PROJECT

LIFECHAMPS: A Collective Intelligence Platform to Support Cancer Champions

GRANT AGREEMENT No.

875329

DELIVERABLE

D2.2 - End-user/stakeholder requirements – initial version

CONTRACTUAL SUBMISSION DATE

31/08/2020

ACTUAL SUBMISSION DATE

31/08/2020

DELIVERABLE VERSION

3.0

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This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement **No 875329**.

PROJECT DOCUMENTATION

Grant Agreement No.	875329
Project Acronym	LIFECHAMPS
Project Full Title	LIFECHAMPS: A Collective Intelligence Platform to Support Cancer Champions
Type of Action	Research & Innovation Action (RIA)
Topic	SC1-DTH-01-2019: Big Data and Artificial Intelligence for Monitoring Health Status and Quality of Life after the Cancer Treatment
Call Identifier	H2020-SC1-DTH-2018-2020
Start of Project	1 December 2019
Duration	36 months
Project URL	https://lifechamps.eu/
EU Project Officer	Alina Lupu

DELIVERABLE DOCUMENTATION

Deliverable Title	D2.2 - End-user/stakeholder requirements – initial version
Deliverable No.	D2.2
Deliverable Version	3.0
Deliverable Filename	LIFECHAMPS_D2.2_v3.0
Nature of Deliverable	R (document, report)
Dissemination Level	PU (public)
Number of Pages	40
Related Work Package	WP2
Lead Beneficiary	UPV

Keywords	End-users; Stakeholders; Patient reported outcomes; Patient reported experiences; Health needs; Requirements.

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REVISION HISTORY

Version	Date	Comment	Author(s)
V0.1	23/07/2020	Draft report sections and initial content	Dr Grigorios Kotronoulas
V0.2	27/07/2020	Content review and edits	Sheena McGowan
V0.3	13/08/2020	Added text to sections 7-10 and to Tables 6-8	Dr Grigorios Kotronoulas
V0.4	14/08/2020	Added text to executive summary and updated data in Tables 6-8	Dr Grigorios Kotronoulas
V1.0	24/08/2020	Deliverable upgraded to review version	Dr Grigorios Kotronoulas
V1.1	27/08/2020	Deliverable updated, amended and submitted	Dr Rebecca Marshall-McKenna
V2.0	27/08/2020	Deliverable upgraded to final review version	Dr Antonis Billis
V2.1	31/08/20	Final Review	Dr Grigorios Kotronoulas

V3.0	31/08/20	Upgraded to final version for EC submission	Professor Panos Bamidis

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ABBREVIATIONS LIST

Abbreviation	Meaning
COVID-19	Coronavirus Disease 2019
EC	European Commission
HRQoL	Health-Related Quality of Life
PRE	Patient reported experience
PRO	Patient reported outcome
PUC	Pilot use case
WHO	World Health Organization

1 EXECUTIVE SUMMARY

The goal of deliverable D2.2 is to outline the research methods and procedures employed within task 2.2 and report on the current progress with recruitment and data collection in line with the task's aim, i.e. to identify the health needs, priority patient reported outcomes (PROs) and patient reported experiences (PREs), and care requirements of potential LifeChamps end-users at the post-cancer treatment period, and explore their expectations from the developing LifeChamps platform. In the report, we provide details of the prospective mixed methods study that was initiated at the four partner sites University of Glasgow (UofG), Hospital Universitario La Fe (HULAFE), Academic Primary Health Care Centre (APC) and Aristotle University of Thessaloniki (AUTH) by employing a descriptive and cross-sectional study design.

In setting up the study, one of the major challenges has been the COVID-19 pandemic that was declared around the same time as our ethics applications were due for submission. We report how, after careful consideration that involved a formal risk assessment plan, we have swiftly adopted a flexible approach to recruitment, sampling and modes of data collection with a view to mitigate the impact of the pandemic and the likely delays posed. To date, our plan has been successful. Ethical approvals at the partner sites were obtained on time, and recruitment started soon after. Currently, our accrual rates stand at 1.3%-9.2% for the patient end-user group, 0%-4.6% for the carer/family/friends end-user group, 5%-11.4% for the health professional end user group and 0%-1.4% manager end-user group, depending on mode of data collection (interview - survey). Our analysis of accrual rates provides us with specific pointers for additional rigorous work to engage more end-users, meet our recruitment targets and collect the necessary data for analysis and interpretation ahead of submitting deliverable D2.5.

2 INTRODUCTION

The steady increase in life expectancy and cancer survivorship rates in the developed world pose a pressing need to deal with the 'age issue' as a key component of global cancer care strategies [1]. In 2012, 6.7 million new cases of cancer were registered in adults aged ≥65 years [2]; that was 47.5% of the total number of new cancer cases worldwide. Older age and comorbidities are often associated with a discriminant lower use of cancer services among older people living beyond cancer, challenged health-related quality of life (HRQoL), and a potential neglect of their long-term needs and preferences for support as they adjust to life after primary cancer treatment is over [1].

The LifeChamps platform will be developed via co-creation with end-users (co-creation task) [3] and subsequently validated in four multinational pilot use case (PUC) scenarios as part of WP7, aimed at demonstrating its applicability and validity in providing prediction, care and advice services (piloting task). To this end, the aim of task 2.2 will be to identify the health needs, priority PROs and PREs, and care requirements of potential LifeChamps end-users at the post-cancer treatment period, as well as their views, preferences and expectations from the developing LifeChamps platform. Co-creation will be crucial for the selection of appropriate outcome measures as identified

within task 2.3 (D2.3), direction of activities within WP5 (D5.3 and D5.4), and subsequent piloting task in relation to appropriate content and functionality of the platform as tested within WP7 (D7.1, D7.3, D7.4).

The present document (D2.2) outlines the aims set as part of task 2.2 and associated methods and research procedures, discusses the impact of the pandemic on initial research plans and actions to mitigate the impact, and presents an update of current recruitment and data collection status ahead of the submission of the final report (D2.5).

3 AIMS & RESEARCH QUESTIONS

Task 2.2 aims to explore:

a) The perceptions of end-users about the health needs, priority PROs, PREs and care requirements of middle-aged/older people with cancer at the post-cancer treatment period, and
b) The views, preferences and expectations of end-users from the developing platform.

Research Questions to be addressed are as follows:

RQ1: What are the perceptions of end-users about the health needs, priority PROs, PREs and care requirements of middle-aged/older people with cancer at the post-cancer treatment period?

RQ2: What are the views, preferences and expectations of end-users from the developing platform?

4 METHODS

4.1 STUDY DESIGN

We planned a prospective mixed methods study, employing a descriptive and cross-sectional study design.

All research activities were planned to take place in accordance to the World Medical Association Declaration of Helsinki, 9th revision (2013).

4.2 TARGET PARTICIPANTS

We used a strong engagement strategy to consult with relevant end-users (c.f. paragraph 8), including:

- Middle-aged and older people with cancer (end-user Group 1),
- Relatives/family caregivers of middle-aged or older people with cancer (end-user Group 2),
- Healthcare professionals (end-user Group 3), and
- Health managers (end-user Group 4).

Eligibility criteria are presented in Tables 1 and 2 below.

Eligibility Criteria
• Middle-aged (50-64 years of age) and older adults (≥65 years of age) men and women. • Relatives/family caregivers aged 18 years and above. • Diagnosed with cancer (preferably breast or prostate cancer or melanoma) and living beyond cancer treatment, or caring for an older person with cancer. • Able to speak, write and communicate in [respective language]. • Access to telephone and/or email and/or an Internet-enabled electronic device (i.e. computer, laptop, tablet or smartphone). • No major cognitive or mental disorder that affects communication.

TABLE 1 ELIGIBILITY CRITERIA FOR END-USER GROUPS 1 AND 2

Eligibility Criteria
• Oncology consultants, geriatricians, acute care nurses, community nurses, general practitioners, physiotherapists, health managers. • Involved in the delivery of care services for (older) people with cancer. • Access to telephone and/or email and/or an Internet-enabled electronic device (i.e. computer, laptop, tablet or smartphone).

TABLE 2 ELIGIBILITY CRITERIA FOR END-USER GROUPS 3 AND 4

4.3 DATA COLLECTION

On 11 March 2020, the World Health Organization (WHO) declared the novel coronavirus disease (COVID-19) outbreak a global pandemic [4]. Governments around the world, including partner countries involved in this task, enforced strict lockdown and social distancing measures to help contain the spread. As a result, the impact on normal daily and work-related activities was immediate and profound. This included both academia and the industry, while the suspension of new research meant that our initially planned research activities had to be revised. Specifically, the restrictions placed on any research involving face to face interaction required us to work towards enabling remote data collection, while minimising the impact on our timelines and quality of information collected.

In line with our mixed-methods approach, data collection we opted for a combination of online surveys and telephone interviews (one to one or focus group where possible) 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 partners, who will also be running PUC scenarios at their respective sites, i.e. APC (Sweden), AUTH (Greece), HULAFE (Spain) and UofG (UK).

Surveys and interviews were planned to run in parallel at the four partner countries. Interviews will 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[2]. This is an established online tool for the management of global surveys offering maximum data protection, confidentiality and translation into multiple languages. All partners were involved with the development of the two questionnaires, which can be accessed by the four end-user groups (patients with cancer, families or health professionals/health managers) in each county via the following links:

(For patients with cancer/families)

https://ec.europa.eu/eusurvey/runner/LifeChamps_patient (Sweden)

https://ec.europa.eu/eusurvey/runner/lifechamps_patientcarer_GR (Greece)

https://ec.europa.eu/eusurvey/runner/LC_Paciente_Cuidador (Spain)

https://ec.europa.eu/eusurvey/runner/LifeChamps_PatientCarer_UK (UK)

[See Appendix 12.3 "EU SURVEY Screenshots"]

(For health professionals/health managers)

https://ec.europa.eu/eusurvey/runner/LifeChamps_kliniker (Sweden)

[2] https://ec.europa.eu/isa2/discover-eusurvey-%E2%80%93-free-online-survey-tool-civil-servants-and-citizens-eu_en

https://ec.europa.eu/eusurvey/runner/lifechamps_clinician_GR (Greece)

https://ec.europa.eu/eusurvey/runner/LC_Clinicos (Spain)

https://ec.europa.eu/eusurvey/runner/LifeChamps_Clinician_UK (UK)

Interviews will be conducted either via telephone/mobile phone and audio-recorded, as detailed on participant information sheets.

The online surveys comprise closed-ended and open-ended questions devised in line with our research questions. The interviews comprise open-ended questions. Surveys and interviews ask similar questions. All questions were translated from English into the respective languages. Potential participants are being asked to take part to the study once, i.e. either take the survey or be interviewed.

4.4 TIMELINES

Revision of our data collection methods was done in parallel with revision of our timelines and the anticipated required extension by two (2) months to accommodate the required ethical amendments in each partner country. Figure 1 is a Gantt chart that provides details of revised timelines, with the overall anticipated duration of task 2.2 being changed from 12 months (M1-M12) to 14 months (M1-M14). Where possible, we will aim to work towards reducing the time required to complete certain research activities, without compromising the outcome, with a view to deliver D2.5 earlier than end of Month 14.

ACTIVITY	START	END	DURATION
Preparatory work	**1**	**3**	**3**
Task 2.2 activities protocol revision	5	5	1
Research activities	**1**	**18**	**18**
Ethics approvals and amendments	6	7	2
Site set up and recruitment (revised)	6	11	6
Data collection (surveys/interviews)	7	11	5
Analysis of data (research summaries)	7	12	6
Transfer of research summaries to UofG	12	12	1
Synthesis of research summaries (UofG)	12	14	3
Writing up of task 2.2 final report	12	15	4
D2.2 initial report delivery	9	9	1
D2.5 final report delivery	15	15	1

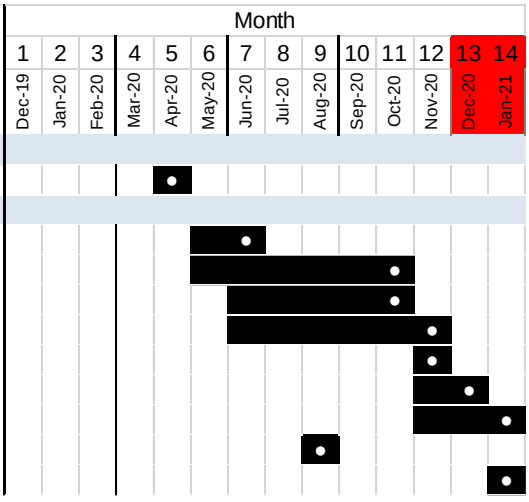

FIGURE 1 GANTT CHART OF TASK 2.2 TIMELINES (REVISED FOR COVID-19)

4.5 SAMPLING AND SAMPLE SIZE

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

4.5.1 PRE-COVID19 PLANNING

Initially, our plan was to conduct up to 16 focus group interviews, i.e. up to four focus group interviews per end-user group, and with a view to achieve an information-rich and diverse dataset. Empirical research has shown that between 3 and 6 focus groups would be enough to identify 90% of all potential themes within a given dataset [5]. Each focus group would involve 4-10 participants for a total of up to 160 participants. Where focus group interviews would prove to be impractical due to time restrictions, e.g. with health managers, one-to-one interviews would be conducted instead.

Focus group interviews (and one-to-one interviews where applicable) were to be organised and conducted by task 2.2 partners, who will also be running PUC scenarios at their respective sites, i.e. APC, AUTH, HULAFE and UofG. A general outline of the required focus group interviews for each partner is presented in Table 3. Deviations from this plan were allowed in line with practicalities and availability of stakeholders.

Target group	UofG	HULAFE	AUTH	APC	Total
Patients (group 1)	1	1	1	1	4
Family carers (group 2)	1	1	1	1	4
Health professionals (group 3)	1	1	1	1	4
Health managers (group 4)	1	1	1	1	4
Total focus group interviews	4	4	4	4	16

TABLE 3 FOCUS GROUP INTERVIEWS PER TASK 2.2 PARTNER (INITIAL PRE-COVID-19 PLAN)

4.5.2 POST-COVID-19 PLANNING

To accommodate for the challenges posed by the COVID-19 pandemic, we revised our original sampling plan to a combination of online surveys and one-to-one interviews.

For online surveys, sample sizes were set to up to 100 individuals per country for a total of up to 400 individuals (Table 4). For a 95% confidence interval and 5% margin error, a sample size of 400 individuals will be adequate regardless of the size of the target population (https://www.surveymonkey.com/mp/sample-size-calculator/).

Telephone interviews were set to be conducted with up to 120 individuals in total depending on availability and according to Table 5. Interviews were split by end-user group, and with a view to achieve an information-rich and diverse dataset. We based

our required sample size per partner and user-group using the formula devised by Fugard and Potts [6]. For end-user groups 1 and 2, for an anticipated theme prevalence of 75% and appearance of 50% (adjusted prevalence of 0.75 x 0.5 = 0.375 or 37.5%) and 2 instances of the theme showing up, 8 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 x 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 [6]. In Table 5, we show how we adjusted the target sample size to accommodate for participant availability and considering the complementary nature of the interview component to that of the online surveys. Where online focus group interviews were feasible, participants would be deducted from the partner's target sample size.

Target group	**UofG**	**HULAFE**	**AUTH**	**APC**	**Total**
Patients (group 1)	20-65*	20-65	20-65	20-65	80-260
Family carers (group 2)					
Health professionals (group 3)	10-35	10-35	10-35	10-35	40-140
Health managers (group 4)					
Total survey participants	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.					

TABLE 4 SURVEY SAMPLE SIZE PER TASK 2.2 PARTNER (REVISED POST-COVID-19 PLAN)

Target group	**UofG**	**HULAFE**	**AUTH**	**APC**	**Total**
Patients (group 1)	4-10	4-10	4-10	4-10	16-40
Family carers (group 2)	4-10	4-10	4-10	4-10	16-40
Health professionals (group 3)	2-5	2-5	2-5	2-5	8-20
Health managers (group 4)	2-5	2-5	2-5	2-5	8-20
Total individual interviews	12-30	12-30	12-30	12-30	48-120
*Where focus group interviews are feasible, they will be carried out instead of individual interviews, and the total number of focus group participants will be deducted from the target total for each partner.					

TABLE 5 INDIVIDUAL* INTERVIEWS PER TASK 2.2 PARTNER (REVISED POST-COVID-19 PLAN)

Deviations from the above plan were allowed in line with practicalities and availability of end-users within and across countries.

4.6 PROCEDURES OF PARTICIPATION

Our revised procedures of participation were set to enable us to maximise recruitment rates in the current COVID-19 situation and ensure diversity of opinions by offering two different options for participation and data collection. Participant information sheets were updated according to the required ethical amendments.

During the consent process (either surveys or interviews), we informed all eligible end-users that all personal and research data collected for the purposes of this project would be treated as strictly confidential.

For online surveys, participants had to complete the online eligibility and consent form. If participants agreed with the statements, they were able to move on to the next screen and take the survey. They could not progress to the survey unless they agree to the statements. This was explicitly stated in the participant information sheets provided to respondents which could be downloaded on the survey link. For telephone interviews, we asked all eligible consenting end-users to sign an informed consent form and return via secure email transfer.

For any end-user group, we anticipated that only basic personal data (i.e. names, home/work/email addresses, phone numbers) would be required to be collected/retained for communication purposes, i.e. to send information sheets to interested parties, send survey links or arrange an interview.

We planned to recruit group 1 and 2 end-users (a) via health professionals/personnel employed at charitable organisations and hospitals, who 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).

We planned to recruit group 3 and 4 end-users via (a) advertisements on social media (e.g. Twitter) and (b) via professional networks. We also used a referral technique to invite group 3 and 4 end-users interested in taking part in the study to invite additional colleagues to consider participation by getting in touch with the researchers.

Given the current COVID-19 situation, all communication with end-users about and during the study was remote, via email, telephone and/or teleconference. Regardless of recruitment route, we invited end-users to opt in if they are interested in participating in the study. We clarified at that stage that participation would be exclusive to either survey or interview, but not both.

4.6.1 END-USERS INTERESTED IN TAKING THE SURVEY

The advertisement/text/email instructed the end-user to click on the survey link to access the embedded eligibility screener, the following link provides an example of the

online advert used in the UK. https://www.callforparticipants.com/study/DW7R5/what-are-the-health-needs-of-middle-aged-and-older-people-with-cancer.

The participant information sheet, privacy notice (where applicable) and consent form was either available either on the direct link to the online survey, or they were signposted to contact the researcher via telephone or email if they were interested and the researcher would send relevant documents via email. Only end-users who met the eligibility criteria and completed the consent form were able to proceed to the survey questions.

Consenting eligible end-users (i.e. research participants) were able to take the survey at their own time and pace, save it and return to it, and submit it when ready. In the online survey, we presented participants with an overview of the project and a visual (low fidelity prototype) of the anticipated LifeChamps platform (Figure 2). The online survey comprised 15-30 questions (the number of questions varied depending on the role of the participant e.g., patient, relative/carer, clinician) and was expected to take 20-25 minutes to complete.

At the end of the survey, we debriefed research participants, asked them to submit their responses, thanked them for their time and contribution, and prompted them to close their Internet browser to exit. All research participants were free to skip any survey question and/or completely withdraw at any point if they so wished (by closing their browser) without a requirement to justify their decision. For ineligible end-users or end-users who changed their mind at the screening/consent stage, the survey automatically ended, and the end-user was thanked for his/her time, assured them that their decision would not affect them in any way, and prompted to close their Internet browser.

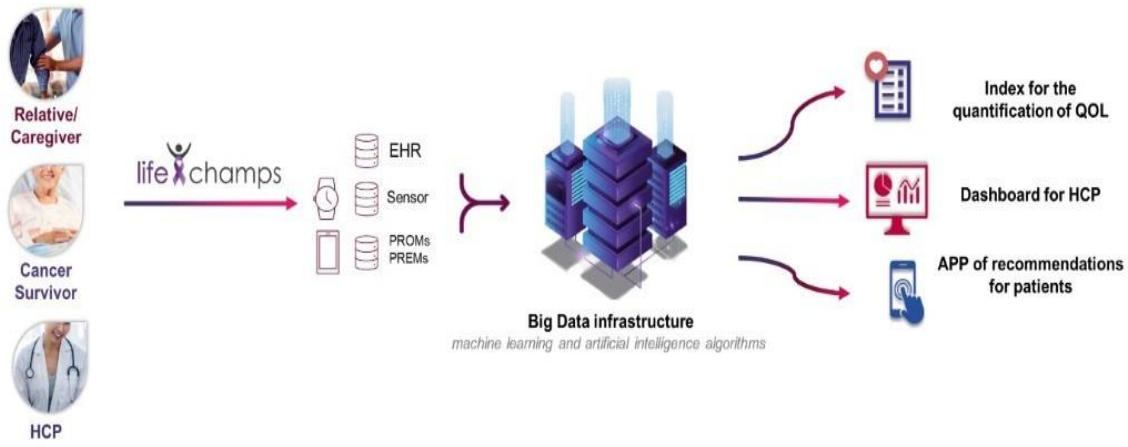

FIGURE 2 DIAGRAM OF LOW FIDELITY PROTOTYPE

4.6.2 END-USERS INTERESTED IN BEING INTERVIEWED

The advertisement/text/email instructed the end-user to contact the researcher via email or telephone to indicate interest in the study. The researcher then provided brief information about the study, established end-user eligibility and subsequently sent a participant information sheet, privacy notice (where applicable), and consent form to the end-user's email address. At this stage, we asked all end-users to confirm participation or not by return email or by calling the researcher.

For consenting end-users, the researcher (a) emailed the end-user a link to secure transfer system for the end-user to return their signed consent form, and (b) arranged with the end-user for a suitable date and time for their telephone interview. For refusing end-users, the researcher thanked him/her and assured him/her that their decision would not affect them in any way. If end-users offered a reason for declining participation, we recorded this for use in data analysis. All participating end-users were free to withdraw at any point if they so wished without a requirement to justify their decision. If the withdrawing end-user offered a reason for withdrawing, we again recorded this for use in data analysis.

We anticipated that telephone interviews would be 30-60 minutes long, with a mean duration of 45 minutes. Data collection was facilitated via standard, commercially available and encrypted digital voice recorders at each partner site (e.g., Olympus VN-541PC). An interview guide was prepared in collaboration with ECPC representatives (see Appendix 12.1). The interview guide allowed systematic exploration of research participants' opinions/views.

Before each interview, the researcher emailed the same visual (low fidelity prototype in figure 2) of the anticipated LifeChamps platform. At the start of each interview, we gave research participants an overview of the project. At the end of the interview, we debriefed research participants and thanked them for their time and contribution. During the interview, the researcher was vigilant for any cues that might indicate that a research participant might struggle with the interview or wanted to stop/withdraw. In such cases, the interview would pause. The researcher would enquire whether the research participant wished to continue or stop the interview altogether. If the research participant wished to withdraw, the researcher would reiterate that (as per the participant information sheet) the participant was free to do so without giving any reason and without penalty. For data analysis purposes, we retained anonymous research data collected up to the point of withdrawal.

5 DATA MANAGEMENT AND ANALYSIS

Research participants' personal data (i.e. names, home/work/email addresses, phone numbers) will be securely destroyed within 3 months after the end of task 2.2. Once personal data have been destroyed, participant ID numbers will only link back to research data, which will be then fully anonymised. Additional personal data (e.g. gender, age but not date of birth, healthcare conditions or clinical role as applicable) that research participants may supply in the course of the surveys/interviews will be retained for the purposes of the research and treated as "research data". Research data

(i.e. data derived/supplied during the surveys/interviews, including survey data, audio files, transcripts and demographic data) will be retained for 10 years after the end of the project or as per University policy.

Survey data will be downloaded from the online survey tool and stored as password-protected Excel files on secure University drives. Any identifiable information will be removed at the data management stage. Audio-files will be transcribed by professional transcription services at each partner site and analysed in the respective language.

Task 2.2 partners will be responsible for the analysis of their own raw research data as generated at their respective sites/countries. Each partner will create a 'Summary of Findings' document containing processed (but no raw) and fully anonymised research data written in English for subsequent evidence synthesis purposes. Specific instructions for the analysis of research data are provided in the data analysis scheme appearing in Appendix 12.2.

6 RISK ASSESSMENT

A detailed risk assessment plan was also put in place and shared with task 2.2 partners to enable for a coordinated approach to minimise risks or mitigate their impact (Table 6).

Source of risk	Likelihood of harm	Severity of harm	Overall risk	Options to reduce or eliminate risk
1. Secure storage of personal and research data is compromised (due to security failure, inadequate security measures or cyber-attack).	Remote	Significant	Medium	We will collect personal and research data in a password-encrypted Excel spreadsheet, which will be stored on a secure University server at all times. University servers are continually protected by a firewall against viruses and malware. Remote access to the Excel spreadsheet will be facilitated via a secure VPN connection. The research team have all undertaken University online Information Security training module and have completed the GDPR online training module.
2. Participants share sensitive/ confidential/ personal information about themselves or information that can identify others during the interview.	Possible	Minimal	Low	The researcher will treat this information as strictly confidential as per "Good Clinical Practice" relating to Research Ethics. The researcher will ask the participant to refrain from using actual people's names during the interview. During data management, any identifiable information will be removed or replaced with generic terms (e.g. 'QEUH' will be replaced with 'hospital') from the transcripts, and transcripts will be double-checked before the analysis begins. The research team have all undertaken online Information Security training module.
3. Online survey tool becomes unavailable.	Remote	Significant	Medium	The researcher will monitor functionality of the online survey tool daily. Any indicators of lost functionality will be immediately reported to the survey tool host (third party) for appropriate action.
4. Voice recorder malfunctions or is misplaced or stolen after an interview.	Remote	Significant	Medium	A back-up voice recorder will be available during the interview to replace another that malfunctions. Immediately after the interview, the researcher will securely transfer the audio-file on to a secure University server and delete it from the voice recorder before they leave the location of the interview.

Source of risk	Likelihood of harm	Severity of harm	Overall risk	Options to reduce or eliminate risk
5. Secure sharing of research data within research team of task group members or across task group members (within Europe) is compromised due to security failure, inadequate security measures or cyber-attack.	Remote	Significant	Medium	To send/receive research data for transcription purposes and subsequently summaries/reports of non-identifiable research data to project partners within Europe, we will use University of Glasgow's secure Transfer platform. Transfer is not a "cloud" service. Everything is stored (even temporarily) on equipment directly owned by the University and managed by its own IT staff. All access to data is very tightly and strictly controlled by the University. Audio-files will be transcribed by a professional transcription service as part of a data processing agreement that will be put in place prior to us sharing data with the service. Professional transcription services will provide task group members with unique usernames and passwords for their website to enable logging in and transferring the files to them via secure file transfer.
6. Sample size not achieved	Possible	Significant	Medium	There is the possibility of not achieving the target sample size. This interim report displays the current accrual rate, which reflects the combined delay due to required amendments to ethical approvals, continuing lock down throughout the countries and the clinical implications/pressures of medical staff involvement. However, recruitment has only recently commenced, and the summer vacation period may have hindered uptake, especially following the unprecedented pandemic this year.
7. Lack of stakeholder participation	Possible	Significant	Medium	If there is a lack of rich source data from the end-user groups we will conduct a literature search using the key terms/themes identified in task 2.2 to expand and cover any potential gaps for development.

TABLE 6 RISK ASSESSMENT PLAN FOR TASK 2.2 RESEARCH ACTIVITIES.

7 SITE ETHICS APPROVALS AND START DATES

Ethics approvals were obtained promptly and within pre-set timelines (M6-7 as per Figure 1) for all sites. Further details regarding the ethical procedures shall be presented in WP9 and the relevant deliverable. Table 7 shows wide variability in turnaround times of ethics committee/board decisions, which were impacted as expected by the pandemic, particularly for UofG. However, data collection began promptly in the UK once the survey/interview questions and survey links were finalised. There was a delay with the rest of the sites due to approval procedures, accurate translation of the survey and interview content in the respective languages and a further delay for HULAFE and APC due to the seasonal holiday period.

	UofG	**HULAFE**	**APC**	**AUTH**
Name of local ethics board/ committee	University of Glasgow MVLS Ethics Committee	Comité de Ética de la Investigación con medicamentos (CEIm)	Etikprovningmyndingheten	Aristotle University of Thessaloniki Ethics Committee
Date of ethics application	2nd week in April 2020	2nd week in April 2020	2nd week in April 2020	2nd 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

TABLE 7 SUMMARY OF SITE ETHICS APPROVALS AND START DATES

8 EFFICIENCY OF RECRUITMENT MODES

Thus far, we have closely followed our revised recruitment plan. For group 1 and 2 end-users, we have engaged with health professionals and personnel employed at local charitable organisations and hospitals, who have indeed provided potential participants with information about the study via text or email. To that goal, help from our project partner, the European Cancer Patient Coalition (ECPC), has been instrumental to identify potential participants from within local networks across the

four countries. At the same time, we have created advertisements on dedicated outreach platforms and extensively used social media (Twitter and Facebook), tagging patient and carer support groups and national charitable organisations with many followers, thus further extending the pool of potential participants. While this opt-in method targets a wide audience, it has known limitations with uptake, which for surveys is often translated into rather low response rates, and thus close follow up with regular reminders is key [7]. In the UK, even a prize draw for shopping vouchers has been implemented to 'entice' end-users to participate by offering a small honorarium to compensate them for their time on the study without increasing the risk for undue coercion [8]. We have seen some expressions of interest likely linked to the honorarium, which justifies our decision to use this technique too.

For end-user groups 3 and 4, we have again posted advertisements on social media (Twitter and LinkedIn) and relied on the partners' professional networks to identify clinicians and health managers. At the same time, we have actively employed our referral technique, asking clinicians to also invite other colleagues to consider participation. This technique has helped us again widen the pool of participants and it seems to work well at least for the purpose of identification of potential participants.

9 CURRENT ACCRUAL RATES

At the end of Month 9, a total of 47 end-users had been recruited across groups and partners. 45 end-users completed the online survey, while 2 end-users took part in an interview. Across partners, accrual rates for end-user groups 1 and 2 (patients and family carers) were 6.9% for surveys and 1.3% for interviews. Similarly, accrual rates for end-user groups 3 and 4 (health professionals and health managers) were 6.4% for surveys and 2.5% for interviews. On a site level, accrual rates varied widely as is shown in Table 8, which can be attributed to several influencing factors, including differences in recruitment start date among sites and differences in annual holiday periods (July for some countries, August for others), which have perhaps affected availability of potential participants.

Data collection mode	End-user group	Target n	UofG		HULAFE		APC		AUTH		Totals across partners		
			Actual n	Accrual rate[1]	Actual n	Accrual rate[1]	Actual n	Accrual rate[1]	Actual n	Accrual rate[1]	Target n	Actual n	Accrual rate[1]
Surveys	Cancer Patients	20-65	4	10.8%	3	4.6%	1	1.5%	4	10.8%	80-260	12	6.9%
	Family / Friends / Carers		3		0		0		3			6	
	Health Professionals	10-35	6	20.0%	1	2.9%	0	0%	1	2.9%	40-140	8	6.4%
	Health Managers		1		0		0		0			1	
	Total target n per partner	30-100	14	14.0%	4	4.0%	1	1.0%	8	8%	120-400	27	6.8%
Interviews	Cancer Patients per partner	8-20	1	5.0%	0	0%	0	0%	0	0%	32-80	1	1.3%
	Family / Friends / Carers		0		0		0		0			0	
	Health Professionals	4-10	1	10.0%	0	0%	0	0%	0	0%	16-40	1	2.5%
	Health Managers		0		0		0		0			0	
	Total target n per partner	12-30	2	6.7%	0	0%	0	0%	0	0%	48-120	2	1.7%

[1]Accrual rate = (Actual n / maximum Target n) x100.

TABLE 8 SUMMARY OF TOTAL AND COUNTRY ACCRUAL RATES

10 CONCLUSIONS

In sum, we have adopted a flexible yet robust approach to the research methods employed in task 2.2 with a view to absorb the impact of the pandemic and maintain the quality of the outcomes. The extended timelines will allow us adequate time to approach and recruit at least the minimum required number of end-users. Our analysis of current accrual rates indicates areas where efforts must be intensified to identify and engage potential participants by the end of Month 11, when recruitment and data collection will stop as per current timelines. Our data analysis will be done in parallel with data collection and be iterative to ensure that research summaries are compiled by the end of Month 12 ready for inclusion in the final report (D2.5 - End-user/stakeholder requirements – final version, due at M14 according to the amendment submitted to the EC). At the same time, working together with the WP2 lead, we will continue to review closely the efficacy and efficiency of our research methods and make changes as needed, particularly in the wake of potential second wave of the pandemic.

11 REFERENCES

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12 APPENDIX

12.1 INTERVIEW GUIDES

Patients with Cancer

Questions	Prompts
Opener Question: 1. Do you have a reason or interest for participating in this project?	
From the contact template clarify the type of cancer they were diagnosed with leading into 2. How many months has it been since you finished your treatment for xx cancer?	
3. Have you been diagnosed with any other health condition by a doctor or healthcare professional? *(If NO, move on the Question 4)* When were you diagnosed? (years/months) How are these health conditions now since you have finished your cancer treatment?	E.g., Diabetes, high blood pressure, osteoporosis. *Remember to address EACH health condition mentioned!* (was it before cancer, same time, since your treatment finished) (Got worse/ stayed the same / got better)
4. What are your priorities in life now that you move beyond cancer and cancer treatment?	What is life like now? Have you returned to your normal activities? What is your 'new normal'?
5. What are your concerns or needs since finishing cancer treatment?	Side effects, work, mobility issues, support, medication
6. In general, due to coronavirus and after having treatment for cancer, what are your experiences, need or concerns?	
7. From your own experience, what kind of support or information has been important from the time you finished treatment to all the follow up appointments?	
8. What kind of support do you feel your family or partner might need right now?	
9. In an ideal world, what type of health services would have been useful to you at the end of cancer treatment?	

10. In an ideal world, what type of advice or information would have been useful to you at the end of cancer treatment?	
Refer to the diagram (low fidelity prototype) sent via email	
11. What do you think about a system like this?	
12. What advantages or disadvantages do you see to a system like this?	
13. How often would you want predictions and advice like this sent to you, or your family?	
14. What would you want your doctor, Consultant or health care professional to do, with the predictions and advice, to help you the most?	
15. In general, how comfortable do you feel using technology?	(For example, using a smartphone or using a smart watch)
16.Finally, is there anything else you would like to add?	

Relative / Friend / Carer

Questions	**Prompts**
Prior to interview: Access the contact template form, clarify the relationship to the cancer patient, age of cancer patient and type of cancer diagnosed. *Opener Question:* 1. Do you have a reason or interest for participating in this project?	
2. People provide varying levels of care to cancer patients, some may need more help than others. In general, what kind of activities or support were you providing?	Think about daily activities, help in evenings, additional needs, living arrangements
3. How many months has it been since the patient you take care of finished his/her treatment for cancer?	
4. Has the patient you take care of been diagnosed with any other health condition by a doctor or healthcare professional?	E.g., Diabetes, high blood pressure, osteoporosis. *Remember to address EACH health condition mentioned!*

(If NO, move on the Question 5) When were they diagnosed? (months) How are these health conditions now since the patient you take care of has finished his/her cancer treatment?	 (was it before cancer, same time, since your treatment finished) (Got worse/ stayed the same / got better)
5. Have you personally been diagnosed with any other health condition by a doctor or healthcare professional? *(If NO, move on the Question 6)* When were you diagnosed? (years/months) How are these health conditions now since the patient you take care of has finished his/her cancer treatment?	E.g., Diabetes, high blood pressure, osteoporosis. *Remember to address EACH health condition mentioned!* (was it before cancer, same time, since your treatment finished) (Got worse/ stayed the same / got better)
6. What are your priorities in life now that the patient you take care of moves beyond cancer and cancer treatment?	What is life like now. How do you feel, have you returned to you usual routine/life
7. Thinking about the patient you were taking care of, what do think his/her priorities are in life now for moving beyond cancer and cancer treatment?	What is life like now. Have they resumed life as it was before cancer, have they had to make any adjustments.
8. (In relation to the patients age eg,50 – 64 years or 65+) Thinking about the patient you take care of, what are his/her concerns or needs since finishing cancer treatment?	Think about the conversations you've had, whether more help is needed.
9. In general, due to coronavirus and after the patient you take care of has received treatment for cancer, what do you think are his/her experiences, need or concerns?	
10. In general, due to coronavirus what are your own experiences, needs or concerns?	
11. What kind of support or information did you need after the patient you take care of finished his/her cancer treatment?	
12. What kind of support do your feel your family or partner might need right now?	
13. What kind of support do you feel the patient you were taking care of might need right now?	
14. After taking care of a cancer patient, in an ideal world, what type of health services would	

have been useful to you at the end of his/her treatment?	
15. After taking care of a cancer patient, in an ideal world, what type of advice or information would have been useful to you at the end of cancer treatment?	
Refer to the diagram (low fidelity prototype) sent via email	
16. What do you think about a system like this?	
17. What advantages or disadvantages do you see to a system like this?	
18. How often would you want predictions and advice like this sent to you, or your family?	
19. What would you want your doctor, Consultant or health care professional to do, with the predictions and advice, to help you the most?	
20. In general, how comfortable do you feel using technology?	(For example, using a smartphone or using a smart watch)
21. Finally, is there anything else you would like to add?	

Health professionals / managers

Questions	**Prompts**
1. What is your current role?	What is their health profession /Health manager
2. How many years have you been in your current role?	
3. What is your area of speciality?	Breast / prostate/ chemotherapy / radiotherapy
4. How many years have you been working specifically in cancer?	
5. What involvement do you have with treatment, advice, support or caring for older patients and their families?	

6. What type of health services for older patients with cancer are you responsible for?	
7. Middle-aged or older patients may have several health needs after completing cancer treatment, what have they told you?	*Conversations with colleagues, persistent problems/symptoms, psychological support, reduced mobility, fatigue, frailty, what do patients find more difficult during this period.*
8. What are your professional priorities for supporting middle-aged or older patients post treatment and during the follow up period?	
9. What kind of support or information do you think middle-aged or older patients, and their families, might need post treatment?	*what you have experienced, where are the gaps, the duration between follow up appoints, what would be useful*
10. What type of health services might be more or less useful, for middle-aged or older patients and their families post treatment?	*what you think is needed, what would be the ideal health service to offer the best support at post treatment, what would this look like.*
11. What patient-reported outcome measures (PROMS), or patient-reported experience measures (PREMS) would be most important for middle-aged or older patients post cancer treatment and during their follow up period?	
12. Covid-19 has caused many changes, what do you think older patients are experiencing *differently* post cancer treatment and during the follow up periods?	*Think about your conversations, your experience and observation*
Refer to the diagram (low fidelity prototype) sent via email	
13. What do you think about a service like this?	
14. What is the potential of this service?	*From your perspective, what advantages or disadvantages do you foresee, would you feel comfortable using this technology.*
15. What information would you be looking for and/or what do we need to monitor in middle aged or older patients?	*From your clinical perspective, ideally what would you want to know e.g, early indicators, any preventative strategies, specific changes in QoL.*

16. How often would you want to have such information available to you?	
17. How would you want this information to be shared with you and other colleagues involved in the post-treatment care of patients?	
18. What requirements do you envisage the system will have to address for this to be implemented in practice?	*workload, infrastructure*
19. Finally, this is our last question. Is there anything else you would like to add?	
Thank clinician for their time and participation. Would they like a summary of the results?	

12.2 DATA ANALYSIS SCHEME

Specific instructions for the analysis of research data are provided in the following data analysis scheme.

Analysis of demographic/clinical data

Basic descriptive statistics will be used to summarise participant characteristics (e.g. demographic data). Descriptive statistics (n, % for all variables) will be computed in Excel on demographic/clinical data generated during both surveys and interviews. Please present aggregated demographic/clinical for both surveys and interviews. When all surveys are closed, please download your dataset in Excel format from your EUSurvey link. Use the Excel spreadsheet as a guide for your statistical analysis.

A list of variables and expected output per participant group is presented below:

A. Patient data	
Variables	**Output**
#01. Country	Code all country entries. Present n, % in descending order of frequency.
#02. Gender	Present n, % in descending order of frequency.
#03. Age (years)	Code as: 50-54y; 55-59y; 60-64y; 65-69y; 70-74y; 75-79y; 80-84y; 85-89y; 90+y. Present n, % in descending order of frequency.
#04. Type of cancer	Present n, % in descending order of frequency.
#05. Time since end of treatment (months)	Code as: 1-6m; 7-12m; 13-18m; 19-24m; 25+m. Present n, % in descending order of frequency.
#06. Comorbidities - number of	Code as: 0; 1-2; 3-5; 6-10; 11+. Present n, % in descending order of frequency.
#07. Comorbidities - name list	Code all entries using the list in this link. Present n, % in descending order of frequency.
#08. Comorbidities - time since diagnosis (years)	Code as: 1-2y; 3-5y; 6-10y; 11+y. Present n, % in descending order of frequency.
#09. Comorbidities - current status	Code as: 'got worse'; 'stayed the same'; 'got better'. Present n, % in descending order of frequency.

B. Caregiver data	
Variables	**Output**
#10. Country	Code all country entries. Present n, % in descending order of frequency.
#11. Gender	Present n, % in descending order of frequency.
#12. Age (years)	Code as: 18-34y; 35-49y; 50-64y; 65-79y; 80+y. Present n, % in descending order of frequency.
#13. Patient's type of cancer	Present n, % in descending order of frequency.
#14. Relationship to patient	Code all entries. Present n, % in descending order of frequency.
#15. Support to patient	Code as: 'emotional support', 'practical support'. Categories aren't mutually exclusive. Present n, % in descending order of frequency.
#16. Time since patient's end of treatment (months)	Code as: 1-6m; 7-12m; 13-18m; 19-24m; 25+m. Present n, % in descending order of frequency.
#17. Caregiver comorbidities - number of	Code as: 0; 1-2; 3-5; 6-10; 11+. Present n, % in descending order of frequency.
#18. Caregiver comorbidities - name list	Code all entries using the list in this link. Present n, % in descending order of frequency.
#19. Caregiver comorbidities - time since diagnosis (years)	Code as: 1-2y; 3-5y; 6-10y; 11+y. Present n, % in descending order of frequency.
#20. Caregiver comorbidities - current status	Code as: 'got worse'; 'stayed the same'; 'got better'. Present n, % in descending order of frequency.
#21. Patient comorbidities - number of	Code as: 0; 1-2; 3-5; 6-10; 11+. Present n, % in descending order of frequency.
#22. Patient comorbidities - name list	Code all entries using the list in this link. Present n, % in descending order of frequency.
#23. Patient comorbidities - time since diagnosis	Code as: 1-2y; 3-5y; 6-10y; 11+y. Present n, % in descending order of frequency.
#24. Patient comorbidities - current status	Code as: 'got worse'; 'stayed the same'; 'got better'. Present n, % in descending order of frequency.

C. Health professional data	
Variables	**Output**
#25. Health professional - specify role	Present n, % in descending order of frequency.
#26. Time working in cancer	Code as: 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#27. Time working in current role	Code as: 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#28. Area of specialty	Code all entries. Present n, % in descending order of frequency.
#29. Gender	Present n, % in descending order of frequency.

D. Health manager data	
Variables	**Output**
#30. Health manager - specify role	Present n, % in descending order of frequency.
#31. Time working in cancer	Code as: 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#32. Time working in current role	Code as: 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#33. Area of specialty	Code all entries. Present n, % in descending order of frequency.
#34. Gender	Present n, % in descending order of frequency.

Aggregated data (n, %) on the above variables to be shared with University of Glasgow for synthesis purposes and inclusion in the final report.

Analysis of interview/survey data

Framework analysis will be used to analyse data from interviews and surveys [7] to enable individual task group members to map out experiences, needs, preferences and priorities of end-users.

Framework analysis will also enable comparisons with similar evidence generated in the partner countries to be made that will then facilitate decision-making among

partners and a consensus to be reached on (a) post-treatment experiences of end-users, and (b) desired functionality of the developing platform.

A working analytical framework will be applied. The analytical framework is available in two versions, one for patients/caregivers and one for health professionals/managers. The analytical framework includes a set of thematic categories, each corresponding to the relevant question asked in the interviews and surveys, with a brief description/definition.

ANALYTICAL FRAMEWORK A -- PATIENTS/CAREGIVERS		
THEMATIC CATEGORY	**CODING**	**CORRESPONDING QUESTION**
#01 - Patient's priorities in life after cancer treatment - patient's perspective	*a. Going back to previous activities* *b. Living life to its full* *c. Family* *d. Finding meaning* *e. Finding a 'new normal'*	*4.1. What are your priorities in life now that you move beyond cancer and cancer treatment?*
#02 - Patient's priorities in life after cancer treatment - caregiver's perspective	*a. Going back to previous activities* *b. Living life to its full* *c. Family* *d. Finding meaning* *e. Finding a 'new normal'*	*4.2. Thinking about the patient you were taking care of, what do you think his/her priorities are in life now for moving beyond cancer and cancer treatment?*
#03 - Caregiver's priorities in life after patient's cancer treatment - caregiver's perspective	*a. Going back to previous activities* *b. Living life to its full* *c. Family* *d. Finding meaning* *e. Finding a 'new normal'*	*4.3. What are your priorities in life now that the patient you have taken care of moves beyond cancer and cancer treatment?*
#04 - 50-64y/o patient concerns or needs - patient's perspective	*a. Concerns* *b. Needs*	*4.4. Only answer if you are between the ages of 50 - 64 years, what are your main areas of concerns or needs since finishing cancer treatment?*
#05 - 50-64y/o patient concerns or needs - caregiver's perspective	*a. Concerns* *b. Needs*	*4.5. Only answer if the person you were taking care of is aged between 50-64 years, what do you think his/her concerns or needs are since finishing cancer treatment?*
#06 - 65+y/o patient concerns or needs - patient's perspective	*a. Concerns* *b. Needs*	*4.6. Only answer if you are aged 65 years or more, what are your concerns or needs*

		since finishing cancer treatment?
#07 - 65+y/o patient concerns or needs - caregiver's perspective	*a. Concerns* *b. Needs*	*4.7. Only answer if the person you were taking care of, is aged 65 years or more, what do you feel his/her concerns or needs are since finishing cancer treatment?*
#08 - Patient COVID needs or concerns - patient's perspective	*a. COVID Concerns* *b. COVID Needs*	*4.8. In general, due to the coronavirus and after having treatment for cancer, what are your experiences, needs or concerns?*
#09 - Patient COVID needs or concerns - caregiver's perspective	*a. COVID Concerns* *b. COVID Needs*	*4.9. Due to the coronavirus and after having the patient you take care of finish cancer treatment, what do you think are his/her needs or concerns?*
#10 - Caregiver COVID needs or concerns - caregiver's perspective	*a. COVID Experiences* *b. COVID Concerns* *c. COVID Needs*	*4.10. In general, due to the coronavirus, what are your own experiences, needs or concerns?*
#11 - Patient experiences of support or information since treatment - patient's perspective	*a. Support* *b. Information*	*4.11 From your own experience, what kind of support or information has been important from the time you finished treatment to all the follow up appointments?*
#12 - Caregiver experiences of support or information since treatment - caregiver's perspective	*a. Support* *b. Information*	*4.12 What kind of support or information did you need after the patient you were taking care of finished their cancer treatment?*
#13 - Caregiver current needs for support - patient's perspective	*a. Support needs* *b. Information needs*	*4.13 What kind of support do you feel your family or partner might need right now?*
#13 - Patient current needs for support - caregiver's perspective	*a. Support needs* *b. Information needs*	*4.14 What kind of support do you feel the patient you were taking care of may need right now?*

#14 - Ideal health services - patient's perspective	*a. Hospital services* *b. Primary care services* *c. Community services* *d. Home care services* *e. Other services*	*4.15 In an ideal world, what type of health services would have been useful to you at the end of cancer treatment?*
#15 - Ideal type of advice or information - patient's perspective	*a. Practical and day-to-day living* *b. Management of physical symptoms* *c. Psychological support* *d. Self-management*	*4.16 In an ideal world, what type of advice or information would have been useful to you at the end of cancer treatment?*
#16 - Ideal health services - caregiver's perspective	*a. Hospital services* *b. Primary care services* *c. Community services* *d. Home care services* e. *Other services*	*4.17 After taking care of a cancer patient, in an ideal world, what type of health services would have been useful to you at the end of his/her treatment?*
#17 - Ideal type of advice or information - caregiver's perspective	*a. Practical and day-to-day living* *b. Management of physical symptoms* *c. Psychological support* d. *Self-management*	*4.18 After taking care of a cancer patient, in an ideal world, what advice or information would have been useful to you at the end of his/her treatment?*
#18 - Perceptions on system benefits and drawbacks	*a. Praise/advantages- patient* *b. Critique/disadvantages - patient* *c. Praise/advantages - caregiver* *d. Critique/disadvantages - caregiver*	*5.1 What do you think about a system like this?* *5.2 What advantages or disadvantages do you see to a system like this?*
#19 - Frequency of predictions	*a. Daily* *b. Weekly* *c. Monthly* *d. On demand* *e. Other*	*5.3 How often would you want predictions and advice like this sent to you, or your family?*
#20 - Health professional actions	*a. Communicate with and inform the patient/family* *b. Adjust follow up care* *c. Share information with other treating health professionals*	*5.4 What would you want your doctor, Consultant or health care professional to do with the predictions and advice to help you the most?*
#21 - Comfort using technology	*a. General competency reported* *b. Low competency or barriers reported*	*5.5 In general, how comfortable do you feel using technology?*
Not applicable.	*Use coding from previous questions to code responses in this question*	*5.6 Finally, is there anything else you would like to add?*

ANALYTICAL FRAMEWORK B -- HEALTH PROFESSIONALS / MANAGERS		
THEMATIC CATEGORY	**CODING**	**CORRESPONDING QUESTION**
#01 - HP/HM **involvement** in patient care	*a. Medical management* *b. Treatment administration* *c. Psychological support* *d. Community care* *e. Pharmacy* *f. Physiotherapy* *g. Other*	*4.1 What involvement do you have with treatment, advice, support or caring for older patients and their families?* *4.2 What type of health services for older patients with cancer are you responsible for?*
#02 - Patient's **post-treatment health needs** - HP/HM's perspective	*a. Practical and day-to-day living* *b. Management of physical symptoms* *c. Psychological support* *d. Self-management* *e. Information* *f. Other*	*4.3 Middle-aged or older patients may have several health needs after completing cancer treatment, what have they told you?* *4.5 What kind of support or information do you think middle-aged or older patients, and their families, might need post treatment?*
#03 - HP/HM **professional priorities**	*c. Survival* *d. Best supportive care* *e. Frequent monitoring, follow up and communication*	*4.4 What are your professional priorities for supporting middle-aged or older patients post treatment and during the follow up period?*
#04 - HP/HM **views on health services** at post-treatment	*a. Hospital follow up services* *b. Primary care services* *c. Patient support groups* *d. Home care services* *e. Remote monitoring services*	*4.6 What type of health services might be more or less useful, for middle-aged or older patients and their families post treatment?*
#05 - HP/HM **views on important PROMs or PREMs**	*a. PROMs* *b. PREMs*	*4.7 What patient-reported outcome measures (PROMs), or patient-reported experience measures (PREMs) would be most important for middle-aged or older patients post cancer treatment and during their follow up period?*

ANALYTICAL FRAMEWORK B -- HEALTH PROFESSIONALS / MANAGERS		
THEMATIC CATEGORY	**CODING**	**CORRESPONDING QUESTION**
#06 - HP/HM **views on patients' experiences due to COVID**	*a. Experiences with symptom management* *b. Experiences with health access* *c. Experiences with follow up services* *d. Experiences with daily living and community care*	*4.8 COVID-19 has caused many changes, what do you think older patients are experiencing differently post cancer treatment and during the follow up periods?*
#07 - Perceptions on **system benefits and drawbacks**	*e. Praise/advantages - HP* *f. Critique/disadvantages - HP* *g. Praise/advantages - HM* *h. Critique/disadvantages - HM*	*5.1 What do you think about a system like this?* *5.2 What is the potential of this service?*
#08 - **Required information and monitoring**	*a. Physical symptoms* *b. Emotional / psychological symptoms* *c. Performance status and functioning* *d. Social and family support* *e. Practical and daily living*	*5.3 What information would you be looking for and/or what do we need to monitor in middle aged or older patients?*
#09 - **Frequency** of information	*a. Daily* *b. Weekly* *c. Monthly* *d. On demand* *e. Other*	*5.4 How often would you want to have such information available to you?*
#10 - **Presentation** of information	*a. Summary report notification* *b. Graph or chart notification* *c. Other*	*5.5 How would you want this information to be shared with you and other colleagues involved in the post-treatment care of patients?*
#11 - **Requirements for system implementation**	*a. Tackle workload / human resources barriers* *b. Tackle infrastructure barriers* *c. Buy-in process*	*5.6 What requirements (workload, infrastructure) do you envisage the system will have to address for this to be implemented in practice?*
Not applicable.	*Use coding from previous questions to code responses in this question*	*5.7 Finally, is there anything else you would like to add?*

The analyst will systematically go through each transcript, highlighting each meaningful passage of text and selecting and attaching an appropriate thematic category/coding label from the analytical framework as a comment.

See example below:

67-year-old patient with prostate cancer

After treatment, I couldn't even climb the stairs, no energy, no nothing. Couldn't even dress, wife had to undress me, shove me in bed. Climb halfway up the stairs, sit on the step, 10 minutes up to the top step, stop for ten minutes, sit on the bed. I wasn't buoyant anymore (….) I got a little bit down and I think I was depressed, and there was all sort of niggly bits starting I didn't I didn't pick up my tai chi sport, (….) I was beginning to get isolated. I would only go out with my wife and didn't go off on my own like I was used to. In the beginning of treatment, the set up was wonderful and the nurse gave me all these things and the information and the phone numbers in case things went wrong (….). But there was not much afterwards, information. That I might feel depressed or down, can't sleep, I mean worrying. (…). I didn't know what to expect. I know there is a lot of people to see but I think it could do with somebody with a bit more time with you. To say how you are feeling, because when you come for an appointment here it's sort of 'how are you today?' blah blah and that's it and you are out. A support group would be a good thing where they can talk about how they feel in front of other people because I think people are probably more open if that was there, and you think 'oh actually' and then you can help someone else as well. Is there a possibility that patients can have some information that you can give them? Some little bit and you can say 'that's what you can do?'

6a

6a

11b

4b

Once all the data have been coded using the analytical framework, the data will be summarised in a matrix for each thematic category using Microsoft Excel - see example below. The matrix will comprise one row per participant and one column per thematic category.

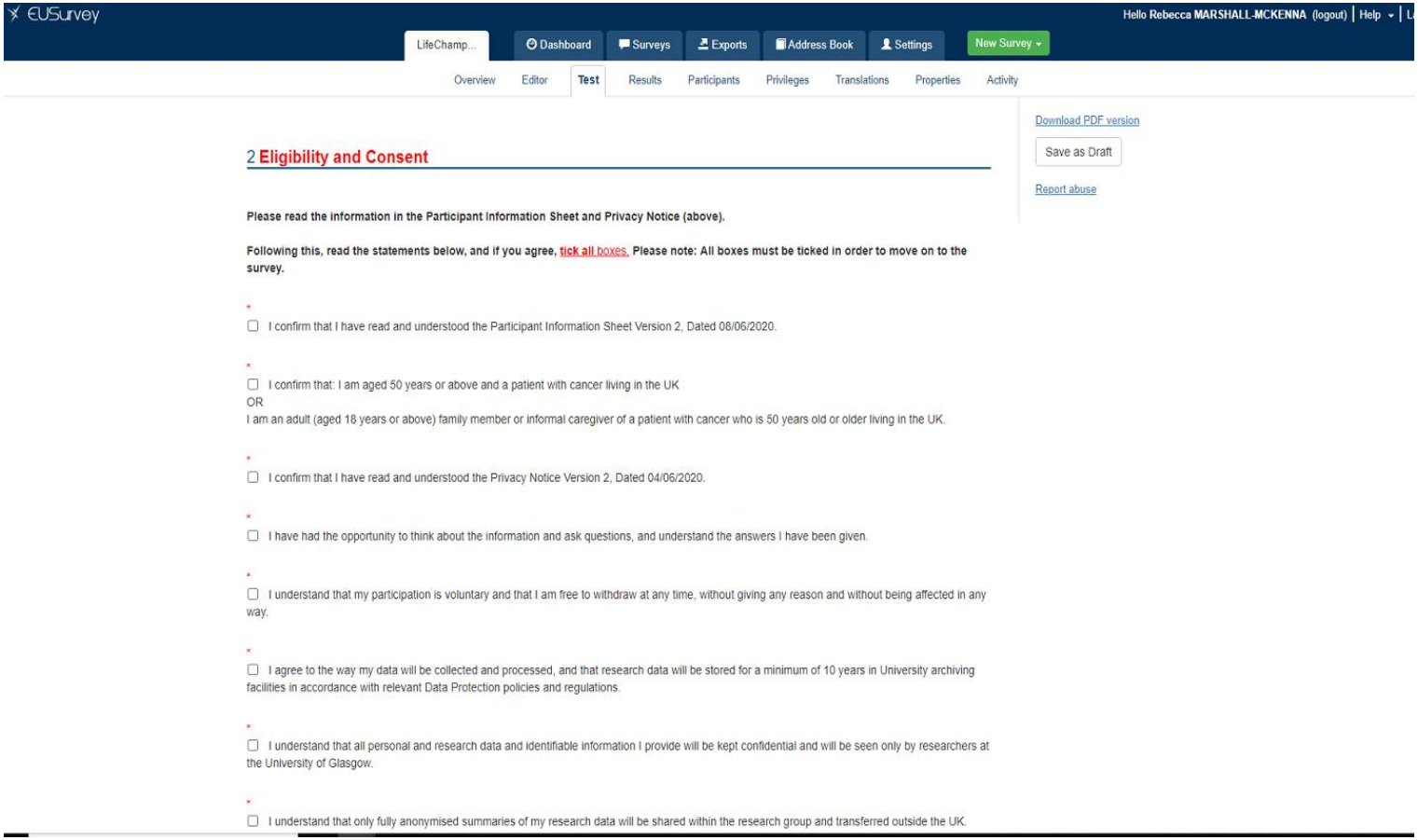
HP/HM	**Thematic category 1**	**Thematic category 2**	**Thematic category 3**	**Thematic category 4**
Participant 1	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes
Participant 2	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes
Participant 3	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes
Summary	*Summarised evidence*	*Summarised evidence*	*Summarised evidence*	*Summarised evidence*

A separate sheet will be used for patients, carers and health professionals/managers. Relevant quotes will then be abstracted from the transcripts for each participant and thematic category and inserted into the corresponding cell in the matrix.

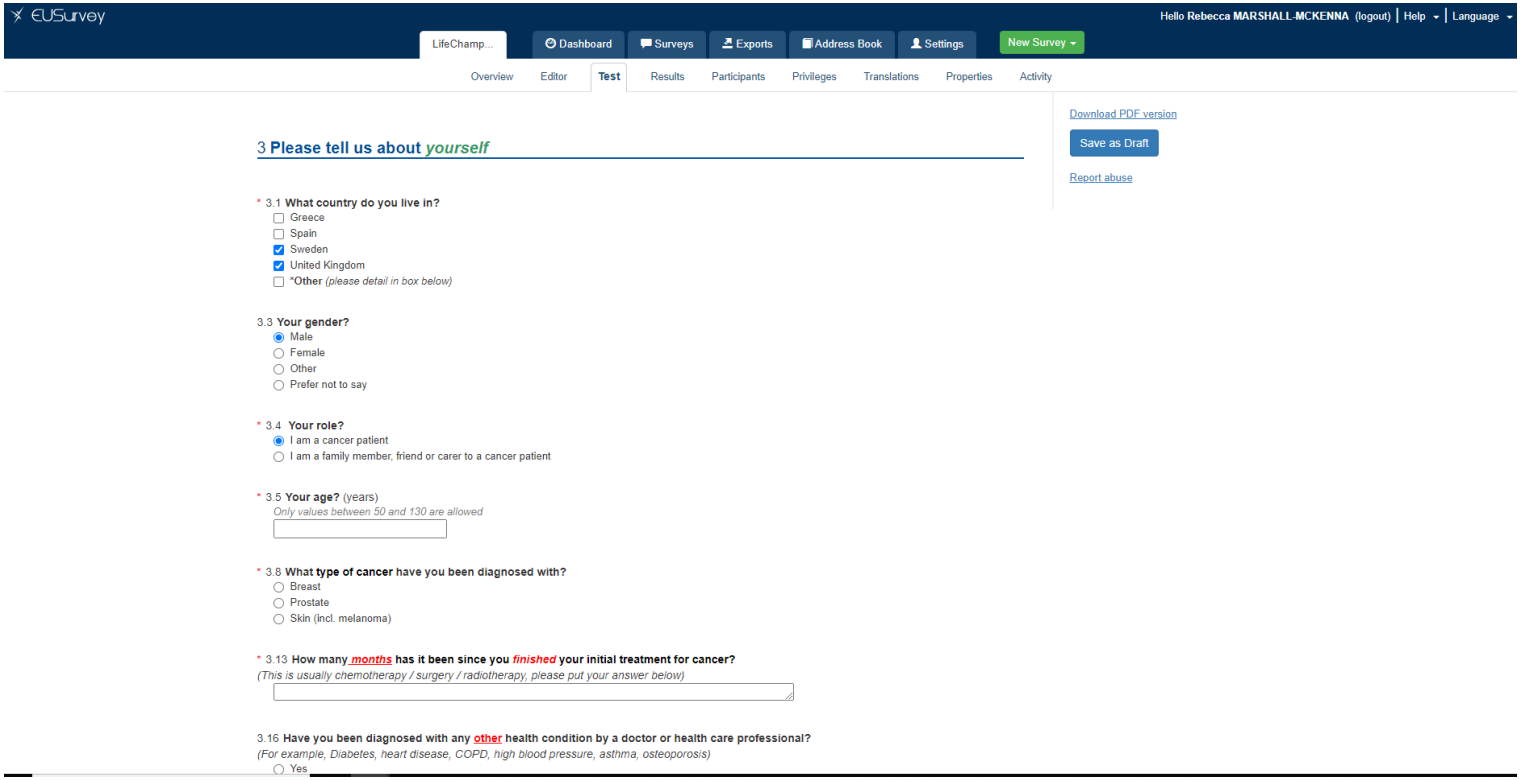
Information from the quotes will be summarised for each thematic category for inclusion into each partner's 'Summary of Findings' document that will be sent to the University of Glasgow for inclusion in the final report for task 2.2.

12.3 EU SURVEY SCREENSHOTS

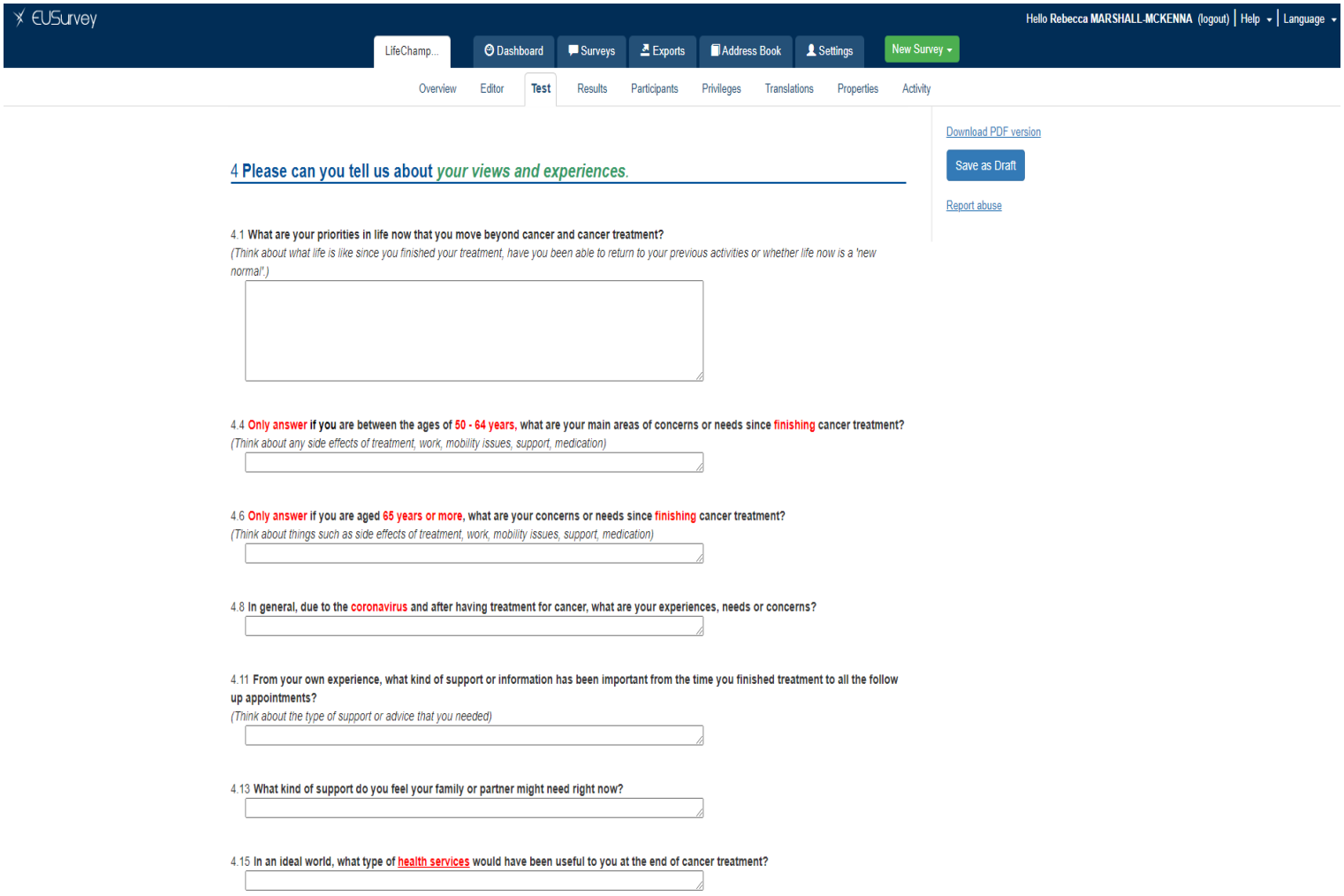
Eligibility and Consent



Please tell us about yourself



Please tell us about your views and experiences



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