ECOSYSTEM

Session content highlights

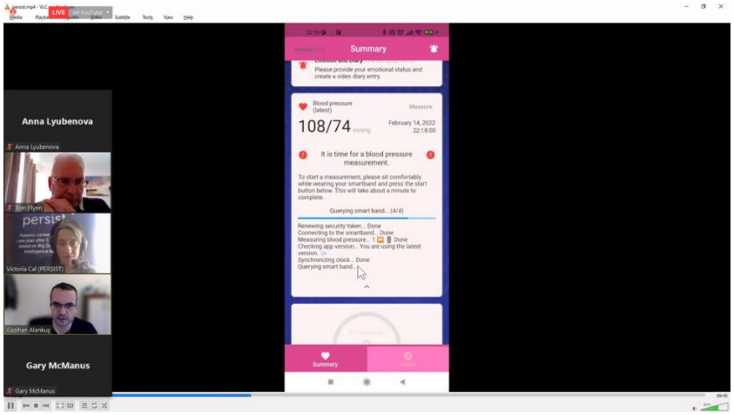
PERSIST project is granted by the European Commission in the frames of H2020 Programme (GA 875406). It is run by a consortium of 13 partners from 10 countries across Europe.

PERSIST main objectives are to address the unmet needs of breast and colorectal Cancer survivors and to help the clinicians in their day-to-day work. The project addresses issues like cancer recurrence, toxic effects after treatment, personalization of treatment, as well as anxiety and depression.

The project's ecosystem includes a Big Data platform, where information from patients is stored. A mHealth application is being developed, which connects with a bracelet for collecting well-being data (i.e., steps, sleeping, heart rate, blood pressure). Anxiety and depression are also detected in patients by recording videos and questions asked by an embodied conversational agent. A multimodal sensing network is extracted and some parameters are processed by AI models. This information is collected for the early detection of cancer recurrence, toxicity effects, anxiety and depression. A clinical decision support system is in place with a user interface for clinicians.

The patient's app is the main access to the PERSIST system. It is backed by the Big Data platform; where data is ingested into the clinician app. The app includes emotional status collection through answering questions, recording a video diary and filling questionnaires. The app also includes reminders.

During the session a demonstration was made of the patient's app and the clinician's interface.



Please provide your emotional status and create a video diary entry

Blood pressure (latest)
108/74 mmHg
February 14, 2022 22:18:00

It is time for a blood pressure measurement.

To start a measurement, please sit comfortably while wearing your smartband and press the start button below. This will take about a minute to complete.

Querying smart band... (4/4)

Renewing security token... Done
Connecting to the smartband... Done
Measuring blood pressure... Done
Checking app version... You are using the latest version.
Synchronizing clock... Done
Querying smart band...

Q&A

Q1. How many patients are enrolled in PERSIST trial?

Presently (Feb 2022), 160 patients are enrolled in the clinical trial – 40 in each hospital of the 4 different countries participating in the trial (Spain, Belgium, Slovenia and Latvia).

Q2. How long does it take for a patient to complete the data?

If patients use the bracelet, they only need to fill the questionnaires once a week. They are expected to spend no more than 20 minutes per week on this task.

Q3. What are the benefits for physicians - do they have more time since the data is coming through the system?

At this stage, the clinicians can only see the data without doing any prediction. This will be done in a next phase of the clinical study.

Q4. Do you expect the data provided to clinicians to affect the clinical practice? Have you considered certifying your solution?

At this stage, the clinicians can only see the data without doing any prediction. This will be done in a next phase of the clinical study. Certification is not foreseen in the timeframe of PERSIST as it is a very long process.

Q5. Do the patients receive alerts from the app?

Patients do not receive alerts from the app because clinicians cannot review the data coming from the app immediately; the patients shouldn't have the feeling that PERSIST is an emergency room. They are advised to go to the emergency room if they feel unwell.

Q6. Do you have any ethical issues with collecting patients' information? Who owns the data?

The project went through ethical approvals in the hospital to guarantee proper storage of patients' information. The owners of the data are hospitals and they transfer data to technical partners.

Key message of the session

The main objective of PERSIST is to address the unmet needs of breast and colorectal cancer survivors and help the clinicians in their day-to-day work. Through the development of a Big Data platform, mHealth app and a multimodal sensing network, the project addresses issues like cancer recurrence, toxic effects after treatment, personalization of treatment, as well as anxiety and depression.

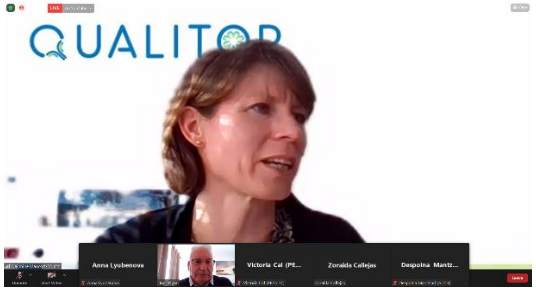
Feedback from the audience was positive.

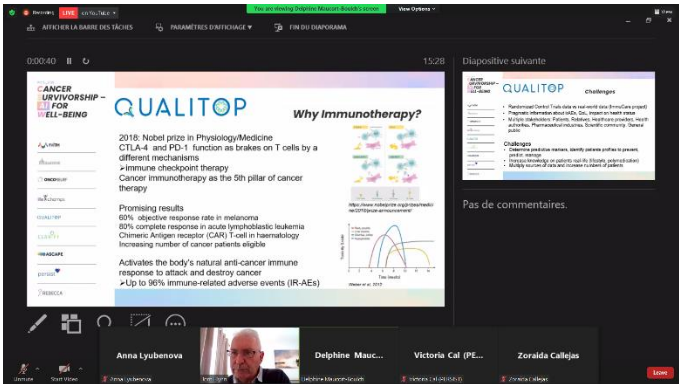
#CS_AIW MoM4 - Day 1

Session 8: QUALITOP - Where we are and what next!

Presenter: Delphine Maucort Boulch, Head of public health & Bio-Statistics and Bio-Informatics, Hospices Civils De Lyon

Delphine Maucort Boulch is a full professor of Medicine in Public Health, and PhD in biostatistics. She is the head of the Public Health department and head of the biostatistics-bioinformatics unit at the University Hospital. As staff member of the Biometry and Evolutionary Biology laboratory, she supervises the research “Individual prediction, Biomarker identification, Bioinformatics”. She is expert in survival analysis and regression modeling in cancer. She is also interested in models’ predictive performances, optimism bias and models selection. She supervised works in Big Data analyses and learned about machined learning. Clinically, her activity is dedicated to the implementation and the development of bio-statistical methods dedicated to medical applications.





CANCER SURVIVORSHIP – AI FOR WELL-BEING

QUALITOP

Why Immunotherapy?

2018: Nobel prize in Physiology/Medicine
CTLA-4 and PD-1 function as brakes on T cells by a different mechanisms
➢immune checkpoint therapy
Cancer immunotherapy as the 5th pillar of cancer therapy

Promising results
60% objective response rate in melanoma
80% complete response in acute lymphoblastic leukemia
Chimeric Antigen receptor (CAR) T-cell in haematology
Increasing number of cancer patients eligible

Activates the body's natural anti-cancer immune response to attack and destroy cancer
➢Up to 96% immune-related adverse events (IR-AEs)

https://www.nobelprize.org/prizes/medicine/2018/prize-announcement/

Weber et al. 2012

Session content highlights

QUALITOP project stands for monitoring multidimensional aspects of Quality of Life after cancer Immunotherapy, and Open smart digital Platform for prevention and patient management.

Immunotherapy stand in the center of the project because of recent scientific discoveries with promising results about activating the body’s natural anti-cancer immune response to attack and destroy cancer.

QUALITOP is realized through randomized control trials vs real-world data. It brings pragmatic information for multiple stakeholders, including patients, relatives, healthcare providers, health authorities, pharmaceutical industries, scientific community and general public.

The main challenges identified by the project are determining predictive markers, increasing knowledge on patients' real-life and multiplying sources of data, as well as increasing the number of patients observed in real life.

The project has the following objectives:

- Develop/implement IT-based European immunotherapy platform,
- Use Big Data analysis, AI and simulation modeling approaches,
- Collect/aggregate real-world QoL data, monitor patients' health status, conduct casual inference analysis,
- Create harm reduction recommendation for patients and stakeholders,
- Disseminate the findings.

"One of the key words of the Qualitop project is the multidisciplinary team and it is based on existing collaborations that were enriched within the European Union, but also out of it." – **Professor Delphine Maucort Boulch.**

The Qualitop project expects to achieve impact in three areas: Healthcare Providers and Patients; Healthcare Institutions; Public Health area.

During its two years of implementation, the project has achieved the first version of the conceptual architecture of Smart Medical Platform, the first patients were involved in prospective study. Also, a casual logo diagram was developed to forecast effect of policies and an analysis was made on the historical datasets.

Q&A

The speaker was asked how many clinical centers are involved in the project and in which countries. Answer: There are four from France, Spain, the Netherlands and Portugal.

Another question raised was about how much challenging is the simulation model.
Answer: The simulations are mainly in the economic part and do not present the most difficult part of the project. The main challenge seems to be to collect enough data for the analysis part.

Key message of the session

The QUALITOP project stands for monitoring multidimensional aspects of Quality of Life after cancer Immunotherapy, and Open smart digital Platform for prevention and patient management. It concentrates on Immunotherapy as a promising approach in activating the body's natural anti-cancer immune response. The project aims to bring impact for patients, healthcare providers and institution by using Big Data analysis, AI and simulation modeling approaches and collecting real-world QoL data. Audience feedback was positive.

#CS_AIW MoM4 - Day 1

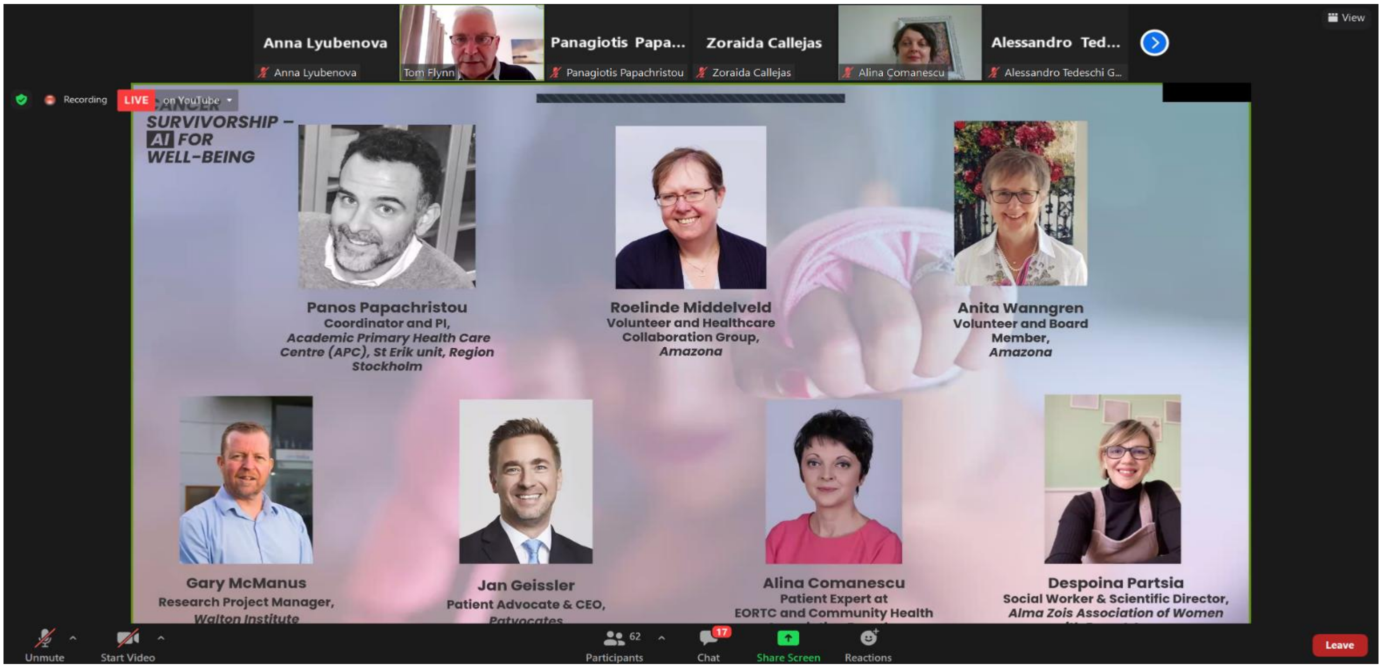
Session 9: Patient & Research - Round Table discussion with patients on engaged Cluster projects

Moderator: Panos Papachristotu, Coordinator and PI, Academic Primary Health Care Center, St. Erik Unit, Region Stockholm.

Panos Papachristotu is a medical doctor (specialist in Family Medicine) and holds a PhD in molecular and developmental neurobiology. His clinical experience is mainly within the field of General/Family Medicine and Primary care, alongside with vaccinology. He is presently the coordinator of an academic primary health care node at APC Region Stockholm and a participator in several ongoing research projects within primary health care. His research focuses on implementing new concepts and methodologies within Primary Healthcare, including ICT supported systems and strategies. He is the PI of 5 ongoing projects, including two H2020 funded projects.

Participants:

1. **Roelinde Middelveld**, Volunteer and Healthcare Collaboration Group, Amazona.
2. **Anita Wanngren**, Volunteer and Board Member, Amazona.
3. **Gary McManus**, Research Project Manager, Waterford Institute of Technology.
4. **Jan Geissler**, Patient advocate and CEO, Patvocates.
5. **Alina Comanescu**, Patient Expert at EORTC and Community Health Association Founder.
6. **Despoina Partsia,** Social Worker and Scientific Director, Alma Zois Association of Women with Breast Cancer.



Session content highlights

Roundtable discussion participants were asked to answer questions, which were preliminary raised by the Cluster projects.

Q1. How much of a barrier do you consider technology when embedded in the routine care process of older adults with cancer?

Jan Geissler: There are no specific barriers, we see 70-year-old people using iPads, the problem is that it creates new vulnerable populations - financially less viable - who cannot afford to buy a smartphone or a tablet. This has nothing to do with their age or education, but with financial capabilities. Another barrier is when people don't see the value, we are asking them to feed a machine with their QoL data, click on their symptoms and side effects, but there is no feedback, in the end it just informs the system, the clinicians, the insurance, but the value for the patient is just the promise that 'you will receive better care'. They don't see it benefitting in any way. Does this empower the patients, or it empowers the healthcare providers to take decisions on their behalf? The highest barrier is that these services are not co-created with the patients. They are usually just involved as testers rather than as co-developers.

Q2. Would you trust newly introduced technologies in healthcare like Artificial Intelligence or wearables to be part of your cancer (post) treatment? What your expectations would be from such solutions? What would you need from us so that your trust increases?

Roelinde Middelveld: It's very important to involve patients from the beginning when developing these tools. We participate in the Rebecca project and what we've done there is that we've taken an active role from the beginning. It is very important to get the input from a broader group of patients. We organized focus groups with patients to collect information on which type of data they are willing to share, how they feel about the security of the data. We sent a questionnaire to a larger group of patients to search which kind of browsers and social media they use, what is really useful. Patients should be involved from the beginning, not at the stage when the app is already completed.

In terms of developing technologies, it is always very well to have these technologies, but also the healthcare providers have to be prepared to use these data to improve the care for the patient. Doctors don't have enough time and, in the end, it is a question how useful it is. They have to be able to deal with this.

Gary McManus: It is important that the co-creation starts at the beginning of the project and follows to the end – in the development stage and also in going to the market. The projects have to know what the stakeholders are looking for, otherwise it is just a research project.

Q3. Which aspects of your daily life of healthcare is more important to you to see improved with the use of wearables and mobile apps?

Gary McManus: It depends on the patients themselves and how much they like to look at data. You have to guarantee that their data is protected.

Roelinde Middelveld: Patients would like to have control of which data is being transferred and have the possibility to close it off for a period of time. They need to have control on which data is sent and when. If it's an app that collects data, patients should be able to switch it off for periods of time, so that no data is collected.

Jan Geissler: This is part of GDPR. If it has been established for good reason, that increases trust, then you would actually feel more conformable. Patients are scared of cases when certain companies sell their genetic and health information. You never know where these companies go in five-year time.

Alina Comanescu: I was part of a focus group on GDPR aspects for cancer patients; patients asked about biomarkers and biobanks and what happened with their information. As you can see from this example, they need to be involved in the co-creation of everything with regard to their personal data.

Q4. Generally speaking, few patients are willing to participate in clinical studies. From your point of view, which are the main drawbacks they foresee?

Alina Comanescu: The first problem of clinical trials is education and communication. There are discrepancies in access and willingness to participate in clinical trials in Western and Eastern Europe. The bureaucracy plays a major role, the new directive on clinical trials I hope will ease this bureaucratic approach in Eastern Europe.

Q5. Do you think the integration of decision support systems with patient engagement strategies would be useful? What kind of patient engagement strategies would you suggest?

Despoina Partsia: What creates trust is the serious commitment. Elderly people need to have a commitment, direct contact, more information, they worry about personal data; they need more information.

Jan Geissler: The decision support systems are designed to support the clinician in the decision making on what he/she would do with the patients while it should support shared decision making. In the end patients might feel more alone, because the doctor or the machine suggests the best way forward for them, but they don't understand how the doctor has come to this conclusion. Having a patient interface, explaining how the decision support system comes to specific conclusions, how the algorithms came to that supportive conclusion, can be useful. Of course, this requires a specific level of literacy, some people trust the doctor, but some people feel uncomfortable if they don't understand how the recommendations came about. Patient engagement needs to have meta-design stage for those systems.

Alina Comanescu: One important strategy is asking patients to review outputs; this is how you empower patients and involve them in the co-creation activity.

Q6. Which kind of incentives/motivation you think should be offered to cancer survivors in order to participate in the design and research of innovative digital health solutions? Should they differ according to age or gender?

Despoina Partsia: These people need to feel that someone cares and they are still protected, to develop a framework of trust.

Roelinde Middelveld: When we asked our members to participate in focus groups and questionnaires, we found that there was a high interest among them – it's very important to give clear information why you want to collect data and information from them and what would be the benefit for them for providing this information.

Gary McManus: People that have gone through the situation are willing to help people going forward and people that get cancer in the future.

Jan Geissler: If you want to involve people in your project, make sure there is a budget for their time. This is hard work, if you really want people in your work packages, in your review teams, people that constantly look at your interfaces or visual designs - this is hard work which takes hours and hours. That is one of the deficiencies in these proposals, there is budget for the staff members of the consortium and for travels, but not for patient advocates for providing their time. That should be foreseen.

Closing remarks

Gary McManus: Another important point for the patients is the simplicity of the information and the education. If a lay person is looking for information, it might be difficult – the information has to be as simple as possible.

Key message of the session

The process of co-development includes involving patients from the beginning in all stages of the research. Patients need sufficient information in order to ensure their trust in clinical trials. Technologies and decision support system should be beneficial for patients and not only for clinicians and systems. The security of collected data needs to be guaranteed.

< End of Day 1>

#CS_AIW MoM4 - Day 2

Session 1: European Commission presentation on patient engagement in research projects and proposals

Presenter: Dr. Barbara Kerstiens, Head of Unit "Combatting Diseases", Research & Innovation DG, European Commission.

Barbara Kerstiens has a long experience in international Public Health, working for Medicines Sans Frontieres, Johns Hopkins Bloomberg School of Public Health and DG Development and Cooperation at the European Commission, prior to joining DG Research and Innovation in 2012, where she has consistently worked in medical research and funding. Dr. Kerstiens received her MD from the Katholieke Universiteit Leuven, a Postgraduate Certificate in Tropical Medicine from the Institute of Tropical Medicine in Antwerp and a Master of Public Health from Johns Hopkins Bloomberg School of Public Health.

CANCER SURVIVORSHIP – AI FOR WELL-BEING

Meeting of Minds 4

#CS_AIW

Barbara has a long experience in International Public Health, working for Médecins Sans Frontières, Johns Hopkins Bloomberg School of Public health and DG Development and Cooperation of the European Commission, prior to joining DG Research and Innovation in 2012, where she has consistently worked in medical research and funding.

She received her M.D. from the Katholieke Universiteit Leuven, a Postgraduate Certificate in Tropical Medicine from the Institute of Tropical Medicine in Antwerp and a Master of Public health from Johns Hopkins Bloomberg School of Public Health.

Barbara Kerstiens
Head of Unit "Combatting Diseases", Research & Innovation DG – European Commission

EUROPEAN UNION

EU MISSIONS CANCER

Mission on Cancer

Challenges
- **2.7 million people** in the EU are **diagnosed** each year
- **1.3 million people die** from cancer each year (this no. will increase)
- **Total cost of cancer** in Europe in 2018: €199 billion

Opportunities
- **Assist Member States to improve cancer control**
- **Put citizens and patients at the centre of Research and Innovation**
- **Give Research and Innovation a central role in new policies by supporting the Europe's Beating Cancer Plan**

GOAL: 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, jointly with the **Europe's Beating Cancer Plan**

Four Mission objectives
1. Understanding cance
2. Prevention & early de
3. Diagnosis and treatm
4. Quality of life

Concrete actions

Session content highlights

In September 2021, the EU launched five missions as portfolios of actions across disciplines intended to achieve a bold, inspirational and measurable goal within a set of timeframes, aimed to have an impact to society and policy making as well as relevance for a significant part of the European population and wide range of European citizens. The Mission on Cancer is one of them.

The goal of the Mission on Cancer 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, jointly with the Europe's Beating Cancer Plan.

***"The Mission on Cancer's pillars are to: prevent what is preventable, optimize diagnostics and treatment and support quality of life."* – Dr. Barbara Kerstiens, Head of Unit "Combatting Diseases", Research & Innovation DG, European Commission.**

UNCAN.eu is to start as soon as a Europe-wide platform, utilizing existing, relevant research infrastructure and investing in the development of new models and technologies.

Research has been put forward to develop and validate a tool to measure the quality of life of cancer patients and survivors. It is being designed in a co-creation mode with patients and survivors in order to include their understanding of what quality of life means for them.

An important feature of the Mission is the development of a European Cancer Patient Digital Center. It will exist on national or regional level and will have different functions: provide information and support for cancer patients, survivors and their families; provide patients with access to data, also to include patients reported outcomes; allow patients and survivors make co-decision on their care.

Another important principle is that the need to put the patient more in the center of the research is of paramount importance. In effect, this involves: a focus on the actual needs of the patients; the removal the inequalities in patient involvement; making patient participation more standard; ensuring patients' activity as co-researchers; and to contribute to cancer prevention.

The implementation of the Mission will have the following guiding principles: ensure equity, access to knowledge, promote innovation, allow risk taking, "coalition of willing", communication. It is understood that the next steps will include a dialogue with the Member States, Horizon Europe work programme 2022, launching of Phase-2 Mission Board and developing of further synergies.

Notably a "Beating Cancer Stakeholder Contact Group" has been established and webinars as well as meetings will be organized through the platform for those who have registered.

Q&A

Some questions were asked related to the Beating Cancer Stakeholder Contact Group:

1. Is the engagement virtual through this group or physical and how does it actually work in practice?
2. What would be the outcomes of the stakeholder group?
3. Would it be useful to set a group of psycho-oncologists who are dealing with patients?

Answers:

1. The Group works virtually for the moment. Depending on the pandemic, in the future there may be hybrid or physical events.

2. The outcomes of the stakeholder group are in few directions – to set up research priorities, to provide valuable feedback to the implementation of the Beating Cancer Plan and to feed the dialogue with the Member states.

3. The Stakeholder platform is open for psycho-oncologists and it provides an opportunity for different stakeholder groups to start discussing among themselves.

The Q&A session also raised the question about the importance of the mental health aspect, which was qualified as an important part within the comprehensive approach taken by the Mission on Cancer.

Key message of the session

The Mission of Cancer is one of the five missions, launched by the European Union. It aims to save more than 3 million lives by 2030 and to ensure better and longer living for cancer patients and survivors. The patient engagement is essential and it is being promoted through initiatives like the European Cancer Patient Digital Center and the Beating Cancer Stakeholder Contact Group. Putting the patient at the center is a guiding principle for future cancer research.

#CS_AIW MoM4 - Day 2

Session 2: CLARIFY Platform: actionable knowledge for improving cancer long survivor´s quality of life

Presenters: Dr. María Torrente, Medical Oncology Department, Hospital Universitario Puerta de Hierro-Majadahonda.

Prof. Pedro Sousa, HOLOS S.A. and Faculty of Science and Technology, NOVA University of Lisbon (FCT/UNL).

Dr. María Torrente completed her clinical fellowship at Mount Sinai Hospital and School of Medicine and works as a medical doctor and researcher. Dr. Torrente has experience as clinical researcher at Cardiology Department. She currently works at Hospital Universitario Puerta de Hierro Majadahonda, and she is responsible for European Projects and Cardio-oncology consultations. This professional activity as a medical doctor is combined with academic activity as a professor at Francisco de Vitoria University.

Prof. Pedro Sousa is president of Holos SA, and responsible for Business Development and Innovation. He holds a PhD in Electrical Engineering and is professor at Universidade NOVA de Lisboa. Prof. Sousa collaborates with the Intelligent Robotics Centre at the UNINOVA Institute in the areas of E-commerce, Multi-agents Knowledge Discovery and Education.

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Session 2

Maria Torrente completed her clinical fellowship at Mount Sinai Hospital and School of Medicine, and worki as a medical doctor and researcher.
She has experience as clinical researcher at Cardiology Department. She currently works at Hospital Universitario Puerta de Hierro Majadahonda, and she is responsible for European Projects and Cardio-oncology consultation. This professional activity as a medical doctor is combined with academic activity as a professor at Francisco de Vitoria University.

Pedro Sousa is president of HOLOS SA, and responsible for Business Development and Innovation. He holds a PhD in Electrical Engineering and is professor at Universidade NOVA de Lisboa.
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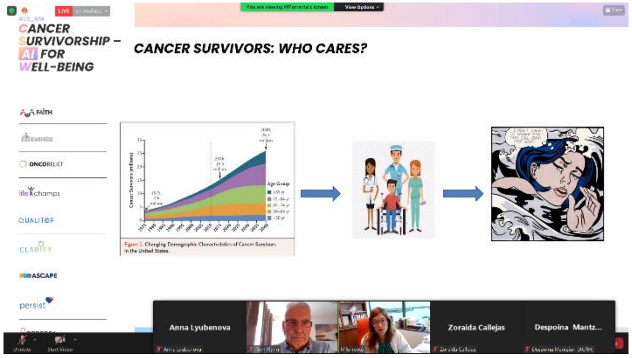

Session content highlights

The number of cancer survivors has increased in recent years due to advances in diagnosis and treatment but ensuring post-treatment quality of life of survivors remains a challenge.

Follow-up models of cancer survivors are considered inadequate and have not evolved in parallel for the effectiveness of treatments. Cancer is still considered an acute disease and the health care model is focused in toxicities during treatment not on secondary effects after treatment. In the meantime, cancer survivors have reported numerous unmet physical, functional, and psychosocial needs that impact on their quality of life and survival.

There are no evidence-based guidelines for the follow up of cancer survivors, and clinicians are instead based on expert consensus.

“With the CLARIFY Platform we can analyze our patients’ data in real time.” **- Dr. María Torrente.**

CLARIFY aims at identifying the post-treatment Cancer survivors who do have ongoing health and supportive care needs, to early determine the factors that predict poor health status. This is done through the analysis of the data collected (i.e., clinical data, and data about the patients´ circadian rhythm, physical activity and quality of life).

Data collected is processed and integrated in the CLARIFY Platform. The platform is a tool, presently under development, that better enables healthcare professionals to understand, work with and make decisions based on real data analysis of patients. It includes not only the integration of data but also algorithms and modules based on the analysis of data from cancer patients and explainable predictive models for clinical decision support. The CLARIFY Platform is capable of extracting and displaying information from several sources of data in a coherent, structured and readable way. Information can be organized and presented according to the clinician. It allows queries about the population or about one single patient for a detailed analysis.

“The CLARIFY Platform is a tool to be used by clinicians. Two different communities, clinicians and knowledge discovery researchers, talk and work together. That´s our main challenge and our hardest task.” **- Dr. María Torrente.**

Through AI and big data techniques, the CLARIFY Platform facilitates the analysis of the data collected and allows clinicians to:

- Obtain patients profiles for risk stratification,
- Obtain population patterns to personalize follow-up based on evidence,
- Design personalized interventions based on the analysis of different data sources.

Key message of the session

The CLARIFY project focuses on identifying risk factors for patient deterioration at the end of oncological treatment. Specifically, it collects data about survivors from breast cancer, lung cancer and lymphoma (the most prevalent types). Using Big Data and AI techniques, the data is analyzed to identify those post-treatment cancer survivors who do have ongoing health and supportive care needs to early determine the factors that predict poor health status. The goal is to provide better and more personalized care and to improve cancer survivors´ quality of life and well-being.

Audience feedback was very positive.

#CS_AIW MoM4 - Day 2

Session 3: Patient engagement in Clinical Trials

Presenters: Kathi Apostolidis, Board Member, European Cancer Patient Coalition

Public Affairs consultant with broad and diversified experience, **Kathi Apostolidis,** is a founding member and President of the Hellenic Cancer Coalition – ELLOK. Kathi is also member of the National Network of Precision Medicine representing cancer patients. Kathi was recently appointed as the ECPC President. Twice, surviving breast cancer, Kathi has been involved for many years in cancer policy advocacy, survivorship and cancer patient rights advocacy on the national and international level. Her activity covers issues of access to cancer care, health technology assessment, digital technology in cancer care, informed shared decision making in cancer, involvement in cancer research, cancer care delivery, health and digital literacy, patient safety.

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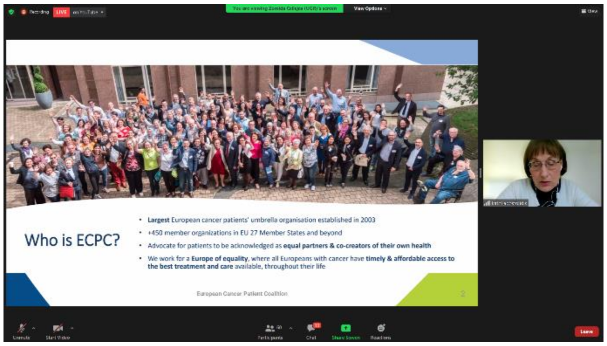
Public Affairs Consultant with broad and diversified experience, Kathi is a founding member and President of the Hellenic Cancer Coalition-ELLOK. She is also member of the National Network of Precision Medicine representing cancer patients. A former ECPC President, she is currently a ECPC Board Member.

Surviving breast cancer twice, she has been involved for many years in cancer policy advocacy, survivorship and cancer patient rights advocacy on the national and international level. Her activity covers issues of access to cancer care, health technology assessment, digital technology in cancer care, informed shared decision making in cancer, patient involvement in cancer research, cancer care delivery, health and digital literacy, patient safety.

Kathi Apostolidis
Board Member,
European Cancer Patient Coalition



Who is ECPC?

- **Largest** European cancer patients' umbrella organisation established in 2003
- +450 member organizations in EU 27 Member States and beyond
- Advocate for patients to be acknowledged as **equal partners & co-creators of their own health**
- We work for a **Europe of equality**, where all Europeans with cancer have **timely & affordable access to the best treatment and care** available, throughout their life

European Cancer Patient Coalition

Session content highlights

ECPC is the largest European cancer patients' umbrella organization established in 2003. It is active in policy, research, education and capacity building, communication and governance. The coalition participates in 17 EU funded projects and actively works towards the EU Cancer Mission and Cancer Plan.

***"Active engagement of patients is vital to improve the quality of healthcare in Europe and to understand patient preferences about their treatment and care."* - Kathi Apostolidis.**

When affected by cancer, the primary interest of cancer patients is to get treatment and recover their health. Initially, patients do not know much about clinical trials. Information is not available in all EU languages, which is a barrier to spread of knowledge about clinical trials among patients. Often when patients participate in clinical trials, they participate as objects.

The two key factors that activate the patients' interest to their care are: the possibility to get the same information as their doctors on the internet; the genome sequencing. The latter facilitated the considerable shift towards more active patient participation in clinical trials.

Patients and patient organizations may have much more to offer in regard to patients' engagement in clinical trials. By using their experiential knowledge patients have a potential role as partners in clinical research. It is very important to involve cancer patients from the start.

"A partnership built between patients and patient organizations and the other stakeholders like pharmaceutical companies, clinical researchers, CROs will create new paradigms for which not only the patients will benefit but also the quality, quantity and effectiveness of clinical research. In the end, such partnerships will contribute to better patient-centered healthcare."
- Kathi Apostolidis.

We need to ensure that the conducted research has a meaning for the patients to be invited to participate in the clinical trial. The research question should be relevant to both patients and researchers. The studies should adopt from the start an appropriate design and methodology.

The availability of published results is a very important issue, which has given rise to a new generation of open-access journals for patients and researchers. The systematic assessment in relation to other relevant studies is important as well.

Q&A

Cluster representatives raised the question about how to avoid losing patients during a clinical trial. Answer: The more the patients are informed before their enrolment in the clinical trial, the less they will drop-off the study. The more questions are answered promptly, the more they will be convinced to stay.

Another question concerned the possibilities on the use of incentives for clinical trial participants and more specifically, the ways to strengthen the method of providing education that would reduce the stigma connected to clinical trials. Answer: This issue depends on the countries and the culture that they have in clinical trials. In some countries, patients receive really good care during clinical trials, which is the real incentive for them - they are much more followed. They should be assured that their care is what the clinicians and the researchers have in mind.

Most of the projects presented in the MoM4 event create solutions for patients like a mobile app to collect information and introduce a web application for clinicians. Sometimes patients doubt if their data is being observed and considered by clinicians. This problem depends on the research team – they have to create trust before starting the trial. Specially trained people – such as cancer research nurses – are especially valuable.

Key message of the session

Patients have a central role in the implementation of clinical research; however, they should participate as active co-creators rather than just as objects in trials. It is essential to involve patients from the very beginning and ensure that the conducted research has a meaning for them, that they are cared for, well informed and properly followed, as well as to guarantee their access to published results.

Audience feedback was positive.

#CS_AIW MoM4 - Day 2

Session 5: ASCAPE: AI-powered framework, clinical testing and patient engagement

Presenters: John Avramidis, Project Delivery Management, Communication, Dissemination and Exploitation Specialist, UBITECH.

Ioannis Avramidis is Project Delivery Manager with UBITECH and has a diploma in Social Studies and MSc in environmental management. Ioannis has participated in several EU funded projects, among them are e-health related projects, where he was responsible for managing medical landscape stakeholders. He has long run experience in dissemination and exploitation activities promoting research outcomes, both scientifically and commercially.

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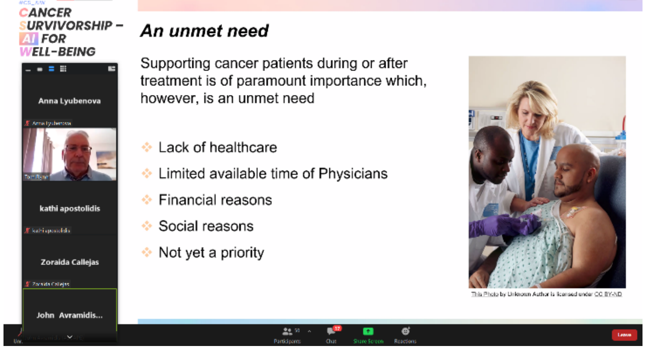
John Avramidis,
Project Delivery Management,
UBITECH



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An unmet need

Supporting cancer patients during or after treatment is of paramount importance which, however, is an unmet need

- Lack of healthcare
- Limited available time of Physicians
- Financial reasons
- Social reasons
- Not yet a priority

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Session content highlights

It is widely accepted that cancer rates are rising worldwide. Cancer patients can live longer thanks to medical advances and new treatment regiments. However, their Quality-of-Life is often reduced due to the side effects of the treatment and the cancer itself. Thus, it becomes increasingly important to support them during and after their battle against cancer. ASCAPE is an EU-funded project working towards this direction.

ASCAPE aims to build a digital platform to support the cancer patients by providing actionable information to their doctor. In this way, the role of the doctor is not replaced, but rather, is supplemented and enhanced, using new technologies like AI and Big Data. These are delivered in an appropriate, fit-for-purpose environment, which safeguards patient data privacy, security, and anonymity, promoting a balanced relationship between patients and doctors.

"Our way to increase healthcare access and quality of services while reducing costs is by making use of patients' data to feed AI models for better recommendations and ill-health projections" – Ioannis Avramidis

The ASCAPE Platform is scrutinized to ensure that works is at a standard matching any other medical application. ASCAPE researchers do this through the process of verification and validation at four healthcare and academic institutions in Spain, Greece, Sweden, and the United Kingdom, specializing in cancer treatment. In this process, a methodology is followed in which the Quality-of-Life issues of breast and prostate cancer patients are first identified and then, possible interventions and a strategy for evaluating the effectiveness of the platform are selected. By studying patient's most common symptoms, ASCAPE selected indicators that make the most sense of the daily challenges that a patient faces based on factors like frequency, magnitude of impact on the patient's life, and self-reporting ability among others.

"It is not just the transmission and management of digital data. We have already seen how this can be turned into critical insights for physicians that leads to saving lives." – Ioannis Avramidis.

However, the set-up and realization of trials in a clinical setting that includes a heterogeneous sample (i.e., different ages and countries, socioeconomic background) of patients is a complicated and a lengthy process that also encompasses a variety of aspects, such as the complexity of interventions, the endless combinations of possible scenarios, and many external factors (COVID-19 is one of these occasions). For example, it was realized that in some countries older aged persons face difficulties in using the wearable or smart phones and there is an initial skepticism from patients on using digital technologies. But in any case, it is clear that all patients reported so far that appreciate the "technology-enabled care and attention" while, there is also positive feedback regarding a sense of ''continuous monitoring''. In any case, the underlining key goal is to prove that these interventions have a real positive impact on patients' Quality-of-Life and in the long term, to build a network of healthcare providers that will improve the access to healthcare services not only for cancer patients but also to people with other diseases.

Q&A

1. *"Does the platform allow the integration of data stemming from different departments within the hospitals?"*
2. *"Patients' data could originate from cardiology or oncology department. When are you using this data for AI analysis is it possible to integrate it within the hospital platform?"*

Answers: ASCAPE adopts a data harmonization based on HL7 FHIR to provide a unique and widely accepted data format entry to all the AI engines. This unique data entry format allows the easy integration of new datasets from different sources without the necessity of changing the AI code. Overall, standardization is needed for the federated learning approach of ASCAPE.

From the whole set of FHIR resource types those that model ASCAPE frame (in the context of ASCAPE trials) are: *Patient, Observation, MedicationAdministration, Condition, Procedure, BodyStructure, Questionnaire, QuestionnaireResponse and FamilyMemberHistory*. In this way, a network of FHIR resources is created and specific to each use case (in the case of ASCAPE, a platform that collects data of interest from breast and prostate cancer patients) and the information is represented in a homogeneous way.

This way we created a common framework that is easy to replicate in different systems, being especially useful in models such as Electronic Health Records (EHR) and Hospital Information Systems (HIS). Based on this homogeneous scheme, the inclusion of a new pilot, use case or clinical frame could be achieved in a simple way. It will only have to collect the information following the ASCAPE common data model defined in the project, being the new data incorporated in an automatic, uniform, and standardized way in the ASCAPE common repository.

Key message of the session

New technologies in healthcare, specifically in related to cancer, like Big Data and AI already exist. As part of this research endeavour, the ASCAPE project aims to support cancer patients by predicting their health status, and helping their clinicians improve their Quality of Life. Through four pilots, hundreds of patients with breast or prostate cancer are taking advantage of state-of-the-art digital technologies. Through our scientific work, we close a gap in patients' quality of life services by providing a better and more personalized physiological and psychological support, improved patient and family counselling and guidance, early diagnosis, identification of disease trajectories and relapse, as well as improved health literacy. Ultimately, this can result to improved access to healthcare services while reducing their cost. This could be particularly useful for people who are still excluded from such services for both socio-economic and geographical reasons.

Audience feedback was positive.

#CS_AIW MoM4 - Day 2

Session 6: REBECCA: Vision and demonstration of the patient mobile application and the web browser plugin

Presenters: Ioannis Sarafis, Postdoctoral researcher, Department of Electrical and Computer Engineering, Aristotle University of Thessaloniki, Greece.

Lazaros Apostolidis, Research Assistant, Information Technologies Institute (ITI) of the Centre for Research & Technology Hellas (CERTH), Greece.

Ioannis Safaris has a PhD in Electrical and Computers Engineering from the Aristotle University of Thessaloniki (AUTH), Greece, with a focus on machine learning. Ioannis is the Technical Manager of the REBECCA project, coordinating the project's scientific and technical work. He has much experience working with data-driven models for the identification of risky eating and physical activity behaviours, big data algorithms for the analysis of behavioural patterns. His research interest focuses on machine learning and data analysis with noisy or incomplete labels.

Lasaros Apostolidis is Research Assistant at the Information Technologies Institute (ITI) of the Center for Research & Technology Hellas (CERTH). As a member of the technical team, Lasaros has been involved in several EU-funded projects. His main research interests reside in the areas of web design and development, data mining and big data visualization, focusing on content sourced from the Web and social media platforms.

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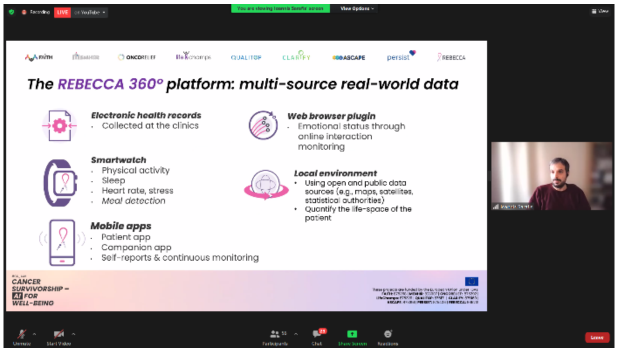
Ioannis Sarafis has a PhD in Electrical and Computers Engineering from the Aristotle University of Thessaloniki (AUTH), Greece, with a focus on machine learning. He is the Technical Manager of the REBECCA project, coordinating the project's scientific and technical work.
He has experience working with data-driven models for the identification of risky eating and physical activity behaviours, big data algorithms for the analysis of behavioural patterns. His research interest focuses on machine learning and data analysis with noisy or incomplete labels.

Lazaros Apostolidis is Research Assistant at the Information Technologies Institute (ITI) of the Centre for Research & Technology Hellas (CERTH). As a member of the technical team, he has been involved in several EU-funded projects. His main research interests lie in the areas of web design and development, data mining and big data visualization, focusing on content sourced from the Web and social media platforms.



The REBECCA 360° platform: multi-source real-world data

Electronic health records
- Collected at the clinics

Smartwatch
- Physical activity
- Sleep
- Heart rate, stress
- *Meal detection*

Mobile apps
- Patient app
- Companion app
- Self-reports & continuous monitoring

Web browser plugin
- Emotional status through online interaction monitoring

Local environment
- Using open and public data sources (e.g., maps, satellites, statistical authorities)
- Quantify the life-space of the patient

Session content highlights

"It is very important that we have patients who are active in the co-creation process, this enables us to understand their background and target their needs." – Ioannis Sarafis

The REBECCA vision is based on using multi-source real world data for improving patient management and supporting clinical research in breast cancer patients.

REBECCA combines data from electronic health records, smartwatch, mobile apps, web browser plugin and the local environment of the patient.

Demonstration of two core prototype technologies of REBECCA: 1/ the patient application and 2/ the web browser plugin were given. The prototype patient application captures annotated photos, PROM questionnaires and continuous location. The continuous location is processed and transformed into location agnostic indicators that characterize functional status in a privacy-preserving way (e.g., time spent outside home, number of daily trips, visits to amenities, etc.)

The web browser plugin is applied for the first time in this context of patient monitoring.

By capturing the online interactions of the patient and applying AI methods, we will be able to infer emotional status indicators for stress, anxiety, depression and fear of recurrence.

Q&A

Q1: Do older patients use social media?

Answer: In fact, that is something we understood through the co-creation activities of REBECCA and actively involving patients: almost all patients – even the older ones – use at least one type of social media, mostly Facebook. In addition, we were able to recognize that Chrome is the dominant browser for our target population.

Q2: How do the patients use the web browser plugin?

Answer: We strive to have few interactions between patients and system and mostly, passively monitor them in their daily life.

Key message of the session

Using multi-source real-world data in combination with causal modeling analysis, we can tackle the problems that arise when we study cancer-related complex chronic conditions and, also, improve treatment and Quality of Life for these patients.

Audience feedback was positive.

#CS_AIW MoM4 - Day 2

Session 7: Cancer Survivorship - AI for well-being - Cluster: Where are we and where collaboratively we are going.

Presenters: Antonis Billis, Aristotle University of Thessaloniki & Tom Flynn, TFC.

CANCER SURVIVORSHIP – AI FOR WELL-BEING

Where are we and where collaboratively are we going

Antonis Billis – Aristotle University of Thessaloniki

Tom Flynn – TFC Research and Innovation

#CS_AIW

The shared presentation re-iterated some of key messages from the opening of the MoM4 event on Day 1, stating that the main objective of the #CS_AIW Cluster is to **share common interest** and **collective ideas to support our project outcomes** through the process of a closed collaboration with related eHealth projects, focusing in on the areas of physician, patient, clinical, technical and business issues and potential remedies in support, for all to learn from and help strengthen outcomes.

The undertaken applies to **all research and development stages** – i.e., from concept through to delivery.

Common interest includes: **mental health, well-being, depression, AI, clinical trials, ethics, business models and patient support**.

Cluster collaboration is based on the adoption of a **highly user-centric approach** to their solution / outputs, learning together based on experiences and knowledge.

In terms of **post-cancer treatment patients**, the Cluster includes project for cancers of Breast, Prostate, Lung as well as Melanoma Rectal Cancer and Leukemia, Depression and anxiety. It also includes patients treated with immunotherapy or CAR-T cells Lymphoma and Colorectal Cancer.

Post-cancer treatment patient focused areas include depression, cancer treatment effects, quality of life, potential drug related toxicities, bowel dysfunctional, cognitive impairment, fatigue, mental health wellbeing scale.

In terms of plans for 2022, the Cluster has set ambitious targets. Some of the activities includes:

1. Define common data sets and ways of sharing with the scientific community regarding cancer and quality of life.
2. Workshop to demonstrate the solutions produced within the Cluster and bring together end-user organization
3. White paper on Cluster activities.
4. Patient involvement and more specifically, how to incentivize both clinicians and patients to participate in novel digital health technologies trials.
5. Organize a series of podcasts (participation of experts within our consortiums) with several thematic – e.g., ethics, perspective of patients on QoL.

We were also very pleased to welcome the CAPABLE project to the Cluster. The MoM4 event provided an ideal opportunity to introduce CAPABLE to the audience and Session 8 was formed and presented by Professor Silvana Quaglini, the Project Coordinator of CAPABLE. Details on the project are provided overleaf.

#CS_AIW MoM4 - Day 2

Session 8: The CAPABLE project (CAncer PAtients Better Life Experience)

Presenters: Silvana Quaglini, Head of the Laboratory of Biomedical Informatics, Department of Electrical, Computer and Biomedical Engineering, University of Pavia, Italy

Silvana Quaglini, MS in Electronic Engineering, PhD in Bioengineering, full professor of Medical Informatics at the University of Pavia, Italy. Professor Quaglini research focuses on decision support systems, shared decision-making, computer-assisted rehabilitation, home patients monitoring and economic evaluation models of healthcare interventions. Application areas include support systems for diagnosis, therapy and monitoring, such as computerized guidelines, economic evaluation models based on decision analysis, telemedicine systems and workflow management within healthcare organizations. Professor Quaglini is author of about 290 scientific publications, h-index=42 (2022, Scopus).

Session content highlights

CAPABLE (CAncer PAtients Better Life Experience) is a European project funded under the Horizon 2020 programme, which is based on Big Data and Artificial Intelligence to monitor the health and quality of life of cancer patients.

Cancer is among the leading causes of death in the world; however, the survival rate is increasing and nowadays, managing long-term care is the real challenge to be overcome. Patients are mostly treated at home, and only enter the hospital for urgent visits or hospitalizations or for scheduled follow-ups. The criticality lies in the aggressiveness of the treatments, which often cause adverse events, which therefore, arise at home and significantly affect the quality of life of the patient and those who care for the patient. Symptoms, usually, if not very serious, are reported to the doctor during check-ups, which would usually take place every two or three weeks or even more. This monitoring is not optimal, because the patient could also forget, underestimate and not correctly report a symptom that arose between the previous visit and the current one. The CAPABLE project will allow the patient, through an app, to directly enter data and symptoms in real-time. The patient will also have a smartwatch that will automatically collect other data related to some vital parameters, as well as physical activity and sleep quality. The app will provide advice on how to best treat the adverse events that occur to the patient, also in accordance with his/her characteristics (e.g., age, comorbidities). The app will give targeted advice on how to deal with toxicities at home when possible, or when it is advisable to contact the doctor. Consequently, all the data and conditions concerning the patient are also notified to the doctor, so that he always has the most possible updated, complete and comprehensive picture.

In addition, CAPABLE does not only want to help from the point of view of toxicity management, but more generally, it wants to increase well-being in a broader sense, addressing the issues of a healthy lifestyle, mental well-being and therefore of the emotional sphere. Therefore, CAPABLE will try to give advice in these fields, with the help of psychologists, nutritionists and physical therapy experts, always in close collaboration with the oncologists. In this way, it is likely that the patient, feeling supported, does not make personal choices (e.g., decrease or suspend the dose of treatment) that can cause serious damage to their health. On the other hand, the doctor will not receive calls or visits from patients even for very mild symptoms, thus, reducing inappropriate access to the hospital.

CAPABLE combines the efforts of 12 partners, in Europe and Israel, coordinated by the University of Pavia (Prof. Silvana Quaglini). The clinical studies will be carried out in 2023 at the hospitals ICS Maugeri in Pavia, NKI in Amsterdam and Policlinico di Bari. In 2022, a substantial number of patients will be studied to assess their quality of life and thus have a term of comparison to understand what benefits the project will provide.

Key message of the session

The CAPABLE team fully realizes the importance of taking part of this Cluster (#CS_AIW), because the quality of life of cancer patients has a broad number of dimensions. Every project focuses on some aspects, and through the process of sharing different views, it may lead to a more comprehensive and efficient approach, which could be proposed in future EU proposals/projects.

< End of Day 2 and the MoM4 event >

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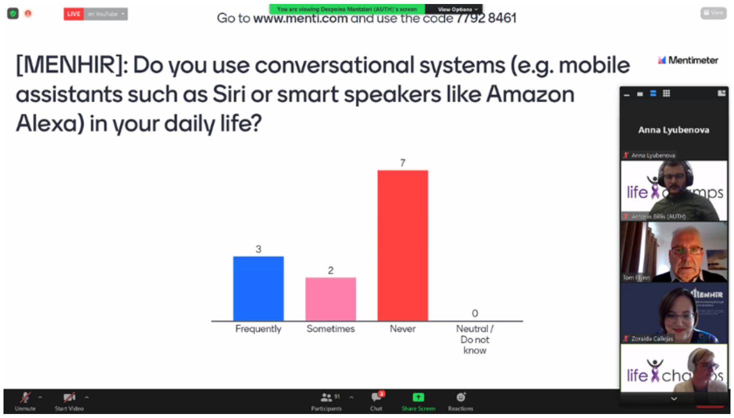
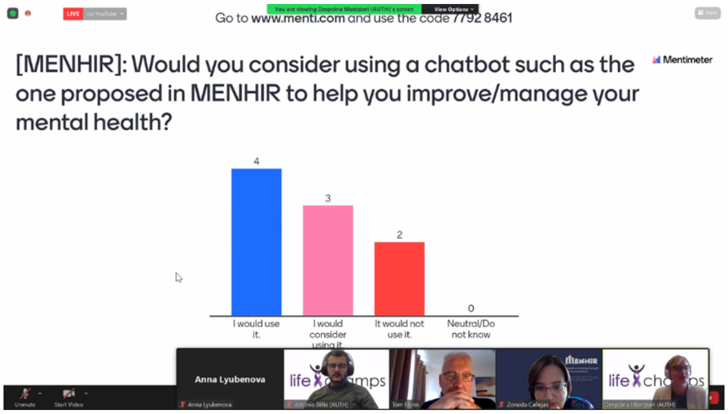
Poll Questions and Relies

During the meeting the audience was asked to respond to certain questions, preliminary defined by projects. The answers are provided below:



Go to www.menti.com and use the code 7792 8461

[MENHIR]: Do you use conversational systems (e.g. mobile assistants such as Siri or smart speakers like Amazon Alexa) in your daily life?



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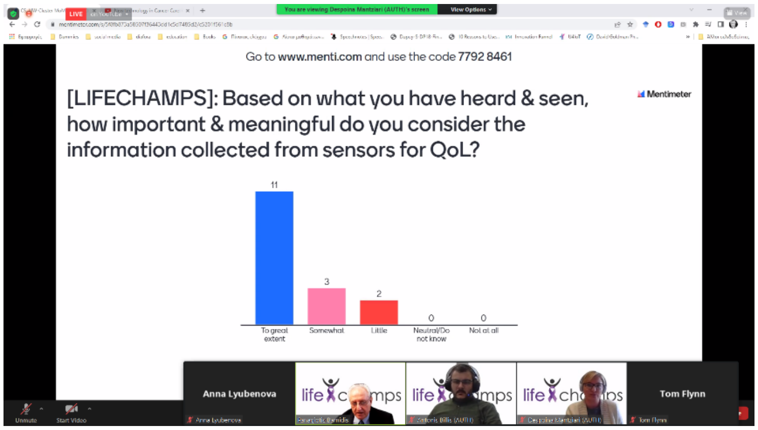
[MENHIR]: Would you consider using a chatbot such as the one proposed in MENHIR to help you improve/manage your mental health?



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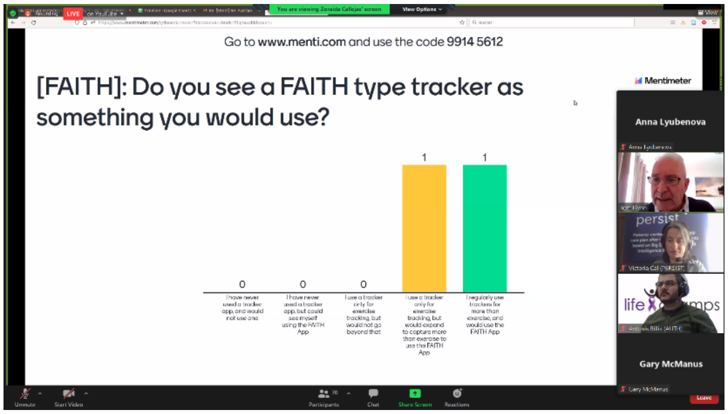
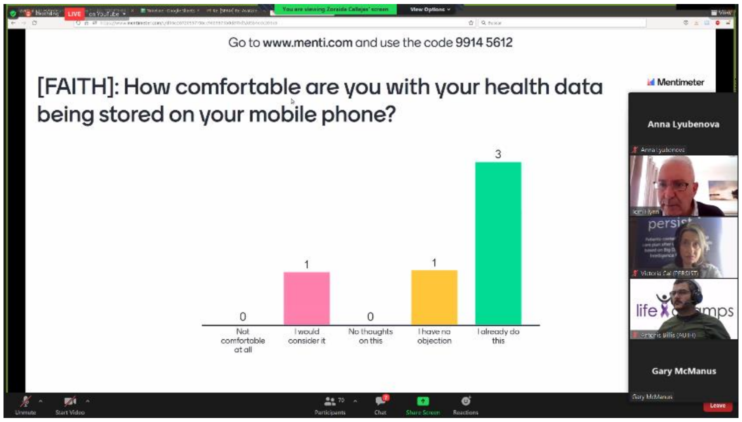
[LIFECHAMPS]: Based on what you have heard & seen, how important & meaningful do you consider the information collected from sensors for QoL?



Go to www.menti.com and use the code 9914 5612

[FAITH]: Do you see a FAITH type tracker as something you would use?



Go to www.menti.com and use the code 9914 5612

[FAITH]: How comfortable are you with your health data being stored on your mobile phone?

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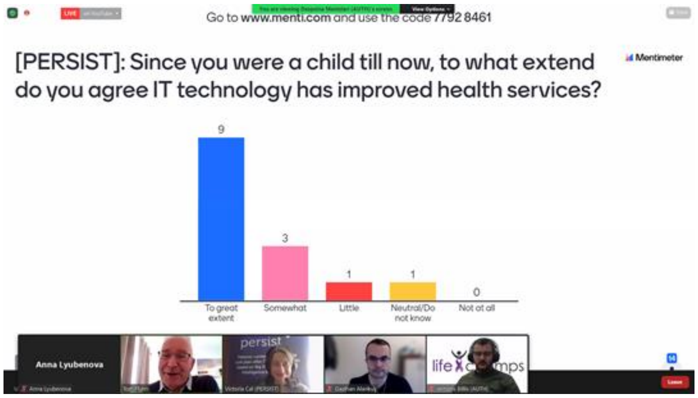
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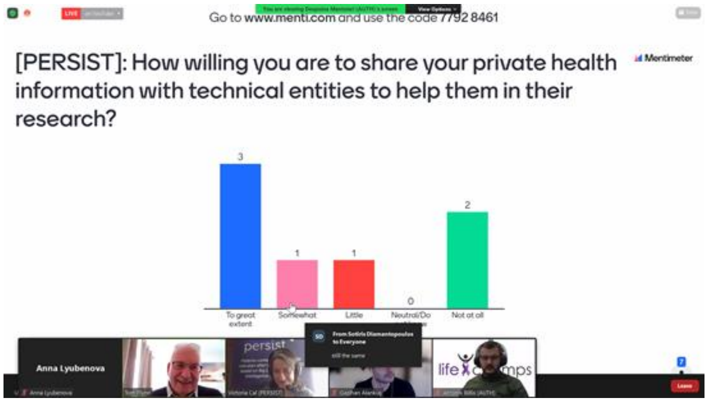
[PERSIST]: Since you were a child till now, to what extend do you agree IT technology has improved health services?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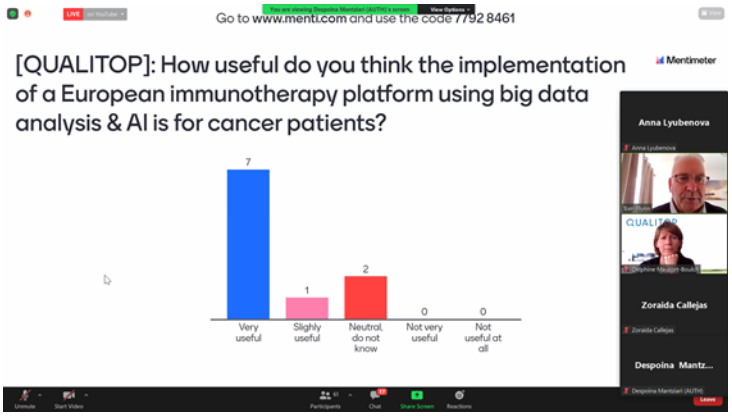
[PERSIST]: How willing you are to share your private health information with technical entities to help them in their research?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[QUALITOP]: How useful do you think the implementation of a European immunotherapy platform using big data analysis & AI is for cancer patients?


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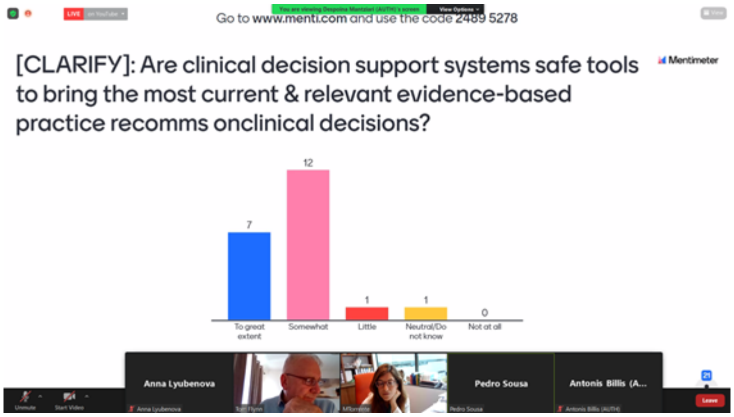
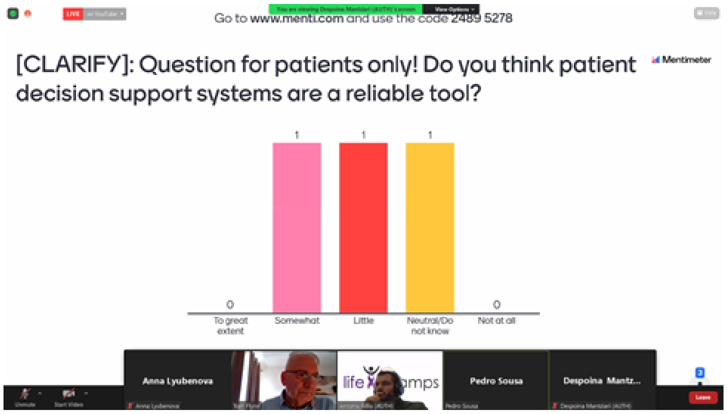
[QUALITOP]: Do you agree with the following? "I trust & feel comfortable with the use of my personal data by doctors, researchers, experts, etc. for he


Go to www.menti.com and use the code 2489 5278

[CLARIFY]: Are clinical decision support systems safe tools to bring the most current & relevant evidence-based practice recomms onclinical decisions?


Go to www.menti.com and use the code 2489 5278

[CLARIFY]: Question for patients only! Do you think patient decision support systems are a reliable tool?

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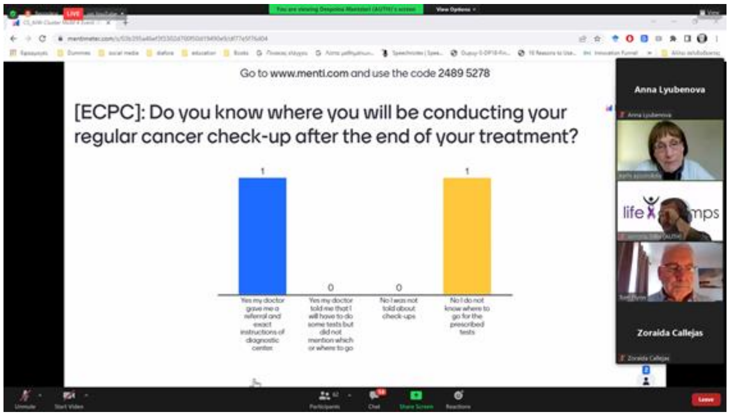

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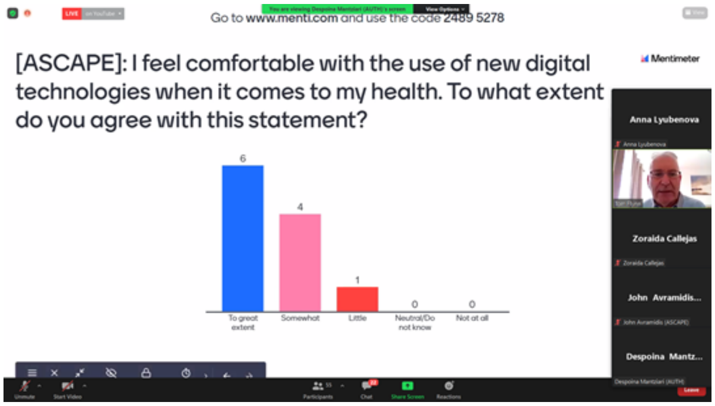
[ECPC]: Do you know where you will be conducting your regular cancer check-up after the end of your treatment?



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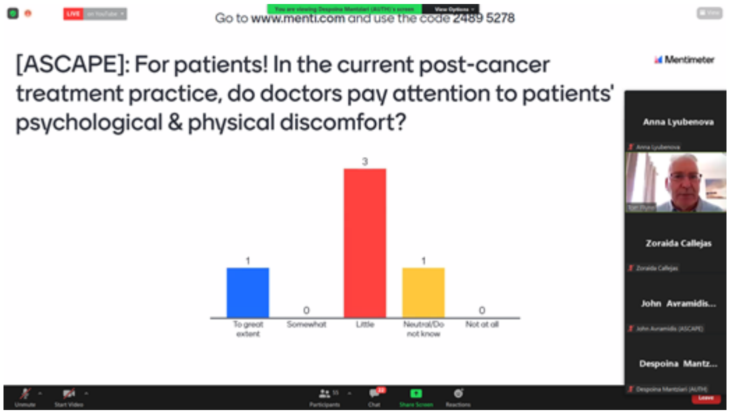
[ASCAPE]: I feel comfortable with the use of new digital technologies when it comes to my health. To what extent do you agree with this statement?



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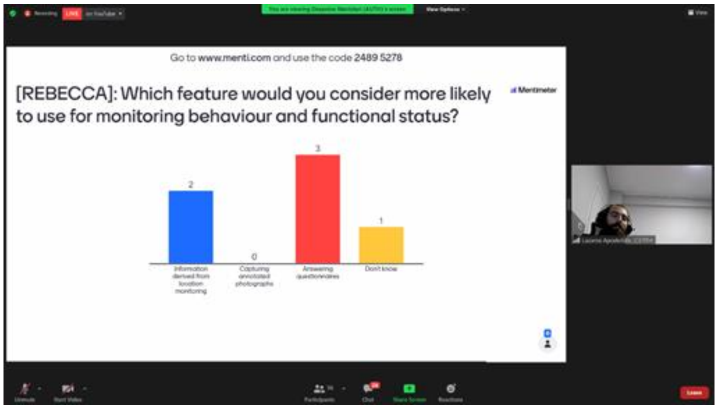
[ASCAPE]: For patients! In the current post-cancer treatment practice, do doctors pay attention to patients' psychological & physical discomfort?



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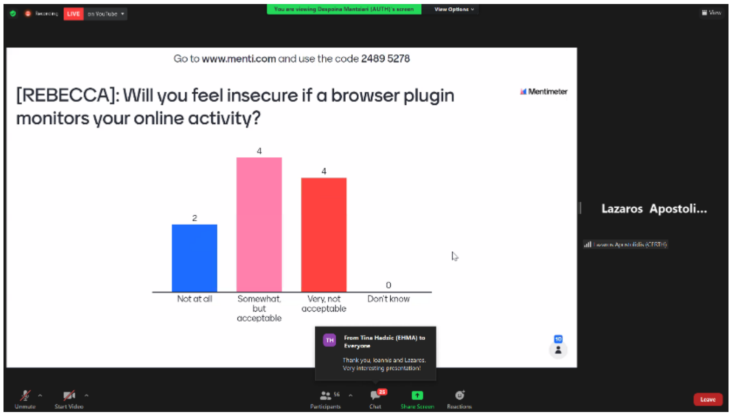
[REBECCA]: Which feature would you consider more likely to use for monitoring behaviour and functional status?



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[REBECCA]: Will you feel insecure if a browser plugin monitors your online activity?

From Tina Hadzic (EHMA) to Everyone

Thank you, Ioannis and Lazaros. Very interesting presentation!

Acknowledgements

We gratefully thank Anna Lyubenova, National Patients' Organization, Bulgaria, for driving the development of this report. Special thanks also to Alessandro Tedeschi Gallo, DeepBlue, Italy, for his incredible support in the build-up and preparation of the MoM4 event as well as to Antonis Billis and Despoina Mantziari, Aristotle University of Thessalonika, Greece, for equally their incredible support in the build-up of the fourth Meeting of Minds event and naturally of course and without hesitation, Zoraida Callejas Carrión, University of Granada, Spain, for hosting the event and supporting all the presenters on both days. You are all great people! We thank our guest speakers, Gerd Murphy, Health Service Executive, Ireland, Kathi Apostolidis European Cancer Patient Coalition, Belgium and of course, Barbara Kerstiens, Head of Unit "Combatting Diseases", Research & Innovation DG, European Commission for their encouragement and support. Panos Papachristotu, Coordinator and PI, Academic Primary Health Care Center, St. Erik Unit, Stockholm, moderated the special round table session on Day 1 and we are very thankful to him and to each of the participants at the table. It was a memorable session. To each presenter and to our audience at the fourth Meetings of Minds event, our sincere gratitude for your commitment and participation. It was truly appreciated.