

# Architecture, Pilot Use Cases, Stakeholder Involvement and Solution Requirements of the LifeChamps project

**White Paper release v1.0**  
**Published March 2021**

## Main Contributors

<b>CLS</b>	Grant Millar, Roger Kaiser, Irene- Maria Tabakis
<b>APC</b>	Panos Papachristou, Emmanouil Kokoroskos
<b>AUTH</b>	Nikolaos Papachristou, Antonis Billis, George Petridis, Evangelos Logaras, Sofia Reppou, Despoina Mantziari, Paraskevas Lagakis, Prof. Panagiotis Bamidis
<b>HULAFE</b>	Gonzalo Collantes
<b>UoG</b>	Grigorios Kotronoulas
<b>UPV</b>	Zoe Valero Ramón



## GLOSSARY

Acronym	Explanation
AI	Artificial Intelligence
EHRs	Electronic Health Records
PUC	Pilot Use Case
QoL	Quality of Life
HRQoL	Health-Related Quality of Life
PREMs	Patient Reported Experience Measures
PROMs	Patients' Health Status/ QoL Perception
WP	Working Package



## ACKNOWLEDGEMENT

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The authors of the present White Paper would like to acknowledge and express their gratitude to the leading Working Package 2 (WP2) contributors, i.e. to the older adult cancer survivors, the healthcare professionals, the caregivers of the older adult cancer survivors and the health managers, who provided their experiences and insights, as well as to the LifeChamps partners, actively involved providing their knowledge & expertise towards the successful completion of the relevant work objectives (within the wider scope of the LifeChamps project). The work reflected within the corresponding LifeChamps tasks and deliverables (D2.1, D2.2, D2.3 and D2.4) has been extremely useful and consists of the main input for drafting the current document in the form of a White Paper.



## ABSTRACT

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The purpose of this White Paper is to provide an overview on the LifeChamps WP2 activities during the first year of the project. More specifically, the current paper focuses on presenting the activities on WP2 “Requirements Analysis, Pilot Use Cases and Functional Architecture”, and especially the outcomes of the deliverables D2.1 “Vision scenarios and use cases definition”, D2.2 “End-user/stakeholder requirements –initial version”, D2.3 “Selected person outcome metrics” and D2.4 “LifeChamps Platform and Reference Architecture –Initial version”.

The main objective of D2.1 is to describe in detail the approach followed to provide an initial definition of LifeChamps’ pilot use cases by the clinical partner sites, while D2.2 outlines the research methods and procedures employed within Task 2.2, as well as the recruitment status and data collection in line with task’s aim. D2.3 focuses on identifying psychometrically robust PROMs (Patients’ Health Status/ QoL Perception) and PREMs (Patient Reported Experience Measures) to enable accuracy in data collection in terms of Task 2.3. Finally, the scope of D2.4 is to elaborate on the reference architecture of LifeChamps.

**The current paper will provide a summary of the work completed by the aforementioned deliverables.**



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## 1 INTRODUCTION

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Within the most recent years, most of the cancer patients are older age. This suggests the need better to understand the biology of ageing and cancer connection, leading to a more comprehensive and cancer-specific assessment and management of older cancer patients [1]. Despite that there is not a unified approach, the broader one refers to ageing as the “all time-associated events that occur during the post maturation period in the life span of an organism. For humans, ageing is defined as a universal biological process that manifests itself as a decline in functional capacity and an increased risk of morbidity and mortality over time”.

Ageing biology describes the progressive changes of the physiological systems with age and underlying biological mechanisms during the post maturation period in life [2]. All the above highlight that age alone adds little information on frailty, which is characterised by decreased physiologic reserve and increased vulnerability leading to severe adverse health outcomes in older adults, including post-operative complications [3], increased mortality [4] in older patients, and survivorship [5].

As people get older, they have to face accumulating life challenges (i.e., family, professional, social responsibilities) and disease burden (i.e., frailty, symptoms, multi-morbidity) [6]. Epidemiological data show that this burden increases significantly after the age of 50 for all genders, as cancer incidence and mortality increase [7]. Furthermore, multi-morbidity, frailty and other discounting factors for the Health-Related Quality of Life (HRQoL) of these people increase [8].

Treatment-related decisions on older cancer patients are frequently a challenge that can be influenced by many factors. However, treatment decisions should also be based on the patient’s QoL and the estimated risk of impacting the QoL through treatment.

It is important that for older cancer patients, we have available data and to look closer to individual patient characteristics such as their performance status, comorbidities, polypharmacy, functional status, mobility, nutritional status, mental health, cognitive status, social situation and also their individual QoL[9].LifeChamps complements the patient movement to support those who have been diagnosed with cancer, including those who have recovered from the disease. It does so with the introduction of novel technologies and clinical methodologies to support them for their HRQoL and care provided during and after their treatment as well.

During the first year of the LifeChamps project lifecycle and towards the completion of defined milestones and objectives, the consortium partners conducted studies



within the context of the analysis, collection and extraction of LifeChamps end-users' requirements and establish their views, preferences and expectations from the developing LifeChamps platform.

To help identify and understand the needs and derive the requirements that the architecture development should address, LifeChamps actors and user scenarios were initially identified, including the relationships among the LifeChamps targeted stakeholders and the defined scenarios. The purpose of this White Paper is to describe the WP2 "Requirements Analysis, Pilot Use Cases and Functional Architecture" activities completed within the first 12 months of the project and more specifically to present D2.1, D2.2, D2.3 and D2.4 output results.

The structure of this White Paper is organized as follows:

**Section 2** describes the LifeChamps approach and its objectives, as well as it also provides some background information.

**Section 3** refers to the LifeChamps architecture as this was described in D2.4.

**Section 4** presents the LifeChamps uses case scenarios as those were defined in D2.1.

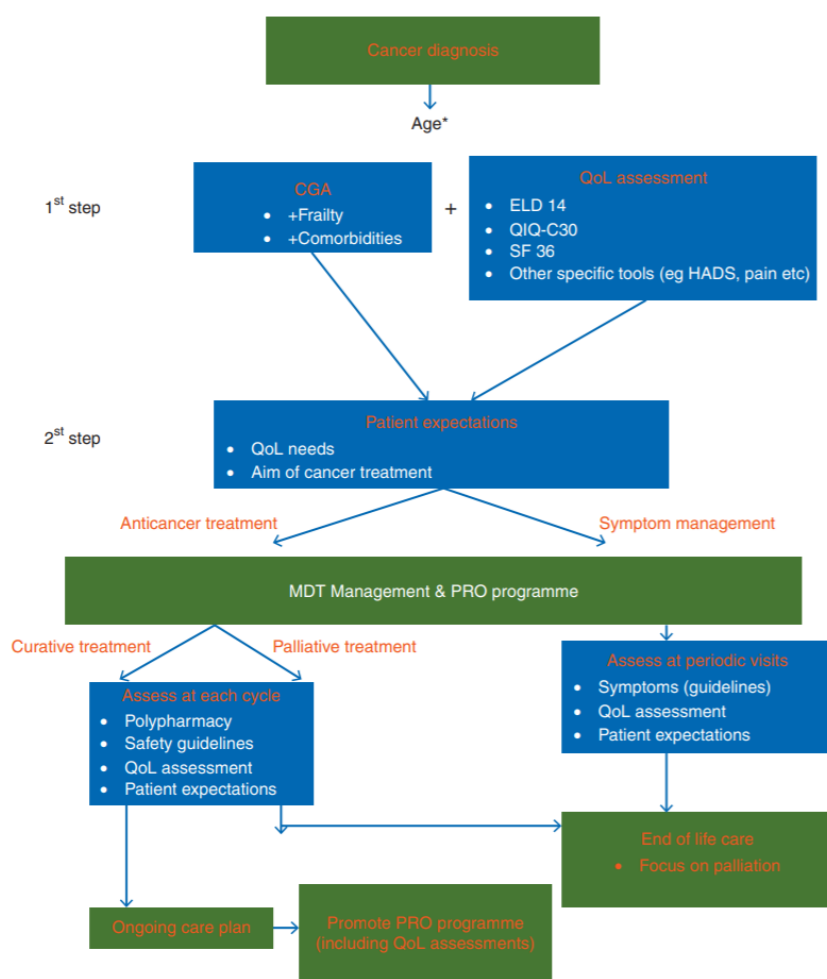
**Section 5** describes stakeholders' involvement and the solution requirements in the context of the LifeChamps project as was defined in D2.1, D2.2 and D2.3.



## 2 THE LIFECHAMPS APPROACH AND OBJECTIVES

### 2.1 BACKGROUND

Cancer prevalence during the past two decades has dramatically increased as people get older with 70% of cases diagnosed in men and women over the age of 50 [7]. In 2012, 6.7 million new cancer cases were diagnosed among older adults, representing 47.5% of the total number of new cancer cases worldwide [10]. Incidence rates are strongly related to age for all cancers combined, with the highest incidence rates being in older people [11]. As such, there are now 4.4 million older adult cancer survivors who have survived over 5 years beyond their diagnosis, while 2.8 million have survived over 10 years [12]. Consequently, age is a risk factor for chronic complications of treatment, including chemotherapy-induced acute leukemia and chronic cardiomyopathy, with obvious implications for QoL or HRQoL [13][14].



**Figure 1:** A management decision tree focusing on QoL in elderly cancer patients [9]



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 875329. The information, documentation and figures available in this information sheet are written by the LifeChamps Consortium partners under EC co-financing (Call: H2020-SC1-DTH-2019, Project ID: 875329) and do not necessarily reflect the view of the European Commission. The information in this document is provided "as is", and no guarantee or warranty is given that the information is fit for any particular purpose. The reader uses the information at his/her sole risk and liability



As older people experience complex health and social care needs alongside their primary cancer diagnosis, their treatment decision, effectiveness, and care support for the patients' QoL are more complicated [15][16]. Due to concomitant multi-morbidity and frailty among these patients, health professionals need to deal with complex treatment decision-making processes [17] (Figure 1).

In order to evaluate treatment options, physicians in oncology care generally focus on short-term complications, morbidity and survival as primary outcomes [18][19]. Especially in older people with cancer, treatment considerations should be based on individual preferences regarding quality or quantity of life. [20][21] Though individual characteristics among cancer patients, such as functional impairment, co-morbidity and psychosocial disabilities have predictive value for QoL [22], most studies on the association between cancer and QoL lack focus on older patients' frailty status.

Frailty assessment may provide novel insight into heightened vulnerability and risk stratification of older patients with cancer [23][24]. According to H. Chen et.al. [25] there is a need for a systematic use of sophisticated assessments, such as the geriatric assessment, that may allow physicians to select appropriate patients and reduce under-utilisation of aggressive treatments in older cancer patients. Additionally, such geriatric assessment focused interventions could identify high-risk patients and support the reduction of long-term adverse health care use in this vulnerable population [26]. The use of different geriatric, QoL and symptom measures [27] along with the use of information technology [27][28][29] provides us with the opportunity to improve the current risk profiling of cancer patients [29] above a certain age. The use of sophisticated data analytics [30] will allow us to explore the determinants that impact older cancer patients' HRQoL and disease progression, measure their interactions and map the different, confounding levels of influence between them.

## 2.2 APPROACH

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 QoL solutions for different cancer life champions. The project addresses the main conditions of fragility in post-cancer treatment for older adults. Hence, with a focus 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 achieve this objective, the LifeChamps project integrates ground-breaking technologies in the areas of Big Data and AI towards delivering a smart, personalised and secure platform that monitors health outcomes and addresses comorbidities of cancer champions by preventing long-term effects and improving QoL.

Its innovative components are built upon three pillars:

- Prediction
- Care providing
- Advice

Overall, the LifeChamps platform is envisaged to enable:

- fast and effective collection of heterogeneous types of data from multiple sources (close to a person treated or to stakeholders' data) and domains (different cancer types, caregivers' scope, etc.) that are responsible for creating a comprehensive network of knowledge, derived from multiple data correlations and analysis;
- correlation between cancer subtype classifications and progression, based on systems medicine analytics, to offer insightful, personalised adaptive recommendations;
- patient-centric tools and applications for the needs of translational research and clinical practice in oncology;
- correlation between PROMs and PREMs and QoL/frailty incidence in older adults;
- a frailty care model for delivering coordinated long-term post-cancer care to older adults and caregivers, where a multi-dimensional QoL index will be a key input;
- the use of digital biomarkers as a valuable driver for monitoring and preventing QoL decline, during and after cancer treatment.

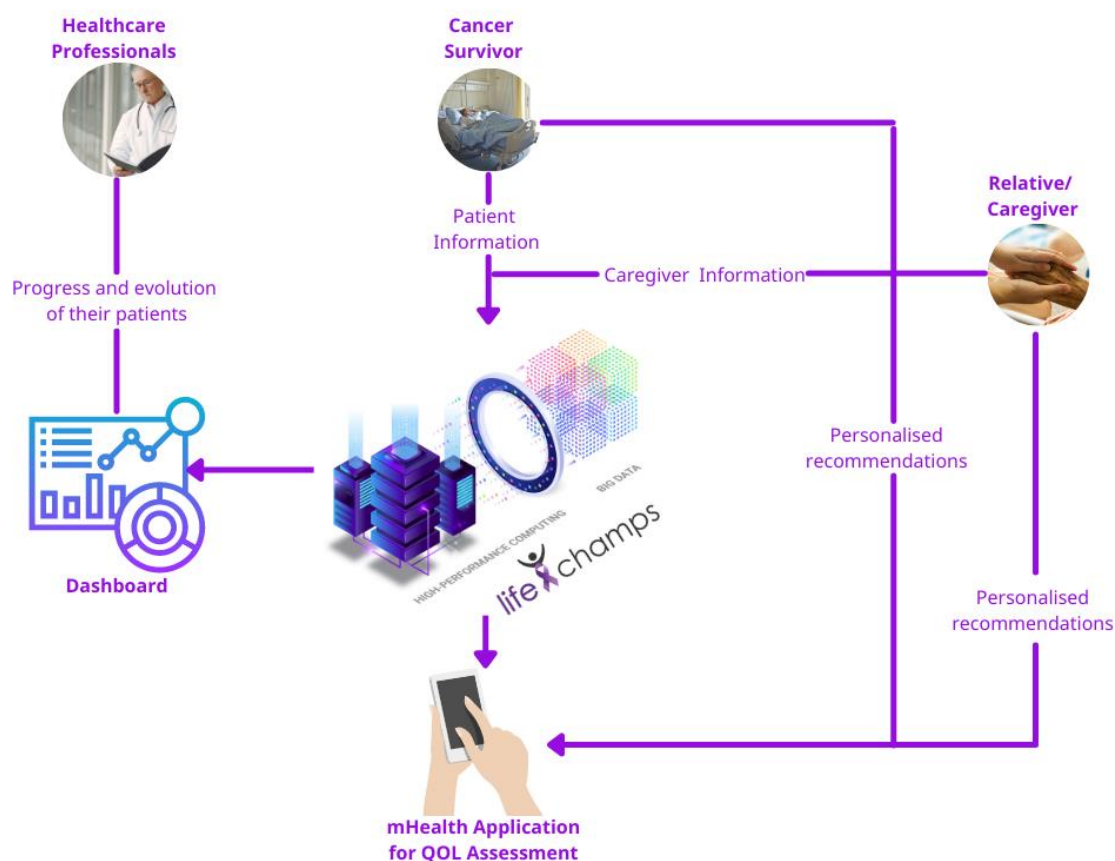


### 3 LIFECHAMPS ARCHITECTURE

LifeChamps aims to address the inherent complexity caused by cancer treatments and to act in the monitoring of health status and improvement of Quality of Life in a significant manner by using emerging technologies in the fields of Big Data, Data Analytics and AI.

It targets older adult cancer patients (pre-frail and frail), caregivers and multidisciplinary healthcare professionals with a comprehensive solution capable of offering tools and mechanisms to promote patients' empowerment and improved Quality of Life via timely and more accurate clinical decision support at the point of care.

The project delivers a comprehensive architecture that can effectively collect and harmonise information sources related to cancer life champions and create a Big Data structure composed of a context-aware, data-intensive and large-scale analytics framework for the collection and processing of streaming data.



**Figure 2:** LifeChamps Architecture



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The LifeChamps architecture comprises three main components, the LifeChamps Dashboard, the LifeChamps Platform and the Mobile Application for QoL Assessment (see Figure 2).

The LifeChamps Platform integrates the ground-breaking technologies in Big Data and Artificial Intelligence towards delivering a smart, personalised, and secure platform for analysing health outcomes and addressing co-morbidities of older adult cancer survivors by preventing long-term effects and improving QoL.

Based on the Platform analysis results, intelligent tools for Frailty monitoring and QoL improvement are defined to provide cancer survivors and their caregivers with mechanisms for empowering their health and lifestyle through the Mobile Application. It provides personalised recommendations to older adult cancer survivors and relatives/caregivers, collects patient-reported outcomes, and monitors continuous information, and feedback.

On the other hand, the LifeChamps Dashboard for healthcare professionals presents the patients' progress and allows detecting and obtaining a persons' progress over time and evolution qualitatively and quantitatively. For this purpose, it includes individual patient ill-health trajectory modelling, patient stratifications, cohort level insights, and quality of clinical cancer care service, combining PREMs, clinical events from Electronic Health Records (EHRs), and patients' responses to treatment.

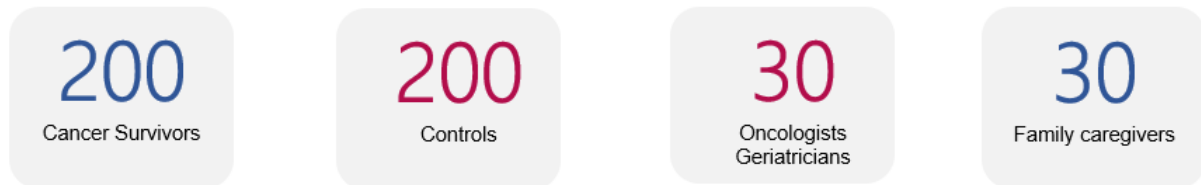
Different architecture levels were defined, from high to low level and from logical to physical views and support an integrated approach, ensuring that all pieces fit together. LifeChamps architecture designed under the "4+1 architecture view model" [31] to provide standards and guidelines for each technical partner to design, implement, and develop the architecture's different components. This work is supported by the LifeChamps platform and reference architecture document (D2.4).

Based on this, the LifeChamps Architecture will deliver an open, data-centric, secure, and smart solution capable of supporting cancer champions in their endeavours from the moment of diagnosis to therapy and recovery.



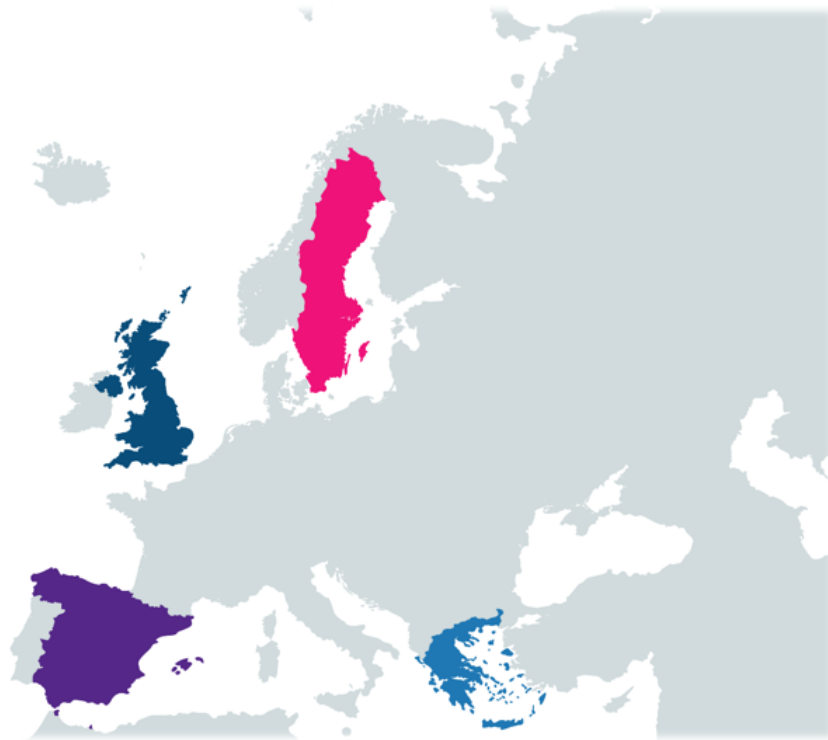
## 4 LIFECHAMPS PILOT USE CASES

LifeChamps architecture and conclusions derived from co-creation activities will be assessed in 4 pilot use cases (PUC) led by the clinical partners of the project: Aristotle University of Thessaloniki (AUTH), Academic Primary Health Care Centre (APC), Hospital Universitario La Fe (HULAFE), and University of Glasgow (UoG).



DECEMBER 2020 – SEPTEMBER 2022

- PUCs**
- PUC1 AUTH (Greece)
  - PUC2 APC (Sweden)
  - PUC3 HULAFE (Spain)
  - PUC4 UoG (UK)



**Figure 3:** Overview of the demonstration pilots



**Table 1:** LifeChamps Pilot Use Cases

ID	Leader (Country)	Scope
PUC1	AUTH (Greece)	Predicting and understanding treatment tolerance based on real-world digital biomarkers and ePROMs
PUC2	APC (Sweden)	Multiple assessment of psychological and lifestyle factors for a person-centred care in aging cancer survivors
PUC3	HULAFE (Spain)	New AI to reduce mental burden and improve QoL for patients during/after cancer treatment
PUC4	UoG (UK)	Predicting the effects of the interaction between late/persisting treatment-related symptoms and multimorbidity/polypharmacy on the frailty and independent living status of older people post-cancer treatment

During Task 2.1 “Scenario Thinking and Initial Technical & Business Requirements Definition” interactive activities with health care providers were conducted to:

- Provide an initial definition of LifeChamps’ pilot use cases
- Gather relevant information about the current use case scenario
- Determine the potential added value of LifeChamps in each specific scenario
- Familiarise clinicians and stimulate their involvement during the project lifecycle.

The methodology and results from interactive activities to define use cases were reported in detail in D2.1. In the following subsections, a brief description of each pilot use case is presented.

#### 4.1 PUC1

Scope: Predicting and understanding treatment tolerance based on real-world digital biomarkers and ePROMs.

Goal: To assist in making a more objective geriatric assessment, by matching real-world data gathered by the technology with clinical tools used in clinical practice to measure QoL of older cancer patients. To be applied at diagnosis, during adjuvant or



first-line treatment and during follow up periods, in breast and prostate older cancer patients provided that there is at least one year of life expectancy.

Repeated monitoring of a patient's state (in a continuous fashion and not fragmentary) is needed, as it is highly likely that immediate indications that this information (patient's state) has changed could exist, even before the patient himself/herself will be able to realise it.

Furthermore, the evaluation of how treatment affects the patients' quality of life and their clinical status, including comorbidities, is also needed. However, the evaluation of whether a patient can receive a certain therapy or not is considered as out of the scope of this pilot use case.

## 4.2 PUC2

Scope: LifeChamps AI analytic platform to assist older skin cancer survivors in coping with stress and fear recurrence and supporting their HRQoL.

Goal: The assessment of psychological and lifestyle factors in person-centred care for ageing cancer survivors. The use case should consider several other chronic diseases, as these have an impact on elderly patients HRQoL as well. The experts identified a clear need for a holistic approach to comprehensively cover all aspects of the pilot use case for the study of HRQoL in cancer survivors.

## 4.3 PUC3

Scope: New AI to reduce the mental burden and improve QoL for patients during/after cancer treatment.

Goal: The purpose of this use case is to understand better patients' needs and priorities regarding their quality of life. Patient-reported information will help clinicians to understand better the real perception of patients, effects of treatments and make personalized and proactive decisions based on this information. Also, older patients' technical skills will be assessed to know their potential and determine if they are currently underestimated.



#### 4.4 PUC4

Scope: Predicting the effects of the interaction between late/persisting treatment-related symptoms and multimorbidity/polypharmacy on older post-cancer treatment's frailty and independent living status.

Goal: To develop a system using artificial intelligence, to support older individuals' post-cancer treatment and to explore how late cancer treatment effects, multimorbidity and polypharmacy may affect active independent living after the end of treatment for breast or prostate cancer, particularly when existing chronic health problems may be exacerbated or when people may be dealing with multiple drug related side effects. We were looking for a contribution towards building our pilot study in a way that would identify the requirements of clinicians to better support these specific patients and consider the potential barriers and facilitators.





## 5 STAKEHOLDER INVOLVEMENT AND SOLUTION REQUIREMENTS

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One of the fundamental concepts in the LifeChamps project is that the platform is being developed as part of a co-creation process [32]. Co-creation is crucial in developing new interventions and services to ensure that they are aligned with the needs, priorities and expectations of potential end-users. This, in turn, can facilitate uptake, implementation, and integration within everyday clinical practice. In LifeChamps, co-creation is crucial for the refinement of the proposed pilot use-case scenarios [33], identifying core clinical and patient requirements and previous experience [34], which could lead to the subsequent selection of appropriate outcome metrics [35] that will be used for the data collection and platform evaluation during the pilot phase of the project.

Co-creation aims to identify the post-treatment health needs, the priority clinical outcomes, and patient care requirements of potential LifeChamps end-users' while establishing their views, preferences, and expectations from the developing LifeChamps platform.

In the co-creation workshops with end-users, our prospective mixed-methods approach, which employed a descriptive and cross-sectional study design, ensured a strong engagement with all the targeted stakeholder groups, which included two different clusters of systems' potential end-users; the primary (active end-users) and the secondary (assistive or advisory end-users) (Figure 4):

### A. Primary Stakeholders

- Older cancer survivors (breast, prostate and skin cancer) [End user Group 1]

### B. Secondary Stakeholders

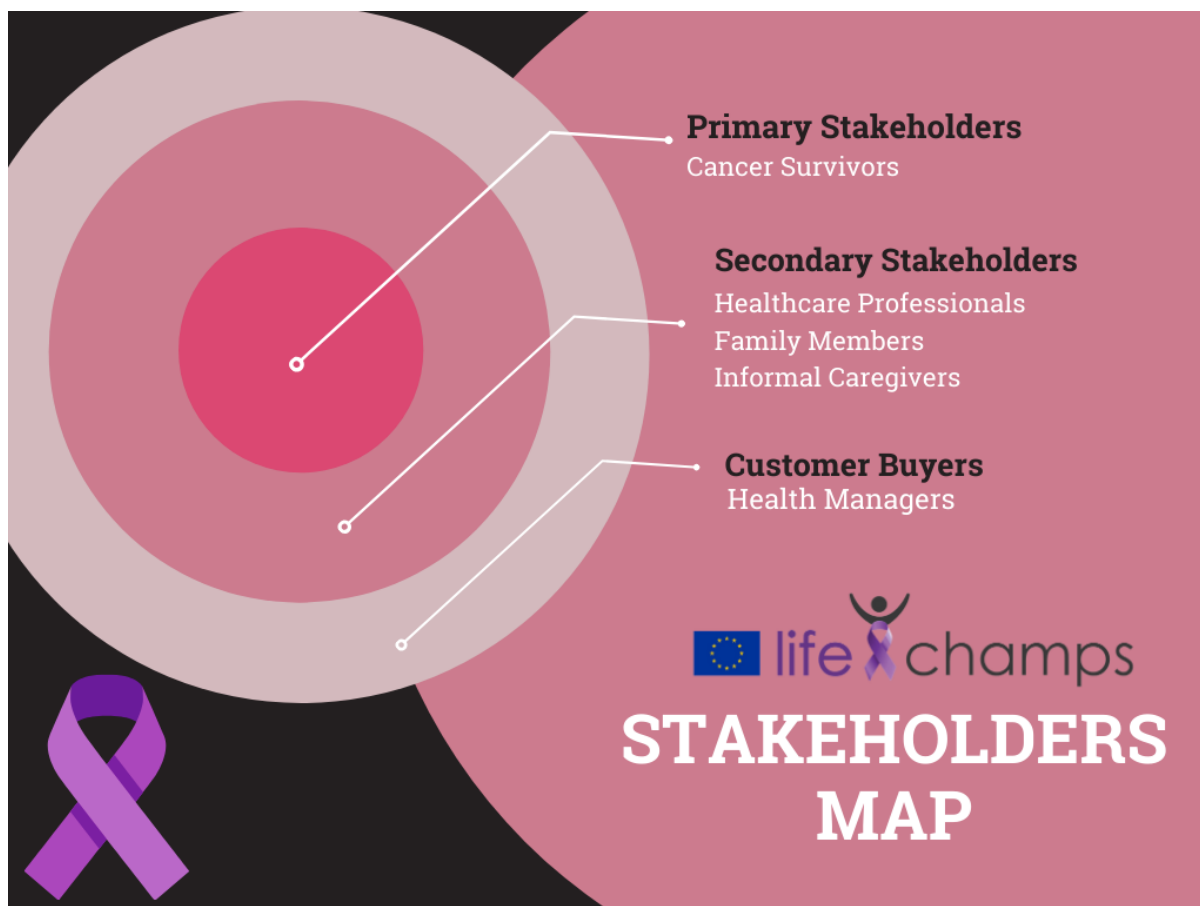
- Healthcare professionals & Professional caregivers (oncologists, geriatricians, nurses, GPs etc.) [End user Group 3]
- Family members/ Informal caregivers of older cancer survivors [End user Group 2]

### C. Customer Buyers

- Health managers [End user Group 4]

Stakeholders' eligibility criteria are presented in details in Table 2.





**Figure 4:** Stakeholders Map

In line with our mixed-methods approach, we opted for a combination of online qualitative surveys and telephone interviews with our goal being to maximise recruitment rates despite COVID-19 restrictions and ensure diversity of opinions by offering two different options for participation and data collection. Data collection was organised and conducted by task 2.2 pilot partners. Surveys and interviews were planned to run in parallel at the four partner countries. Interviews were planned to complement survey data and allow for exploration of opinions/issues following a guided script.

The online surveys were set up via the EU Survey tool [36]. This is an established online tool for the management of global surveys offering maximum data protection, confidentiality and translation into multiple languages. We conducted interviews via telephone/mobile phone and audio-recorded them.



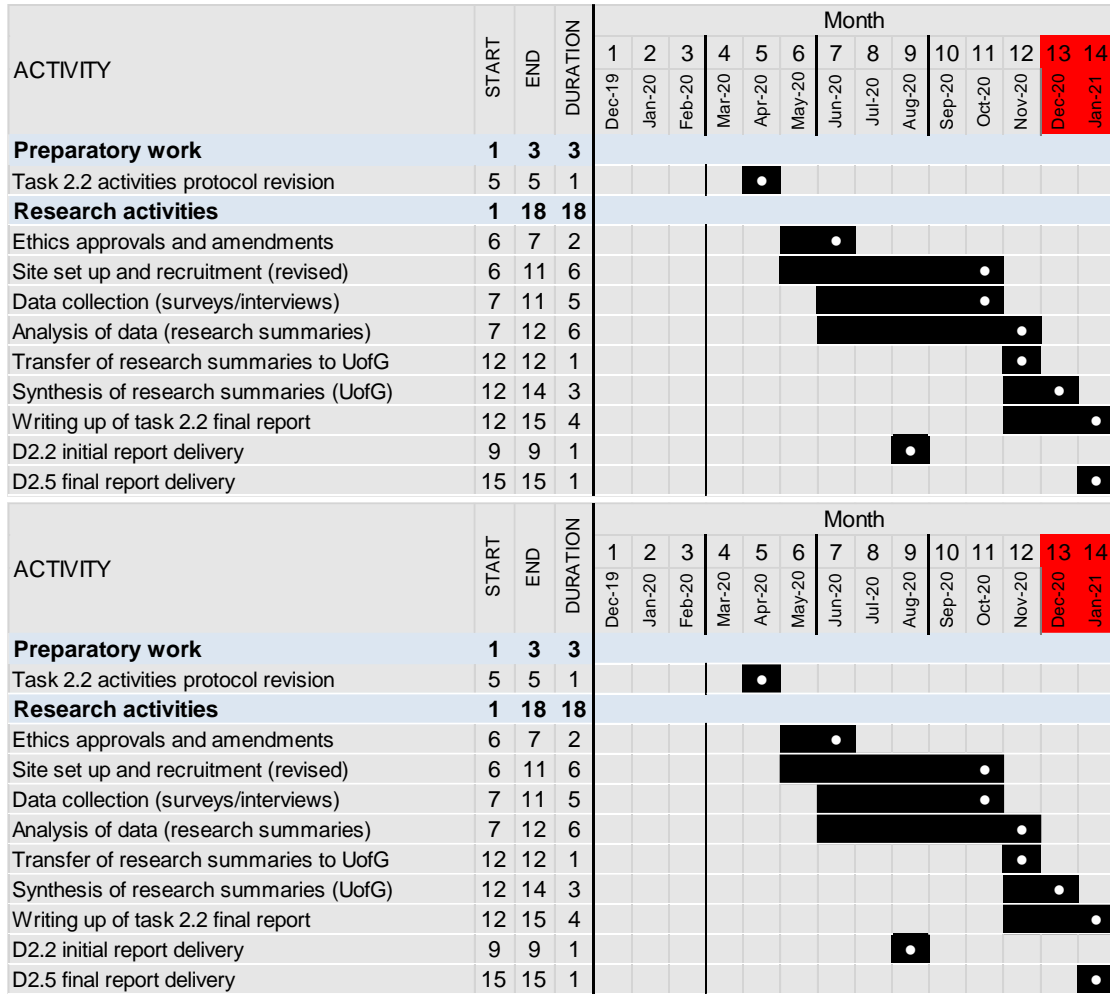
**Table 2:** Eligibility Criteria for All End-User Groups

<p><b>End-user Groups 1 and 2</b></p>	<ul style="list-style-type: none"> <li>• Older cancer survivors -both male and female.</li> <li>• Relatives/family caregivers aged 18 years and above.</li> <li>• Diagnosed with breast, prostate or skin (melanoma) cancer and living beyond cancer treatment or caring for an older person with cancer.</li> <li>• Able to speak, write and communicate in [respective language].</li> <li>• Access to telephone and/or email and/or an Internet-enabled electronic device (i.e., computer, laptop, tablet or smartphone).</li> <li>• No major cognitive or mental disorder that affects communication.</li> </ul>
<p><b>End-user Groups 3 and 4</b></p>	<ul style="list-style-type: none"> <li>• Oncology consultants, geriatricians, dermatologists, acute care nurses, community nurses, general practitioners, physiotherapists, health managers.</li> <li>• Involved in the delivery of care services for (older) people with cancer.</li> <li>• Access to telephone and/or email and/or an Internet-enabled electronic device (i.e., computer, laptop, tablet or smartphone).</li> </ul>

The online qualitative surveys comprised a mix of closed-ended and open-ended questions devised in line with project's research questions. The interviews comprised open-ended questions. Surveys and interviews asked similar questions. All questions were translated from English into the respective languages of the four pilot sites. Potential end-users were asked to take part in the study.

Figure 5 provides details of the timeline of task 2.2, which lasted 14 months in total.





**Figure 5:** Gantt Chart of Task 2.2 Timelines.

To ensure diversity in experiences/views/opinions of end-users was opted heterogeneous convenience sampling as a pragmatic approach.

For the online surveys, the sample sizes were set to up to 100 individuals per country for a total of up to 400 individuals (Table 3). For a 95% confidence interval and 5% margin error, a sample size of 400 individuals was adequate regardless of the targeted population's size [37].



**Table 3:** Survey Sample Size per Task 2.2 partner

Target Group	UoG	HULAFE	AUTH	APC	Total
<b>Patients (Group 1)</b>	20-65*	20-65	20-65	20-65	80-260
<b>Family Caregivers (Group 2)</b>					
<b>Health Professionals (Group 3)</b>	10-35	10-35	10-35	10-35	40-140
<b>Health Managers (Group 4)</b>					
<b>Total Survey Participants</b>	30-100	30-100	30-100	30-100	120-400

*\*Cells reflect total numbers across Groups 1 & 2 and across Groups 3 & 4 per country.*

Telephone interviews were set to be conducted with up to 120 individuals in total, depending on availability (Table 4). Interviews aimed to achieve an information-rich and diverse dataset. To this end, a distinct guide of questions was developed for each end-user group. The required sample size per partner and user-group was calculated using the relevant formula, defined by Fugard and Potts [38]. For end-user Groups 1 and 2, for an anticipated theme prevalence of 75% and appearance of 50% (adjusted prevalence of  $0.75 \times 0.5 = 0.375$  or 37.5%) and 2 instances of the theme showing up, a total number of eight participants per end-user group would be enough to detect the theme with 80% power. For end-user Groups 3 and 4, for an anticipated theme prevalence of 75% and appearance of 75% (adjusted prevalence of  $0.75 \times 0.75 = 0.56$  or 56%) and 2 instances of the theme showing up, 5 participants per end-user group would be enough to detect the theme with 80% power [38].

**Table 4:** Individual Interviews per Task 2.2 partner

Target Group	UoG	HULAFE	AUTH	APC	Total
<b>Patients (Group 1)</b>	4-10	4-10	4-10	4-10	16-40



<b>Family Caregivers (Group 2)</b>	4-10	4-10	4-10	4-10	16-40
<b>Health Professionals (Group 3)</b>	2-5	2-5	2-5	2-5	8-20
<b>Health Managers (Group 4)</b>	2-5	2-5	2-5	2-5	8-20
<b>Total Individual Interviews</b>	12-30	12-30	12-30	12-30	48-120

Emerging difficulties with recruitment, mainly due to the COVID-19 pandemic, led to a decision for targeted sample sizes for surveys and interviews to be merged (owing to the complementarity of these activities) as summarized in Table 5. A further new goal was set for partners to recruit at least their minimum allocated target sample size, i.e.  $\geq 20$  end-users from Groups 1 and 2,  $\geq 10$  end-users from Groups 3 and 4. Combined across partners, this would provide data from at least 120 end-users across all end-user groups, thus resulting to an information-rich dataset.

**Table 5:** Revised Target Sample Size per Task 2.2 partner

<b>Target Group**</b>	<b>UoG</b>	<b>HULAFE</b>	<b>AUTH</b>	<b>APC</b>	<b>Total</b>
<b>Patients (Group 1)</b>	<b>20-65*</b>	<b>20-65*</b>	<b>20-65*</b>	<b>20-65*</b>	<b>80-260</b>
<b>Family Caregivers (Group 2)</b>					
<b>Health Professionals (Group 3)</b>	<b>10-35</b>	<b>10-35</b>	<b>10-35</b>	<b>10-35</b>	<b>40-140</b>
<b>Health Managers (Group 4)</b>					
<b>Total Participants</b>	<b>30-100</b>	<b>30-100</b>	<b>30-100</b>	<b>30-100</b>	<b>120-400</b>

\*Target sample size range for surveys and interviews combined. Minimum target sample size appears in bold.

In terms of recruitment, Group 1 and Group 2 end-users were recruited (a) via health professionals/ personnel employed at nursing homes and hospitals, which would



provide end-users with information about the study via text or email, and (b) via advertisements on dedicated outreach platforms (e.g. <https://www.peopleinresearch.org/>) or to social media (e.g. Twitter). Moreover, Group 3 and 4 end-users were recruited via (a) advertisements on social media (e.g. Twitter) and (b) via professional networks. Furthermore, a referral technique was used to invite Group 3 and 4 end-users interested in participating in the study to invite additional colleagues to consider participation by getting in touch with the researchers. Given the restrictions placed by the COVID-19 pandemic, all communications with end-users about and during the study was remote, via email, telephone and/or teleconference. Regardless of the recruitment route, end-users were invited to opt-in to participate in the study. At that stage was clarified that participation would be exclusive to either survey or interview, but not both. For end-user Groups 1 and 2, the LifeChamps consortium engaged with health professionals and personnel at local charitable organisations and hospitals, which provided potential participants with information about the study via text or email. Additional help from the European Cancer Patient Coalition (ECPC), LifeChamps project partner, helped identify potential participants from within local networks across the four countries. In parallel, were created advertisements on dedicated outreach platforms and extensively used social media (Twitter and Facebook), tagging patient and caregiver support groups and national charitable organisations with many followers, thus further extending the potential participants' pool. In the UK, a prize draw for shopping vouchers was implemented to offer a small honorarium to compensate participants for their time on the study without increasing the risk for undue coercion [39]. Similarly, for end-user Groups 3 and 4, were posted advertisements on social media (Twitter and LinkedIn) and the partners' professional networks to identify clinicians and health managers were used. Simultaneously, the referral technique was actively employed, asking clinicians to invite other colleagues to consider participation. This approach contributed to widen the pool of participants having a remarkable impact at least on the identification of potential participants.

Ethical approvals were obtained promptly and within pre-set timelines for all pilot sites. Table 6 shows wide variability in turnaround times of ethics committee/board decisions, which were impacted as expected by the pandemic.



**Table 6:** Summary of Site Ethics Approvals and Start Dates

	UoG	HULAFE	APC	AUTH
Name of local ethics board/committee	University of Glasgow MVLS Ethics Committee	Comité de Ética de la Investigación con medicamentos (CEIm)	The Swedish Ethical Review Authority	Aristotle University of Thessaloniki Ethics Committee
Date of ethics application	2 <sup>nd</sup> week in April 2020	2 <sup>nd</sup> week in April 2020	2 <sup>nd</sup> week in April 2020	2 <sup>nd</sup> week in April 2020
Date of ethical approval	12/06/2020	22/04/2020	18/05/2020	29/07/2020
Recruitment start Date	06/07/2020	23/07/2020	07/08/2020	29/07/2020
Weeks the study has been open for recruitment as 30/08/2020	8	5	3	4

In terms of participation, were collected/retained only necessary personal data (i.e. names, home/work/email addresses, phone numbers) for communication purposes, i.e., sending information sheets to interested parties, sending survey links or arrange an interview. All eligible end-users were informed that all personal and research data collected for this project's purposes would be treated as strictly confidential. For online surveys, participants were asked to complete an online eligibility and consent form. If participants agreed with the statements, they could move on to the next screen and take the survey. They could not progress to the survey unless they agreed to the statements. We asked all eligible consenting end-users for telephone interviews to sign an informed consent form and return via secure email transfer.

In terms of data management and analysis, survey data were downloaded from the online survey tool and stored as password-protected Excel files on secure University drives. Any identifiable information was removed at the data management stage. Interview audio-files were transcribed by professional transcription services at each partner site and analysed in the respective language. Task 2.2 partners were





responsible for analysing their own raw research data as generated at their respective pilot sites/countries. Each partner created a 'Summary of Findings' file, containing processed and fully anonymised research data, written in English for subsequent evidence synthesis purposes. The data analysis will be reported separately. Here, we provide preliminary information on our accrual rates below.

At the end of M12 (November 2020), a total of 155 end-users were recruited across groups and partners (accrual rate 129%). Across partners, the accrual rate for end-user Groups 1 and 2 (patients and family caregivers) was 129%. A slightly higher accrual rate (155%) was achieved for end-user Groups 3 and 4 (health professionals and health managers). At a country-specific level, accrual rates varied widely (Table 7), which can be attributed to several influencing factors, including differences related to the recruitment start date among the pilot sites, as well as the local annual holiday periods, which affected potential participants' availability.

Data analysis is currently under way.

**Table 7: Accrual Rates**

Accrual Rate <sup>1</sup>				
End-user group	UoG	HULAFE	APC	AUTH
Patients	215	70	35	129
Family/ Caregivers				
Health Professionals	230	30	130	155
Health Managers				
Totals	220	57	67	129

<sup>1</sup>Accrual rate = (Actual n / min Target n) x100.



## 6 CONCLUSIONS

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This Whitepaper, as part of a dissemination action, has provided an insight into the activities developed in LifeChamps during the first year of the project within the scope of WP2. Despite derived difficulties from COVID-19, interactive activities with end-users (patients, caregivers and health care professionals) were successfully conducted and allowed us to understand their needs, priorities, concerns and expectations about LifeChamps. This feedback has been translated into technical and functional requirements and will be crucial to develop all the Platform components in the following months. Finally, it was possible to provide an initial definition of 4 pilot use cases where LifeChamps will be implemented, and their potential will be assessed. More information can be found in the deliverables mentioned above (D2.1, D2.2, D2.3, D2.4).

All the above will be incorporated in an artificial intelligence and behavioural science based health recommender system to provide personalized recommendations and guide regarding social inclusion among other elements to increase quality of life of older cancer patients by:

- Establishing best models for delivering coordinated, long-term cancer care to older people and families to sustain independent living, social inclusivity, and long-term adjustment.
- Realising the person-led care by understanding and abiding by the unique needs (and interactions thereof) of older people (and families) living with and beyond cancer.
- Paving the way towards predicting which older people (and families) living with and beyond cancer are at risk for decline in independent living post-treatment to prevent/minimise long-term ill health and proactively plan care in a cost-effective way.
- Substantiating supported self-management by personalising evidence-based advice to accommodate the complexities that post-treatment late effects, multimorbidity and polypharmacy pose to older people with cancer and their families, and promote positive, patient-tailored lifestyle changes.
- Improving and sustain inter-professional communication regarding advanced care planning, and patient-professional communication regarding supported self-management.



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