Digital Platform to Evaluate and Predict Quality of Life of older cancer survivors

White Paper release v1
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Glossary

Acronym	Explanation
AI	Artificial Intelligence
ML	Machine Learning
EHRs	Electronic Health Records
PUC	Pilot Use Case
QoL	Quality of Life
HPC	High Performance Computing
HRQoL	Health-Related Quality of Life
PREMs	Patient Reported Experience Measures
PROMs	Patients Reported Outcome Measures
SAE	Scalable Analytics Engine
WP	Work Package
LC	LifeChamps
EAE	Edge Analytics Engine

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Contents

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1. Introduction

Quality of Life (QoL) is a term widely defined in the cancer related literature. One of the most frequently cited definitions of QoL is "a state of wellbeing that is a composite of two components: (1) the ability to perform everyday activities that reflect physical, psychological, and social wellbeing and (2) patient satisfaction with levels of functioning and the control of disease and/or treatment related symptoms."[1]. Several outcomes have been used to represent QoL in people with cancer, such as: symptoms, functional status, and general health perceptions [2].

The terms QoL and health-related QoL (HRQoL) are often used interchangeably [3]. QoL refers to the individual's perception of their wellbeing in terms of their physical, emotional, and social functioning, as well as their satisfaction with life domains such as work, relationships, and leisure activities [1]. It is important to note that QoL is a subjective and multidimensional concept, which includes both objective and subjective elements, making it difficult to measure and compare across populations. In this aspect, QoL could be defined as the gap between an individual's expectation of life and his or her reality [4], [5] meaning that a person in poor health can report good QoL, if their experience meets expectations. Domains such as family, relationships, spirituality, sense of control, and autonomy may be more important to patients than are physical experiences [4], [6]. HRQoL is a subset of QoL, which specifically relates to the impact of health status and medical interventions on an individual's functional status, physical and mental health, and overall wellbeing [7], [8]. While QoL encompasses a broader range of life domains, HRQoL is focused on the impact of health on an individual's life, and it is a crucial component of understanding the impact of illness and medical interventions on patients' lives.

In conclusion, QoL and HRQoL are related but distinct concepts, with HRQoL focusing specifically on the impact of health on an individual's life.

Continuous improvement in cancer treatments led to increasing numbers of survivors, which in turn resulted in growing interest in studying and measuring QoL parameters [9]–[11].

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2. LIFECHAMPS PLATFORM

The LifeChamps project aims to harness techniques for Big Data modelling, analysis, and aggregation under a novel context-aware, data-intensive, and large-scale analytics framework towards delivering multi-dimensional Quality of Life solutions for different cancer life champions. Hence, focusing on frailty in geriatric oncology, the LifeChamps concept is designed to answer the targeted population's particular needs, concerning high quality and independent living, where integration with a personalised care pathway for long-term adjustment and health care management is essential.

To meet end-users' needs and relevant stakeholders' expectations a co-creation approach was followed, conducting several studies within the context of the analysis, collection, and extraction of LifeChamps end-users' requirements, establishing their views, preferences, and expectations from the under-development LifeChamps system. These outcomes were the entry point for the design and implementation of the LifeChamps Platform and reference architecture.

The LifeChamps Platform comprises all the central components and services of the LifeChamps system, that is the end-user applications, the computation components, the analysis components, and transversal services to satisfy the system requirements, such as the user authentication and authorisation service, and the ingestion of data from multiple sources to a centralised location.

2.1 LifeChamps Sensing Platform

The LifeChamps sensing solution (Edge Sensor Platform) is designed to be installed inside the patient's home. It gathers and pre-processes patient data collected regarding their quality of life. The data is then forwarded to the LifeChamps Platform. It is stored, analysed, and subsequently made available to the clinicians involved in the patient's care. There are specific settings for each patient participating in the

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LifeChamps pilot, such as the MAC addresses of the motion sensors installed in their home. Thus, each LifeChamps Edge Solution collects data from a single patient.

Each LifeChamps Edge Solution is a self-contained subsystem and encompasses all the patient's home components, including the IoT sensors and wearables, and the mHealth Application (powered by Adhera Health) that besides personalised education and self-management techniques (e.g., meditation and mindfulness self-guided exercises), it also provides questionnaires, for QoL assessment. While each patient's solution is connected to the LifeChamps Cloud Platform and downloads configuration files and application updates, it is separated from the LifeChamps' system and every other LifeChamps Edge Solution. This was a deliberate security decision to make the solution in each patient's home self-contained, protecting it from malicious third-party actors that could maliciously gain access to the platform and use it as an attack vector into the LifeChamps' system.

2.2 Edge Analytics Engine

The advanced computational potential of the edge devices allows us to perform analytical tasks on the edge, which a few years ago would have to take place on the cloud. The edge analytics engine can support both elementary processing, complex event processing and more advanced edge analytics.

The Edge Analytics Engine receives data from the mHealth Application powered by Adhera Health, the MYSPHERA LOCS Gateway and the Movesense Gateway and performs pre-processing and aggregation on the data streams before forwarding the data to the central LifeChamps system. The engine is connected to the central system over an MQTT link, which accesses the Internet via the patient's home WiFi. The Edge Analytics Engine can only push data to the central system over a secure SSL link. Using a pre-defined JSON message format, further diminishes the possibility of an injection attack into the central LifeChamps' system.

The LifeChamps edge analytics engine's objective is to support real-time monitoring of patients, using a combined edge-to-cloud architecture. The EAE is hosted on the Raspberry Pi that is installed in each patient's house. Its main purpose is to collect, process and finally push the data coming from the sensors to the Cloud.

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2.3 Scalable Analytics Engine

The LifeChamps project targets recovering senior (pre-frail and frail) cancer patients, with the objective of improving their QoL, by providing caregivers, and multidisciplinary health professionals Big Data-driven insights. In that sense, a Scalable Analytics Engine (SAE) was developed. It is a highly personalized, autonomous, and scalable component, capable of generating machine learning models to monitor the QoL of the patients, using relevant medical, behavioural, and environmental data as input.

Due to the Big Data structure, the heterogeneous data sources, and the architecture requirements of LifeChamps, the need for a scalable analytics engine is to accelerate the time to value of analytics by allowing the easy deployment into data streams and the implementation of quick changes or adaptations of deployed analytics, thus accelerating conversion of data into valuable insights. This can be done by leveraging a highly scalable, personalized, and autonomous engine – the SAE. The SAE is a containerized platform capable of generating predictive models to monitor the QoL of the patients and to pinpoint relevant healthcare indicators, such as frailty, anxiety, or depression, using metrics such as symptoms reported by the patients (PROMs), and behavioural data.

The data stored in a centralized Data Warehouse is then ingested by the SAE. This is followed by an ETL (Extract, Transform and Load) process – where the extracted data is conjugated with a database, confirming the data's validity, thus contributing to a generic filtration of the results. These curated results are then used for the development of Machine Learning models aimed at the prediction of the QoL of the patients. The models' outputs are stored in the DW for posterior use.

The SAE plays a crucial role in the LifeChamps platform. Its purpose is to facilitate the ingestion of data relevant to the models from the DW, through Kafka, enabling the execution of predictive models and the storage of the results back in to the DW. This integration with Kafka enables a secure and efficient data transfer.

The SAE represents a novel approach since is highly personalized and scalable, allowing it to meet to the specific needs of the LifeChamps platform, as the existing orchestrator tools, like Airflow, were not able to answer specific needs inherent to the project.

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2.4 Big Data analytics on High Performance Computing Cluster

The High-Performance Computing (HPC) cluster provides a common facility to perform computationally intensive data analytics processing required by the LifeChamps system. It is implemented as a centralized execution environment specifically developed and built to meet the requirements of the LifeChamps project. The facility is hosted in Dell Technologies' HPC lab in Frankfurt, Germany, on dedicated hardware infrastructure. LifeChamps partners access the HPC platform by means of a secure VPN connection. The facility executes isolated data analytics tasks and can therefore be used for both test and production tasks.

HPC platforms by processing a set of data sources from clinical trials, experimental laboratory notes and patients' health history help doctors adopt the best solutions with less effort and time consumption. This task performed by HPC platforms saves time compared to manual data processing and reduces overall costs for medical facilities.

Patient data are collected from sensors close to the edge gateways located in their homes. The edge gateways run light inference tasks to factorise the data and extract meaningful conclusions. The original sensor and factorised data are then forwarded to the main LifeChamps system where it is stored in the data warehouse for further analysis by more powerful inference models. The data can then be used to train ML models for frailty analysis and QoL on the HPC platform. So, the HPC platform can be thought of as an analysis PaaS component for the rest of the LifeChamps system.

2.5 Secure Data Warehouse

Within LifeChamps, time-series databases are of high relevance, especially for data sources providing sensory data with biomedical information. The different storage techniques are interlinked to allow tracking to the original source of the different data entities. This will provide provenance information of data exchanges. The data coming from IoT data bridges and other external data sources will be pre-processed (internal) and aggregated in various filtering tables to allow efficient access for the data analytics engines. Finally, data retrieval algorithms are developed to gather relevant data for

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specific events across multiple database components. In conjunction with "LifeChamps Sensing Platform", data sharing, and protection methods are developed to allow the efficient exchange of data within the scope of LifeChamps. This activity is coupled with the development of security mechanisms crucial for achieving security assurance. The combination of the latter techniques are the basis for developing the Health Data Intelligence Cloud Service (HICS).

For LifeChamps to guarantee flexible storage and communication as well as intelligent management of the stored data, the DW was developed on the cloud. The LifeChamps' Data Warehouse (DW) is a cloud-based infrastructure designed for managing data, both structured and unstructured. It has been carefully configured to prioritize privacy and security through various critical mechanisms, including node-to-node encryption and security measures at different levels such as index-level, document-level, and field-level security[1]. This DW functions as an external component within the LifeChamps platform and is exclusively interfaced with the Message Bus (Kafka).

2.6 LC Dashboard

Overall, the LC Dashboard is designed to be used by healthcare professionals, clinical researchers, and clinical managers in the field of cancer. It allows for detecting and obtaining patients' progress over time and evolution qualitatively and quantitatively. Concretely, the LC dashboard will allow the healthcare professional(s) at each pilot site to view processed data about individual patients and groups of patients to stay abreast with patients' health status and possible changes, thus offering continuous integrated monitoring of a patient's condition at follow-up intervals.

It aims to gain early insights into whether there may be a substantial deterioration in the participants' QOL and whether the care offered can be more cost-effective than standard oncology care by analysing processed data about individuals and groups of patients.

The LC Dashboard will contribute for QOL assessment by its three core functionalities:

[1] "Open Distro for Elasticsearch.," https://opendistro.github.io/for-elasticsearch/, 2021.

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1. **Patient-level monitoring powered by Adhera Health:** It enables healthcare professionals to monitor patients' QoL-related health data by visualising data self-reported by the patients through the mHealth app and data collected by the sensors.
2. **Analytics monitoring:** It presents individualised models from the artificial intelligence-based monitoring algorithm about frailty and QoL subdomains at patient level. It allows monitoring clinically meaningful changes of frailty subdomains (e.g., mobility deterioration, cognitive decline, emotional disturbances, social deprivation etc.) based on the analysis of time-series data collected either by patients' themselves (sensors and ePROMs) or by the clinical teams during encounters (EHR data). It also presents ill-health transitions with an emphasis on the identification of fit, pre-frail clinically, and frail older cancer survivors to assess patients' status and changes in their QoL.
3. **Cohort-level monitoring:** It presents models at population/cohort level, considering a group of patients, such as all patients at a pilot site, from a temporal perspective. These models are obtained applying Artificial Intelligence techniques to data from different sources, like patients' self-reported information and collected by the sensors.

   These models have been developed following a co-creation and co-design approach with the healthcare professionals. Thus, the models will be clinically meaningful and will support healthcare professionals in what they want to analyse. The models will enable data analysis between the data scientist and healthcare professionals to transform raw data (clinical, demographic, sensors and patients' self-reported information) into comprehensive insights and information.

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3. DATA COLLECTION

3.1 End-user Application

Adhera Health brings to the LifeChamps project its patent-pending AI-based Adhera Health Recommender System (AHRS) which has been clinically tested [14] and that enables the delivery of motivational messages following a behaviour change model to foster positive changes in end-users' lifestyle to improve their health-related quality of life. The AHRS can be adapted to encourage end-users to achieve different goals (i.e., to improve physical condition, improve sleep habits, support smoking cessation, etc.) and can also be tailored to the end-user profile based on his/her role (patient or caregiver) and specific diseases and chronic conditions. This HRS has already been tested in cancer (Clinical Trials Registry No: NCT03475433), COVID-19 (Clinical Trials Registry No: NCT04659746), smoking cessation (Clinical Trials Registry No: NCT03206619), and auto-immune diseases (Clinical Trials Registry No: ISRCTN11896540), among others. The AHRS incorporates an algorithm to select and send recommendations from a pool of pre-generated motivational messages based on a pre-defined taxonomy tailored to the end-user profile and collected feedback. The data from patients, including sensor data and subjective answer to questionnaires is used by AHRS to enhance the recommendations of health content.

The LifeChamps mHealth application powered by Adhera Health is integrated with the overall LifeChamps ecosystem. These include sensor like the activity tracker (FitBit Charge 4®), and a smart weight scale (Withings Body+®), Ultraviolet (UV) index information from a 3rd party Application Programming Interface (API) (https://www.openuv.io) for melanoma patients only. All this information collected by the application, along with the answers to the Patient Reported Outcome Measures (PROMs) administered to the patients via the mobile application, is then forwarded to the LifeChamps Platform via the Raspberry Pi kit installed at patients' home (sensors-

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related information) and via an API enabled in the LifeChamps platform (PROM-related information).

The specific sensing elements developed in the frame of the LifeChamps project and integrated with the LifeChamps mHealth application powered by Adhera Health so far are the following:

1) Common PROMs:
   a. PHQ-4 (Screening for anxiety and depression)
   b. VES-13 (Screening for frailty and vulnerability)
   c. LASA (Quality of Life self-assessment)
   d. ESAS-r (Common symptoms assessment)
   e. MARS (Medication adherence)
2) Site-specific PROMs:
   a. IIEF-5 (Screening of erectile function status)
   b. FCRI-SF (Fear of cancer recurrence assessment)
   c. PROMIS-PF (Physical functioning assessment)
   d. CMSAS (Cognitive symptoms assessment)
3) Devices:
   a. FitBit Charge 4® smartwatch
   b. Withings Body+® smart scale
4) External data providers:
   a. UV index (https://www.openuv.io)

3.2 Sensor/IOT Devices

In addition to the smartwatch and smart scale, several other sensors (e.g., motion sensors, Movesense) monitor the patient's biometrics and activity. These sensors primarily feed into the MYSHERA LOCS Gateway and Movesense Gateway components. As they are fixed sensors, it is anticipated that they will be in continuous communication with the Raspberry Pi. The sensors are connected to the Raspberry Pi over a Bluetooth connection, where the Raspberry Pi acts as the Bluetooth server. In addition, the UV index at the patient's location is pulled from a 3rd party service (www.openuv.io) into the mHealth application for QoL assessment, which in turn forwards this information to the Raspberry Pi along with the rest of the biometric parameters.

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3.3 Electronic Health Records

EHRs play a pivotal role in the LifeChamps project, offering valuable, holistic insights into the health history of the study participants. By examining EHR data, we can identify past medical events, medication use, comorbidities, and lab measurements. This retrospective information helps us build a comprehensive picture of the patient's health trajectory, enabling us to better predict their frailty and QoL risks.

Furthermore, by combining EHR data with real-time data from wearables, sensors, and PROMs/PREMs, we create robust predictive models. This comprehensive data collection strategy allows us to address the unique health needs and circumstances of cancer survivors over 65, ultimately contributing to improved care strategies and patient QoL.

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4. AI-ENABLED QUALITY OF LIFE MONITORING AND FRAILTY ASSESSMENT

An integral aspect of the LifeChamps Platform lies in its incorporation of intelligent models that enable the monitoring, assessment, and risk prediction of the quality of life for older cancer patients. These models are designed to track and analyse clinically relevant indicators, with a particular focus on assessing frailty. This innovative feature equips healthcare professionals with valuable insights into the well-being of their patients, facilitating proactive interventions and tailored support to enhance the overall quality of life for this vulnerable population.

4.1 Clinical Prediction Models

The development of a frailty prediction model represents a critical endeavour in healthcare, aiming to identify and predict the onset or progression of frailty in older adults. In the LifeChamps project, we proposed a comprehensive framework for developing a robust frailty prediction model. The model was built upon a diverse range of data sources, including wearable devices, and PROMs. By leveraging this multidimensional data, our approach sought to capture a holistic view of an individual's health and functional status, enabling accurate and timely risk of perceived frailty predictions.

The development of the frailty prediction model involved several key steps. Firstly, data collection was undertaken to gather relevant information from various sources (data collection). Wearable devices such as fitness trackers and smart scales offer objective measures of physical activity, sleep patterns, and weight changes. Additionally, PROMs allow for capturing subjective patient experiences and health-related quality of life. Integration of these diverse data sources enables a comprehensive and personalized assessment of an individual's frailty risk.

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To build the prediction model, an advanced tree-based machine learning algorithm, suitable for handling large-scale data while minimizing the required computational resources, were employed. Feature engineering was undertaken to extract relevant information, derive meaningful features from the raw data, and normalizing data, ensuring, in this way, an effective integration of the different data sources. Furthermore, rigorous model validation and evaluation was conducted, using techniques such as cross-validation and independent sample validation, to ensure the model's accuracy and generalizability. Finally, a layer of a comprehensive explainability for clinicians' assessment was developed allowing for closer monitoring of early signs of frailty of their patients. The ultimate goal of this risk of frailty prediction model is to move towards the enablement of healthcare providers to identify at-risk individuals early, guide targeted interventions, and improve overall health outcomes and quality of life in older adults.

4.2 Quality of Life Monitoring and Modelling

QoL measurement in healthcare is a complex, multidimensional concept that encompasses both positive and negative aspects of an individual's life. Quantifying QoL poses challenges due to its subjective nature and the varied interpretations from different individuals and organizations. Domains such as work, housing, education, and community also significantly contribute to overall QoL, along with cultural values and spirituality. Assessing these abstract aspects is more intricate than capturing conventional quantitative variables like temperature or hemoglobin levels. Nevertheless, researchers have developed methodologies and instruments to conceptualize and measure the various domains of QoL and their interconnections. HRQoL focuses on the domains of physical and psychological health, independence, and social relationships, which can directly be influenced by healthcare interventions. HRQoL is often used interchangeably with Patient Reported Outcomes (PROs) and PROMs, which provide valuable insights into patients' perspectives on their care beyond clinical outcomes. PROMs are self-report surveys that capture patients' views on their health conditions directly, distinct from clinical rating scales that rely on physician assessments of illness severity or treatment effects.

Apart from PROMs, the widespread availability of affordable IoT devices has facilitated the development of smart home projects, where older adults' living spaces are

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equipped with monitoring and computing capabilities. This enables the collection of high-frequency data on various aspects of daily life. Smart home data, combined with information from wearable devices, allows for longitudinal monitoring of behavioral patterns such as mobility, ambulation, sleep, mood, activities of daily living, and socialization.

In the LifeChamps project, efforts have been made to establish a correlation between the digital patterns, which capture the behavioral phenotype of a patient, and clinical assessment tests and scales. This approach enables the estimation of a patient's health status at any given time by mapping the outputs of sensors (such as statistical features representing longitudinal patterns) to scores on clinical assessment tools.

4.3 Frailty Domain Knowledge Models

Frailty is a clinical condition characterized by a decline in reserve and function across various physiological systems, leading to an increased susceptibility to adverse outcomes. While this concept is widely acknowledged, there is no clear consensus on the optimal method for assessing frailty. There are two primary approaches to identify frailty. Fried et al [15] proposed a frailty phenotype that focuses on measuring physical manifestations of frailty, such as reduced grip strength, low energy levels, slowed walking speed, diminished physical activity, and unintentional weight loss. On the other hand, Rockwood et al [16]. introduced a Frailty Index, which quantifies frailty as an accumulation of deficits, encompassing disability, diseases, physical and cognitive impairments, psychosocial risk factors, and geriatric syndromes.

This lack of consensus becomes particularly crucial when addressing cancer patients, as there is need to establish standardized criteria for efficiently assessing frailty status. Considering that oncology settings are usually busy clinical environments, the International Society of Geriatric Oncology (SIOG), recommends that at least, screening tools are used to identify patients in need of further evaluation of Geriatric Assessment (GA) [17]. Therefore, it becomes evident that comprehensive tools based on clinical consensus are needed for the identification and prediction of frailty.

In this context, LifeChamps aimed to develop a model for defining and assessing frailty based on the knowledge from experts on the domain. A Fuzzy Cognitive Map (FCM) was created involving a panel of five experts from AUTH, HULAFE and SIOG. These experts represented the different clinical profiles involved in the follow-up of older cancer patients. The FCM was created following an interactive process of four phases.

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In the first phase, participants identified and agreed on the most relevant concepts affecting frailty. In the second phase, individual interviews were conducted with the experts to capture their individual perspectives on the system containing the previously decided concepts. In the third phase, an individual FCM was created for each of the experts. In the fourth phase all FCMs were combined obtaining a high-level frailty domain knowledge representation.

The main strength of this model is the active involvement of clinical experts during the development of the FCM. As a result, it is expected to be acceptable by clinicians and easily adopted into their clinical practice.

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5. Conclusions

This white paper briefly summarizes the core artefacts that constitute the innovative prototype delivered to the LifeChamps pilots. Novel data sources, including patient-reported information, smart home sensors etc, Big Data infrastructure capable of handling in real-time heterogeneous streams of data with a focus on data quality, personalised patient support through the mhealth app and the delivery of AI-powered clinical prediction models for oncogeriatrics keeping clinicians in-the-loop constitute some of the key innovations of the LifeChamps digital supportive care solution.

Finally, the delivery of an integrated digital platform, following the edge-cloud architecture paradigm allows the seamless deployment of the technology closer to the patient, shifting the provision of care from the clinic to the home environment of the cancer survivors in a robust way.

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References

[1] C. C. Gotay, E. L. Korn, M. S. McCabe, T. D. Moore, and B. D. Cheson, "Quality-of-Life Assessment in Cancer Treatment Protocols: Research Issues in Protocol Development," *JNCI J. Natl. Cancer Inst.*, vol. 84, no. 8, pp. 575–579, Apr. 1992, doi: 10.1093/jnci/84.8.575.

[2] E. D. Hacker, "Technology and Quality of Life Outcomes," *Qual. Life Outcomes Cancer Care 1990-2010*, vol. 26, no. 1, pp. 47–58, Feb. 2010, doi: 10.1016/j.soncn.2009.11.007.

[3] M. Karimi and J. Brazier, "Health, Health-Related Quality of Life, and Quality of Life: What is the Difference?," *PharmacoEconomics*, vol. 34, no. 7, pp. 645–649, Jul. 2016, doi: 10.1007/s40273-016-0389-9.

[4] B. Fougère *et al.*, "Frailty Index and Quality of Life in Nursing Home Residents: Results From INCUR Study," *J. Gerontol. Ser. A*, vol. 71, no. 3, pp. 420–424, Mar. 2016, doi: 10.1093/gerona/glv098.

[5] K C Calman, "Quality of life in cancer patients--an hypothesis.," *J. Med. Ethics*, vol. 10, no. 3, p. 124, Sep. 1984, doi: 10.1136/jme.10.3.124.

[6] C. McCABE, C. BEGLEY, S. COLLIER, and S. McCANN, "Methodological issues related to assessing and measuring quality of life in patients with cancer: implications for patient care," *Eur. J. Cancer Care (Engl.)*, vol. 17, no. 1, pp. 56–64, Jan. 2008, doi: 10.1111/j.1365-2354.2007.00809.x.

[7] K. Haraldstad *et al.*, "A systematic review of quality of life research in medicine and health sciences," *Qual. Life Res.*, vol. 28, no. 10, pp. 2641–2650, Oct. 2019, doi: 10.1007/s11136-019-02214-9.

[8] N. E. Mayo, *ISOQOL Dictionary of Quality of Life and Health Outcomes Measurement.* International Society for Quality of Life Research (ISOQOL), 2015. [Online]. Available: https://books.google.pt/books?id=cKjksgEACAAJ

[9] J. Z. Ayanian and P. B. Jacobsen, "Enhancing Research on Cancer Survivors," *J. Clin. Oncol.*, vol. 24, no. 32, pp. 5149–5153, Nov. 2006, doi: 10.1200/JCO.2006.06.7207.

[10] M. van Leeuwen *et al.*, "Understanding the quality of life (QOL) issues in survivors of cancer: towards the development of an EORTC QOL cancer survivorship questionnaire," *Health Qual. Life Outcomes*, vol. 16, no. 1, p. 114, Jun. 2018, doi: 10.1186/s12955-018-0920-0.

[11] J. Firkins, L. Hansen, M. Driessnack, and N. Dieckmann, "Quality of life in 'chronic' cancer survivors: a meta-analysis," *J. Cancer Surviv.*, vol. 14, no. 4, pp. 504–517,

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Aug. 2020, doi: 10.1007/s11764-020-00869-9.

[[14] S. Hors-Fraile *et al.*, “Opening the Black Box: Explaining the Process of Basing a Health Recommender System on the I-Change Behavioral Change Model,” *IEEE Access*, vol. 7, pp. 176525–176540, 2019, doi: 10.1109/ACCESS.2019.2957696.

[15] L. P. Fried *et al.*, “Frailty in Older Adults: Evidence for a Phenotype,” *J. Gerontol. Ser. A*, vol. 56, no. 3, pp. M146–M157, Mar. 2001, doi: 10.1093/gerona/56.3.M146.

[16] Kenneth Rockwood *et al.*, “A global clinical measure of fitness and frailty in elderly people,” *Can. Med. Assoc. J.*, vol. 173, no. 5, p. 489, Aug. 2005, doi: 10.1503/cmaj.050051.

[17] L. Decoster *et al.*, “Screening tools for multidimensional health problems warranting a geriatric assessment in older cancer patients: an update on SIOG recommendations†,” *Ann. Oncol.*, vol. 26, no. 2, pp. 288–300, Feb. 2015, doi: 10.1093/annonc/mdu210.

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