

# BD<sub>4</sub>QoL

BIG DATA FOR QUALITY OF LIFE

Newsletter #6 July '23 – December '23

## 1. ABOUT THE BD4QoL PROJECT

BD4QoL aims at **improving head and neck cancer survivor's Quality of Life** through person-centred monitoring, post-treatment support and personalised follow-up.

BD4QoL takes advantage of **technologies for social communication and unobtrusive personal monitoring** embedded in smartphones to **improve head and neck cancer survivor's Quality of Life**. Physical activity, social interactions, sleep, and health data are automatically collected by a mobile app for over two years after treatment and will be analysed to early intercept quality of life deterioration and health risks.

The project will last until December 2024. Would you like a closer look on how BD4QoL works and is implemented? See the project's presentation video: <https://youtu.be/90YmWxytn0>

Give a look at the BD4QoL [leaflet](#) and [presentation](#) to know more about the first projects results!

For more information about BD4QoL, visit: [www.bd4qol.eu](http://www.bd4qol.eu)

## 2. BD4QoL EVENTS

### *5<sup>TH</sup> Plenary meeting*

On September 12<sup>th</sup> the BD4QoL consortium met in Milan at the premises of Istituto Nazionale Tumori. The meeting was held in mixed modality, in person and virtually, hosted by INT. The objectives were:

1. Check the status of the clinical study (enrolment, INT subcontract, issues, data quality, etc.) and plan next actions
2. Check the status of WP6 and take decisions regarding timing for data analysis and results interpretation
3. Plan the work in T7.2 and T7.5 (T4.4, where the impacts on the PoC tool will be analysed, if any)
4. Agree on solutions for open issues on the BD4QoL apps and PoC tool (improvements ongoing and planned, but also the proper usage of the tool)
5. Launch the activities in WP8 and check initial results for T8.3 (logging system and surveys)
6. Launch exploitation – Business Planning actions and discuss IPRs; address the comments received after review 2 (Business planning workplan and discussion about what will be exploited)
7. Organize the dissemination activities (workshops, publications, publication plan)
8. discuss administrative issues concerning the project.

### ***Workshop with patients' Associations***



On October 17th Regione Lombardia and ARIA S.p.A. jointly organized a workshop with patient's associations for sharing the digital tools developed in BD4QoL and collect feedbacks from different stakeholders, mostly possible future users.

On behalf of the project consortium the following partners attended the meeting: Università degli Studi di Milano, Fondazione IRCCS Istituto Nazionale dei

Tumori di Milano, DOTSOFT SA, Universidad Politécnica de Madrid, Casa Sollievo della Sofferenza, patients' associations European Cancer Patient Coalition, Euracan, Federazione Italiana Associazioni Volontariato Oncologia, physicians of the regionale oncological networks and some solution providers.

The goal of the workshop has been to promote the dialogue and interaction among different stakeholders, as well as with patients involved in the ongoing experimentation.

Moreover, working groups have been created to focus on each of the three digital solutions (MobileApp, Point of Care, Chatbot): very useful feedback and ideas on how improve the solutions have been collected from all the attending participants.

Thanks to the active participation of the different stakeholders, it has been possible to collect very useful feedback on the solutions and inputs on how these can be improved. Finally, the workshop contributed to sharing knowledge and further disseminate the project.

### 3. BD4QoL NEWS

#### *What is the BD4QoL historical cohort?*



The BD4QoL project focuses on studying the quality of life of people who have survived head and neck cancer. But what does it mean to be a survivor? What are the characteristics of these survivors? How well do they cope with daily life one year after treatment? To find answers to these questions and more, University of Oslo created the BD4QoL historical cohort. Data were gathered from previous studies, with the help of partners in Italy, Germany, and the United Kingdom. Together, the literature was discussed and reviewed to define who could be considered a survivor. Then the data based on these criteria were screened to build a group of survivors. This group is made up of 4573 former patients and includes information about their medical treatment, personal details, and their quality of life. This valuable data has allowed to learn more about these survivors, develop prediction models, and provide important insights for our ongoing BD4QoL

prospective study.

University of Oslo is excited to announce that they are currently preparing a manuscript detailing the findings and insights derived from the BD4QoL historical cohort study. This manuscript will provide comprehensive information about the characteristics, experiences, and quality of life of head and neck cancer survivors within this extensive cohort. Stay tuned for the forthcoming release of this publication, which will contribute to a better understanding of survivorship, inform future interventions and support for individuals who have overcome head and neck cancer. "

#### *Inequalities in returning to work after H&N cancer*

Starting from a cohort of residents in Turin (Piedmont, Italy) from 2008 to 2018 it was possible to select 255 incident cases of H&N cancer related to workers in the year of diagnosis, who had no cancer in other sites in the considered period. Within this subset, about 34% of patients didn't work during the two years after the diagnosis.

Latent Class Analyses (LCA) allowed to define the profiles of these workers on the basis of sociodemographic and clinical variables. The most relevant variables to define the profiles were: sex, age class, education level, deprivation index (census level section), social support, tumor stage.



Statistical models were used to investigate whether some profiles were associated with a different probability of stop working during the two years after the diagnosis. Results showed that low educated and highly deprived people are more likely to stop working than less deprived and more educated ones, also considering age. This is probably linked to the type of job performed, given that usually less educated are employed as blue-collar workers. Further investigations are in progress on this.

### ***Experience on patient engagement from CSS***



This is the case of Marco (a fictional name) who has reported how the BD4QoL project has helped improve his well-being. In fact, within the context of a healing process that had already begun before he was enrolled in the study, the patient has described how, after a period of illness, he felt encouraged to resume his usual activities and hobbies, such as dancing, gardening, traveling, and wood carving, for example. Even the simple fact of achieving his physical activity goals, which he monitored using the project's app, motivated him and

made him look more positively towards his future. All of this served as a stimulus for him to regain his sense of humor, curiosity, and the joy of doing new things, both alone and in the company of friends and family.

The experience of CSS researchers tells us that often, in the context of research projects involving aspects of well-being or health monitoring, it is possible to observe signs of an improvement in the quality of life because patients feel more at ease specifically because they are being monitored.

### ***BD4QoL Poster within CHIGreece23 Conference***

DOTSOFT is excited to share a moment of remarkable significance that unfolded at the CHI Greece 2023 Conference. This esteemed gathering of visionaries in the realm of Human-Computer Interaction (HCI) bore witness to the emergence of the BD4QoL project, a project of innovation and hope.

In an environment pulsating with discussions on the cutting edge of HCI and technology, BD4QoL poster stood out as a pioneering force poised to reshape the future. The project's vision, rooted in the transformative power of big data, artificial intelligence, and user-centric design, captured the admiration of attendees from diverse backgrounds.



### ***HTA analysis for D6.1 predictive models***

The BD4QoL Deliverable D6.1 Benchmark risk stratification models, has produced interesting models that can predict Health Related Quality of Life (HRQoL) trajectories, based on demographic and clinical variables.

The BD4QoL Consortium is now analysing such models through a Health Technology Assessment exercise, to assess their value potential, when deployed in the clinical practice.

To do this, a workflow for the application of the predictive model in the clinical workflow must be hypothesized, and a Markov Model for simulating such “augmented” workflow and comparing it to the standard of care, must be designed and run.

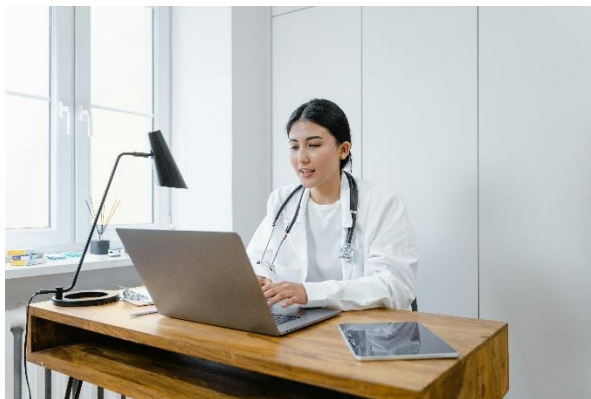
For example, since the model would allow to predict which cancer survivors are more at risk of HRQoL decrease, an appropriate intervention to mitigate such risks could be enacted for these individuals, lowering the proportion of them that would transition to lower HRQoL levels.

Overall Quality of Life gained (measured in Quality Adjusted Life Years, or QALY) and costs saved (e.g., because of less Adverse Events to be treated, or swifter return to work, etc.) are then computed and aggregated by the Markov Model. From this, the final Incremental Cost Effectiveness Ratio (ICER) would be derived, expressing how much one additional QALY gained would cost or save.

If the ICER is under the Willingness-to-pay threshold (normally, around several tens of thousands of Euros per QALY) then the application of the D6.1 predictive models is indeed cost-effective and worth considering for addition into clinical guidelines.

Results will be reported in the Project Deliverable D8.1 Cost-effectiveness analysis, which the Consortium will dedicate to the public domain.

### ***Point of Care tool training session with healthcare professionals***



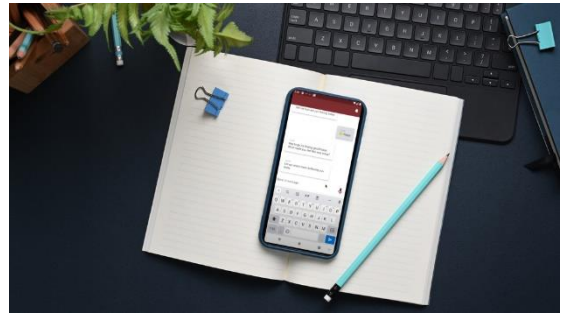
As the BD4QoL medical team grows and the latest updates are incorporated into the clinical dashboard, the Point of Care tool, the past 23rd of October took place a Training Session between technical partners and clinicians. During this session, participants revised all the steps necessary to appropriately manage the different types of alerts that, based on patients' lifestyles recorded by the BD4QoL mobile app, appear in the PoC tool. These are technical alerts that give information about the current status of the data collection and detect any

inconsistencies with the patients' phones or operative systems; clinical alerts based on behavioral and symptom-related reports, and those messages unrecognized by the AI-based chatbot that may require further attention. As the platforms are working smoothly and patients are collaborating in the study, we are excited to further analyze how this novel approach for personalized daily monitoring can enhance Head and Neck Cancer survivors' Quality of Life.



### ***Ensuring privacy and access to data in the BD4QoL project***

The aim of the European project BD4QoL is to improve the quality of life of people who have overcome a head or neck cancer, through individual monitoring and follow-up of patients. In order to carry out this task successfully, daily data on the activities and habits of the participants are collected through mobile applications, which after being processed with artificial intelligence, allow the development of personalized interventions on individuals during treatment to prevent risks and avoid negative effects derived from the disease.



Inetum's role, as a project partner in addition to providing and maintaining the cloud infrastructure that allows the different medical specialists to monitor the study participants in real time, guaranteeing their privacy and the security of access to the resources, also actively participates in the consortium by providing new tools to meet the needs that arise during the achievement of the objectives.

In recent months, Inetum has been involved, together with the other partners, in the development of a set of quality rules that allow to detect and analyze the use that patients make of the monitoring applications provided by the consortium (if they have the latest versions installed, if they log in frequently, if they complete questionnaires, if they read medical alerts, etc.). This new quality framework, designed by Inetum, allows the other partners and clinical users to be autonomous in defining new quality rules as their understanding of the collected data enables them to discover new findings about patients' behavior and adherence to prescriptions.

In today's rapidly changing world, health maintenance remains paramount. Inetum, as a digital services and solutions company, is aware that people's medical needs are constantly evolving and, therefore, seeks to innovate and stay ahead of the curve to also provide its contribution.

### ***BD4QoL attending the FAITH project networking event "AI in Healthcare"***



BD4QoL attended on November 16th the networking event "AI in Healthcare", dedicated to artificial intelligence in the healthcare domain organized by the FAITH project, partner of the Cluster "Cancer Survivorship - AI for Well-being".

The event featured presentations from experts in the field of AI in healthcare, as well as opportunities for networking and discussion. Key topics covered included:

- a) The ethical and social implications of AI in healthcare.
- b) The need for explainable and transparent AI models.
- c) The role of human-in-the-loop AI systems.
- d) The future of AI in healthcare.

The session featured multiple short keynotes on AI challenges arising from different case studies, such as: using AI for diagnosis; liability aspects of AI usage (who is responsible and what happens when AI systems fail in critical contexts like healthcare); interpretability of AI.

### ***Embracing the Future of Health: Following the steps of BD4QoL***

In a world where personalized well-being takes center stage, BD4QoL pioneers a groundbreaking approach for those navigating life after Head and Neck Cancer treatment. Imagine a future where wearables and personal devices seamlessly intertwine with Big Data-driven AI algorithms, fostering real-time monitoring and support for individual Quality of Life (QoL).

As we embark on this journey, the need for wearables goes beyond trendy gadgets; it's about empowerment and self-management. BD4QoL doesn't just track steps; it monitors your emotional well-being, detects early signs of diseases, and provides a personalized roadmap for improvement.

Yet, challenges loom large. Striking the delicate balance between privacy compliance and harnessing the potential of real-time data poses hurdles. BD4QoL tackles this head-on, ensuring your data is secure while delivering insights that matter.

Over 400 individuals who have faced Head and Neck Cancer already take part in a groundbreaking trial across Italy and the UK, evaluating the impact of these innovations on their quality of life.

Together, let's redefine the future of health management. BD4QoL isn't just a project; it's a revolution in self-care, where wearables become guardians of your well-being, helping you achieve more for your health.



### ***Participating in the BD4QoL project can represent a sign of hope for patients to return to a normal life***



During the follow-up visits scheduled in the BD4QoL project, the CSS team has observed that some enrolled patients, upon completing treatments, have managed to return to a lifestyle close to normalcy and resume work, albeit with limitations due to changes they had to make in their lifestyle due to the illness. However, for many of them, returning to a normal work life has proven challenging. Several found themselves unemployed because they were limited in performing certain activities required by their profession

or were deemed unfit for them.

The CSS team gathered testimonies from patients who, due to work-related issues, fell into depression, expressing a reluctance to engage in activities that involved even minimal effort. For some of them, joining the BD4QoL project represented a new challenge, a sort of turning point. Participation in the project provided them with the opportunity to find new motivations and consider activities they had never been interested in before. The difference in mood was more than evident between one visit and another: in several cases, smiles and willpower returned.

These experiences make it clear to the patients themselves, their families, and the medical staff how significant the impact of the disease can be in terms of losing daily habits and self-confidence. At the same time, they encourage exploring the real usefulness of the tools developed in BD4QoL and to consider them for patients with other medical conditions.

### ***INT - UMIL attending the Health & Tech Summit 2023***



INT - UMIL partners presented at the Health & Tech Summit 2023 the technological solutions developed and used in the prospective clinical study for remote monitoring Head and Neck patients Quality of Life.

Digital technology is a major lever for structurally modifying the organization of healthcare services to improve their

overall quality. The use of data and artificial intelligence (AI), at the heart of this year's news, are a good illustration of this and will be the main focus of the Health & Tech Summit 2023. While these technologies are in full development and at the center of all discussions on the future of care, it's time to take the time to analyze, and see what really works for patients, caregivers, and public health. Many use cases exist to date, in hospital departments or within research teams, but what are the best use cases for AI and Data in healthcare? And what can these use cases teach us? All these questions have been addressed on December 13<sup>th</sup>, 2023 at the Health & Tech Summit, bringing together all French and international stakeholders to reflect on the promises and real potential of integrating AI and data tools in the healthcare sector.

#### **4. BD4QoL PUBLICATIONS**

Do you want to know more about the first outputs of the BD4QoL project? Have a look at [deliverables published](#) by BD4QoL project so far!

#### **5. BD4QoL activities on social network**

BD4QoL social channels are constantly updated with all the **latest news**. Follow us for more updates!

- [X](#)
- [Instagram](#)
- [LinkedIn](#)
- [YouTube](#)